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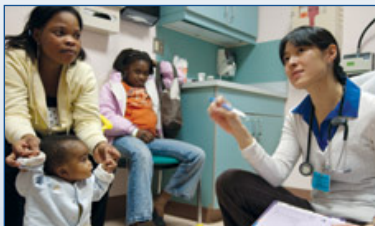
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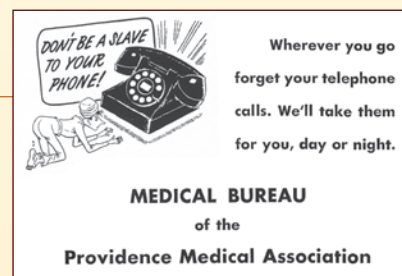
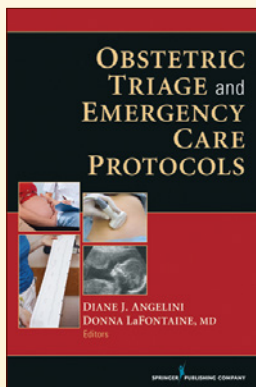
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Joe's Prior Auth Service

JOSEPH H. FRIEDMAN, MD
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DID YOU KNOW THAT IF your patient's insurer denies the drug the patient has depended on for the past 10 years, requiring the patient to FAIL two other drug regimens before the first drug can be resumed, and then the patient subsequently comes to harm, the insurer cannot be sued? It's time to fight back! It's time for Joe's Prior Authorization Emergency Response Program.



With the recent change of drug insurers in Rhode Island leading to extraordinarily time consuming reviews and potential life threatening outcomes, it is more urgent now than ever to sign up for Joe's Prior Authorization Service (JPS). The time is ripe to strike back at the faceless corporate exploiters who are squeezing your patients and your practice. With Joe's PA Service, you not only get some consolation, but you also help your patients and, not incidentally, help me pay off my mortgage.

How does it work? First of all, JPS only hires the hearing impaired. This increases employment in a group of chronically underemployed and discriminated-against workers. We have found that by hiring hearing impaired telephone workers who use TTY, we can increase the amount of time required by the insurer by at least 78%. When JPS calls insurers they are immediately told that our service employs partially deaf "prior authorization specialists, skilled in timely resolution of prior authorization requests. Please note that attempts to disconnect because of communication difficulties will result in an immediate filing of a discrimination suit that will join a class action suit currently in progress."

JPS has a clearly stated preference for the speech impaired, as well. Stuttering and slurring slows down the usual discussion, allowing for a more considered opinion at the insurer's end. We encourage free communication so that all the information that we provide is spoken. While this often involves repetition, we believe that this makes for a more sensitive and

voice-focused insurance representative.

"Better to get it right the fourth time than get it wrong the first," is one of our mottos. We also never give the correct member ID the first time, and we then give an incorrect birth date as a safety measure to confirm that the insurer has the correct client's data, in addition to making sure the insurance agent is alert.

We have developed innovative software that prevents telephone disconnection. Once our PA specialist has been put on hold, music from our end will be piped in, overriding whatever music is being used by the insurer. We have found that Hebrew rapper, Mogen David and the Grapes of Wrath, at a decibel level of 100 is appreciated by many of our employees, encouraging perseverance in the face of lengthy holds. On reconnecting, the insurer will be able to choose from several options:

"Please enter the member's ID number, social security number, your own name, birthdate and social security code. Please enter the name and telephone number of your company's lawyer. Please listen to the entire message as our menu has recently changed. There are eight options." The last option allows for the second menu to be offered, which then allows the insurer

to be reconnected to the PA specialist.

Upon reconnection to JPS, the true name, ID number and birthdate of the client are correctly given. We then provide 10 diagnoses, including ICD codes, and a list of all medications and doses. These are spoken and then spelled out. The insurer is asked to repeat them to confirm that they are correct. The JPS communications specialist then explains the rationale for the choice of medication. When questions arise, the JPS communications specialist puts the insurer on hold and consults with the ordering physician. On occasion this causes delays but these cannot be avoided if accuracy is to be maintained.

JPS has an ongoing quality assurance program. We have noted that our program is initially not very helpful, but generally after 7 working days, and 15 notifications of impending discriminatory lawsuits for employment discrimination, we have found that prior authorization denials have plummeted at every office. We have been unable to expand our communications specialist staff because the amount of time required at each office declined so precipitously after the first 2 weeks of service. Almost all offices now employ our service only part-time.

We have noticed, unfortunately, that some of our laid-off and underemployed workers have begun to work for the drug insurance companies. ▼

Disclosures

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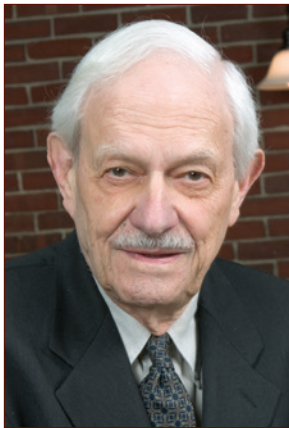


*Our Passion Protects
Your Practice*

Seeking Rest in a Nation that Never Slumbers, Never Sleeps

STANLEY M. ARONSON, MD
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IT PROBABLY BEGAN THIS way: Back in 1837 a German educator named Friedrich Froebel created a new and more humane curriculum for very young children in his community. He was motivated by the curious belief that the formal education of very young children need not be designed to prepare them immediately for adulthood and its remorseless practices; instead, he believed that children, say three years of age, should be educated solely to prepare themselves for the many problems that they will necessarily confront when they reach ages four or five. An ideal classroom, he therefore contended, should not be modeled after



Still, there is much that we can learn from those indolent creatures who have replaced their diligent pursuit of rodents with purposeless, nonproductive naps.

a factory workplace or an infantry basic training program; rather it should be designed much like a friendly garden for playful children (a kindergarten, in German), a place to learn, first, to coexist and, simultaneously, to do no harm.

Froebel declared that there was sufficient time, later in childhood, for youngsters to absorb the uncompromising

lessons of a competitive, unforgiving world. And so his model school encouraged children, in their diminishing innocence, to tend gardens, sing songs, admire the neighborhood birds; and after a light lunch, take naps with their youthful peers.

Where did napping begin? Certainly not with the feral creatures of the jungle nor with the nomadic hunter-gathers. Their survival, most assuredly, depended on an uninterrupted attitude of vigilance. The Romans eventually learned to take naps (perhaps, some think, the cause of the decline of their Empire) calling them their *sexta hora*, meaning the sixth hour beyond dawn; and the origin, eventually, of the Spanish word, siesta.

Napping, as a daily event, is tolerated (if not actively advocated) in certain southern European nations despite, concurrently, a northern European philosophy which regards pursuit of leisure, daydreaming or daylight napping as things emblematic of non-productive, wasteful, even slothful behavior adopted largely by

vagrants, social malcontents and the senile. Furthermore, declared some Nordic thinkers, daytime naps such as the siestas of some southern nations were the external manifestations of a deeply rooted backwardness and congenital lack of industry.

Naps are declared to be nonproductive, not in the best interests of the nation and clearly contrary to the will of nature. Furthermore, since these siestas are free of charge, Americans fear them; nothing that good, that sensuous, can



COURTESY OF PETER MANDELSON, MD

Chloe Mandelson

possibly be in keeping with acceptable Puritan virtues. In general, when there is work yet to be done, how can it be deemed morally proper to nap while the sun is still above the horizon? (And furthermore, how will I ever be promoted to assistant vice president if I despoil my afternoons with stolen naps?) And so adult Americans, much as they fear the outcomes of ill-gotten gains, are disquieted by the moral consequences of taking naps.

But what do sleep physiologists tell us about those afternoon naps taken by adults? Those spontaneous interludes of rest – recklessly snatched from the adult work-schedule – turn out to be more refreshing and with a depth of sleep that is frequently quite profound and intense. Nightmares rarely interrupt the sleep interlude and a sense of refreshment welcomes the napper upon arising.

Admittedly, we humans are measurably higher on the evolutionary scale than our domesticated house cats. Still, there is much that we can learn from those indolent creatures who have replaced their diligent pursuit of rodents with purposeless, nonproductive naps. How rarely have your house cats been observed pacing the floor worrying about the Dow Jones Average or their impending collegiate grades? Nor does a cat, in his anxiety, construe his afternoon naps as a dress rehearsal for death. For that cat, sleep is merely an unencumbered gift to be enjoyed whenever sleep beckons. And sleep is not a bauble to elicit shame nor proof of some inherited form of indolence.

Sleep, like breathing, is a fundamental part of our lives. And whether it is sought for or not, sleep will periodically overtake us. Sleep arrives as a periodic

gift both to the homeless vagrant and to the prince, to the simpleton and to the wise one, to the innocent child and to the elderly adult not yet weary of life. Sleep, too, is in the kingdom of honesty; and as there are no atheists in the foxholes of combat, so too there is no enduring hypocrisy, duplicity or self-deception in that alternate realm called dreams. **v**

Author

Stanley M. Aronson, MD, is Editor emeritus of the *Rhode Island Medical Journal* and dean emeritus of the Warren Alpert Medical School of Brown University.

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The author has no financial interests to disclose.

Quotes: Rx for Life

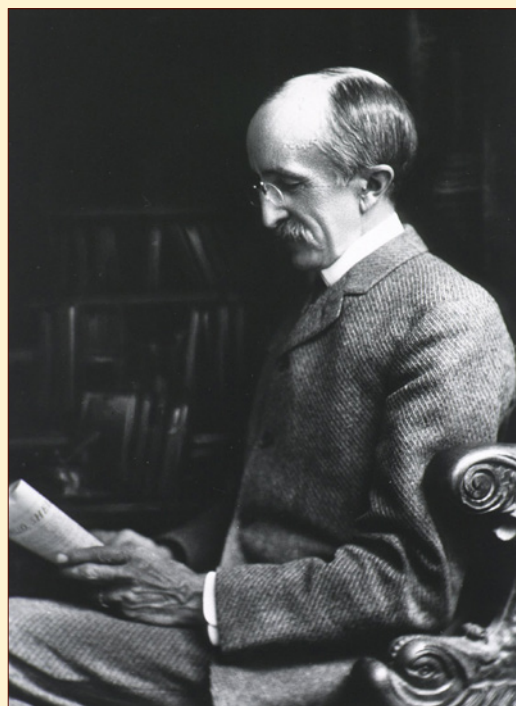
"To cure sometimes, to relieve often, to comfort always."

— Dr. Edward Livingston Trudeau (1848–1915)

Submitted by Fred J. Schiffman, MD, of Providence



Dr. Edward Livingston Trudeau was the first in this country to cultivate the tubercle bacillus. His laboratory and sanatorium at Lake Saranac, N.Y., was the first devoted exclusively to the treatment of tuberculosis in the United States and opened in 1894.



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Suboxone Pharma Foibles/FDA Does Its Job Well

ALAN GORDON, MD; ANDREA KRETZSCHMAR, MD; ELIZABETH GILBERT

OF THE 37,485 AMERICANS WHO LOST their lives in 2009 to illicit drug use, prescription pain medications caused more deaths than heroin and cocaine combined. Opiates are misused more than any other class of prescription medications. Opiate dependence affects an estimated 1.9 million Americans. Reckitt Benckiser, a British-based company, brought Suboxone (buprenorphine/naloxone) to market in 2002. Since then, Suboxone has made a very valuable contribution to treating those with an addiction to prescription pain medications and heroin. Suboxone is an effective medication, and studies have shown that patients on Suboxone maintenance therapy have a significantly reduced chance of relapse on opiates.¹ The availability of Suboxone has saved untold lives but has been costly as a patented product.

Reckitt Benckiser's U.S. patent on Suboxone tablets expired in 2009. Since then, it has encouraged physicians and patients to change to its patented sublingual film-strip version of Suboxone. Though exclusivity for the Suboxone film ends in 2013, the patent for the technology itself extends through 2023. Encouragement changed to dictation on September 25, 2012, when the company stopped manufacturing Suboxone tablets. Furthermore, it asked the U.S. Food and Drug Administration (FDA) to prevent future production of tablets, including generic versions via a citizen petition.

Reckitt Benckiser based its petition on data the company "received" (i.e. commissioned itself) from an organization called RADARS (Researched Abuse, Diversion and Addiction-Related Surveillance). Reckitt Benckiser argued its own tablets were unsafe to children and presented an unacceptable risk of

pediatric exposure. This argument was particularly disingenuous and cynical given the timing of the expiration of its tablet patent. As noted by Alison Knopf, editor at *Alcoholism & Drug Abuse Weekly*, "there are tons of kids who die from ingesting other narcotics, including methadone, and these aren't required to be (packaged) in film or are in film."

Like many other pharmaceutical companies, Reckitt Benckiser tried to exploit the use of a citizen petition to the FDA to preserve their market. The FDA is a consumer protection agency – all prescription medications have to pass a lengthy review process before they are available to physicians and their patients. In order to ensure that these concerns are addressed, the FDA is mandated to review these petitions. However, most of these petitions are submitted not by laypersons but by large pharmaceutical companies, often as a mechanism to block the development of generic versions of drugs with recently expired patents. Congress recognized this problem, and passed the FDA Revitalization Act of 2007, which attempted to limit abuse of citizen petitions by large corporations. Unfortunately, large pharmaceutical companies have managed to find ways to bypass these restrictions.

This example of a pharmaceutical company trying to protect profits under the veil of safety highlights one of the problems with the American healthcare system and the need for a more thoughtful FDA body. Misuse of prescription opiate medication incurs direct costs of up to \$72.5 billion a year, in addition to 300,000 ER visits, according to the results of a national survey by the Substance Abuse and Mental Health

Services Administration (SAMHSA 2009), as well as contributes to a significant portion of poisoning deaths. Reducing access to an effective treatment of opiate dependence would have delivered an incredible financial blow to a health system that is already struggling.

The good news is that the FDA threw out Reckitt Benckiser's petition, even referring the matter to investigators at the Federal Trade Commission. In addition, the FDA gave two generic drug makers, Anneal and Actavis, both based in New Jersey, the green light to market buprenorphine/naloxone tabs. Actavis said that it "intends to begin shipping the product immediately." This is a wonderful example of the FDA protecting Americans – increasing access to life saving treatment and reducing healthcare costs. **v**

Reference

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The Long and Winding Road Toward Alzheimer Prevention

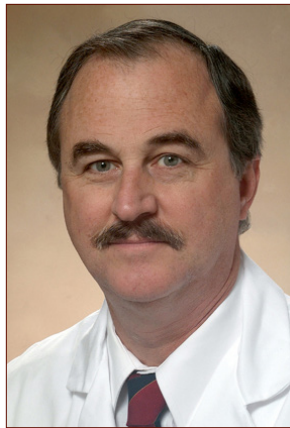
FDA offers new guidance on developing drugs for early-stage AD; seeks input

BRIAN R. OTT, MD

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ON FEBRUARY 7, 2013, the U.S. Food and Drug Administration (FDA) issued a "guidance for industry" proposal titled, "Alzheimer's Disease: Developing Drugs for the Treatment of Early Stage Disease."¹ An accompanying press release² stated that, "This proposal is part of U.S. Department of Health and Human Services' (HHS) efforts under the National Plan to Address Alzheimer's Disease,³ which calls for both the government and the private sector to intensify efforts to treat or prevent Alzheimer's and related dementias and to improve care and services. It responds to recommendations from a May 2012 HHS and National Institutes of Health Alzheimer's research summit to conduct clinical trials in at-risk individuals without symptoms and to develop and validate new measures so that Alzheimer's can be measured at the earliest possible time in the course of the disease."

At the core of the FDA guidance are proposals that a drug for Alzheimer's disease (AD) can be approvable based on relatively new criteria.⁴ Typically to get approval for a treatment for AD, a pharmaceutical company must provide evidence from two separate large-scale clinical trials showing safety as well as efficacy on both a cognitive and a functional or global assessment scale. This approach, however, can't be practically applied to interventions aimed at treating patients at a very early or preclinical stage of their illness, when there is little if any functional impairment in daily living to improve. For clinical trials



LIFESPAN

targeting prodromal AD or mild cognitive impairment (MCI), the guidance suggests that a composite measure that includes both cognition and function may be appropriate as a single primary outcome measure. For clinical trials targeting preclinical AD, since by definition there is no functional impairment

to assess, initial approval could be made upon demonstration of significant reduction in decline on a valid and reliable cognitive measure. Given the current state of our knowledge about AD biomarkers, these types of additional tests may provide supportive evidence of a "disease modifying" effect but could not be used as a surrogate primary efficacy measure at any stage.

There is now a wealth of research supporting the view that the pathology of Alzheimer's begins decades before the onset of symptoms, with amyloid deposition being the most widely recognized biomarker of the early pathologic cascade. With the help of insights gained from large longitudinal biomarker and brain imaging studies like the Alzheimer's Disease Neuroimaging Initiative, it is now possible to design prospective clinical trials whose goal is primary or secondary prevention of AD. The implications for controlling AD are substantial. It has been estimated that a treatment breakthrough that delays the age of onset of AD by five years would reduce the prevalence in Americans age 65 and older from 10 percent to 7 percent in 2020, and from 16 percent to 9 percent in 2050.⁵

Efforts to carry out studies using

conversion to AD as an endpoint, however, are limited in their power by the fact that AD is a disease that steadily progresses from a long asymptomatic period through a symptomatic period on a continuum rather than in discrete stages. The FDA guidance wisely proposes that future studies demonstrate change in the rate of cognitive decline as the clinical outcome rather than delay to conversion to disease stage. This should allow for trials of shorter

At the core of the FDA guidance are proposals that a drug for Alzheimer's disease (AD) can be approvable based on relatively new criteria.

duration and smaller sample sizes, two factors of major importance for the feasibility of prevention designs.

Despite such advances in our understanding of AD pathogenesis and clinical trial designs, unfortunately amyloid-modifying clinical trials to date have been unsuccessful. The past year has witnessed announcements that two large-scale, multicenter, multi-trial programs using anti-amyloid antibodies failed to show differences from placebo on prespecified endpoint analyses of cognition and function in patients with mild to moderate AD. Secondary analyses of one of these agents, solanezumab, however, suggest that a significant effect on slowing cognitive decline occurred for the milder cases, sparking hopes that this approach may be more effective when applied to upcoming trials enrolling subjects with prodromal or preclinical AD.

Considerations

So the question arises whether a drug or biological agent should be approved for early treatment of AD if it shows significant effects on highly sensitive cognitive measures, supported by effects on biomarkers of the disease such as cerebrospinal fluid amyloid and tau levels or amyloid PET, in the absence of a global or functional outcome. The FDA guidance provides a potential roadmap to such approval, prompting some concern that approval based on marginal effects on sensitive disease markers in the end may be very costly, along with producing adverse effects in some people, without providing the clinically significant outcome of delaying the onset of dementia.⁶ There are checks and balances that should preclude a premature rush to approval. First of all, approval of new therapies requires consideration of risks as well as benefits, and the balance of these two would no doubt be thoroughly weighed in FDA deliberations. The guidance states that even if a drug for slowing disease progression at the preclinical stage were to get initial accelerated approval based on demonstration of significant effects on cognition, the pharmaceutical company would still have to continue with longer-term studies to prove benefits in the overall course of patients with AD.

Costs, reimbursement

Furthermore, if a new treatment is approved by the FDA, there is no guarantee that insurance carriers would agree to pay for such treatments, based on their own cost/benefit analyses. An example of potential progress in AD care that is currently bogged down by such cost-effectiveness considerations is the recently approved Amyvid® (florbetapir) PET imaging agent. On April 10, 2012, this imaging agent was approved for clinical use by the FDA, yet it is still not covered by Medicare and other insurers. On January 30, 2013, a panel convened by the Centers for Medicare & Medicaid Services recommended against coverage of

amyloid PET, citing only “intermediate” confidence that results affect health outcomes. While a final decision on whether to cover AV-45 amyloid PET will not take place until July, based on the panel’s review, a negative response is expected, while it awaits results of ongoing research studies aimed specifically at demonstrating significant effects on clinical decision making.

Overall, the recent FDA guidance on development of AD drugs has been welcomed by researchers in the field, because it provides a scientifically reasonable roadmap to at least weigh the evidence that will be coming from upcoming clinical trials of potentially disease-modifying therapies. The new day is dawning when a more enlightened approach to dealing with the huge and impending problem of AD is becoming a reality. In this regard, Rhode Island physicians will be interested to know that the Lieutenant Governor’s office in concert with the Department of Elderly Affairs is having regular meetings with health care professionals as well as town meetings with community members to design a statewide plan for AD care as part of the national AD plan. Interested people should contact Lindsay McAllister, Esq, Director of Health Policy, Office of the Lt. Governor, 82 Smith Street, Providence, RI 02903-1105; 222-2371, lmcallister@ltgov.state.ri.us.

Also, by the end of this year, a multicenter secondary AD-prevention trial, called Anti-amyloid Treatment in Asymptomatic Alzheimer’s Disease (A4), will be starting. In this study 1,000 people at risk for developing dementia of the AD type by virtue of having a positive amyloid PET scan will be assigned to placebo vs. solanezumab anti-amyloid antibody infusions and followed for three years for evidence of reduced cognitive decline along with effects on biomarkers. People interested in prevention trials such as A4 can enroll now in the Rhode Island Alzheimer Prevention Registry (“Prevent AD”) by calling 401-444-0789 or

emailing to memory@lifespan.org. In addition to being notified about current and upcoming prevention trials, registry participants receive quarterly newsletters about the latest news in brain health.

The FDA is seeking public comment on the draft guidance for 60 days. Instructions on how to submit comments are included in a Federal Register notice.

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The Pulse of Pediatrics in Rhode Island

SHARON W. SU, MD, FAAP
GUEST EDITOR

Sharon W. Su, MD, served as Assistant professor of pediatrics in the Division of Pediatric Nephrology, Department of Pediatrics at The Warren Alpert Medical School of Brown University. She recently relocated to Portland, Oregon, to become medical director in pediatric nephrology at Randall Children's Hospital and affiliate assistant professor of pediatrics at Oregon Health and Science University.



I was invited to introduce hot topics in pediatrics presenting in Rhode Island. Many exciting and innovative projects and services are currently underway in the Department of Pediatrics at Hasbro Children's Hospital, a major teaching hospital for the Warren Alpert Medical School of Brown University. Below is a sampling of local issues that are being addressed by its pediatric faculty.

Articles at a glance:

Health Care for Gender Variant or Gender Non-Conforming Children

Dr. Michelle Forcier and Emily Haddad, LCSW, aim to educate healthcare providers regarding a very high-risk and vulnerable population – children who exhibit gender non-conforming behaviors persisting into adolescence. They argue that early recognition, collaboration among medical providers, and supportive family interventions may improve social and mental health outcomes for these children.

Preschool-aged Wheezing

Dr. Nico Vehse re-addresses a common but often misinterpreted physical finding – wheezing. He reiterates the old adage, “all that wheezes is not asthma,” by delineating the difference between bronchiolitis and pre-school asthma.

Health Care Transition in Rhode Island for Adolescents with Special Health Care Needs: A report on the development and use of a clinical transition service

As children with chronic illnesses survive into adulthood, pediatricians are faced with the challenge of transitioning these patients over to adult medical care. Dr. Sue McLaughlin and colleagues tackle this emerging problem by developing a pilot program that offers multidisciplinary transition services to healthcare providers in Rhode Island.

Health Screening of Newly Resettled Refugees in a Primary Care Setting

The federal Refugee Act of 1980 has resulted in more than 4300 refugees resettling in Rhode Island. Dr. Sylvia LaCourse and her colleagues discuss the success of the Medicine/Pediatrics Primary Care Center (MPPCC), an outpatient residency clinic at Rhode Island Hospital, in providing medical care to newly resettled adult and adolescent refugees since October 2008.

Building International Collaborations from the Ground Up: Brown University Partnership in Haiti and Ukraine

Global health is one of the fastest growing fields in medicine, particularly in the area of medical education. For over a decade, the Warren Alpert Medical School of Brown University has been a leader in global health. Dr. Natasha Rybak and her colleagues continue Brown's legacy in global health by discussing the development of 2 international medical programs – Haiti and Ukraine – and sharing the lessons they learned during the process.

Health Care for Gender Variant or Gender Non-Conforming Children

MICHELLE M. FORCIER, MD, MPH; EMILY HADDAD, LCSW

ABSTRACT

Most children explore various aspects of gender and sexuality as children. Youth with consistent, persistent, and insistent gender non-conformity or gender dysphoria are important to identify in the pre- and early-pubertal years as early intervention and support may be lifesaving. Those whose gender non-conformity persists into puberty and adolescence are most likely to identify as transgender. Blocking pubertal development at Tanner stage 2 for pre-pubertal, gender non-conforming children is a relatively new but reversible and highly beneficial strategy to delay puberty, giving patients and families time to come up with a transition plan. Early identification, collaborative support from healthcare providers and mental health clinicians, and supportive interventions for both children and families grappling with gender variance may improve social and mental health outcomes for what has traditionally been considered a high-risk, vulnerable population.

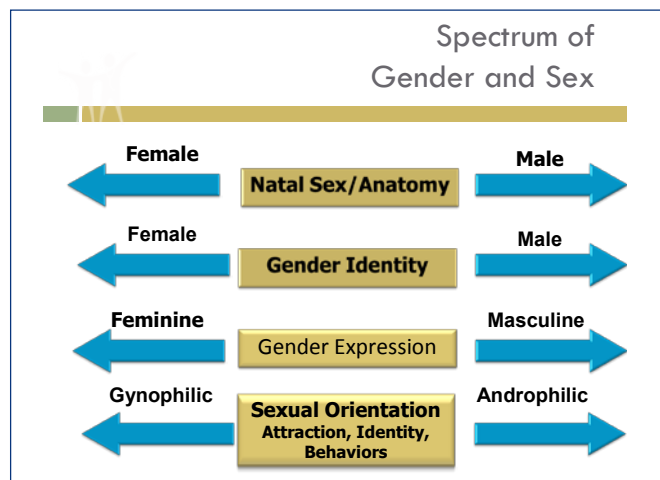
KEYWORDS: transgender, LGBTQ youth, child gender play

INTRODUCTION

Typically children are assigned their sex or gender at birth based on chromosomes, gonads and hormones, as well as visible genital anatomy. For most people the assignment of gender at birth is congruent with their gender identity, their innate sense of their own maleness or femaleness, as well as their social gender expression (appearance and behavior). However, there are some individuals whose internal gender identity does not correlate with natal or assigned gender. Gender-variant or non-conforming children may challenge parents, health care providers and society with issues and needs that extend beyond our typical binary approach to sex

CASE 1: Patient J. is an 8-year-old genetic and anatomic male who has a long history of playing with dolls, dressing up in female clothing, and using make-up. He would like to grow his hair long and wear more feminine clothing at school. Most of his friends are girls. His mother comes to your clinic concerned about what his behavior means and asks, "Is he gay?"

Figure 1. Spectrum of Gender and Sex



and gender. This article will provide a brief introduction to paradigms, terminology, and issues common to pre-pubertal gender variant children, as well as why early identification is important for those who have gender non-conforming behaviors persistent into adolescence.

Current western society views gender in a binary manner – male/man and female/woman – often with rigid internal and external expectations that people adhere to as hetero-normative gender and sexual conformity. Recent paradigms incorporate a more fluid or spectrum approach to gender and sexuality. These more fluid paradigms allow persons to define where they might fall and move along a spectrum of gender and sexuality (Figure 1).

Gender, sex, and sexuality are often confused (Table 1). Persons who have long standing incongruity between their natal gender assigned at birth and the gender they identify with are often called transgender, an umbrella term for individuals and communities whose identities do not conform unambiguously to conventional notions of male or female gender roles, but blend or move between them. While gender play and experimentation is common in all children, most children who play or explore outside the gender norms do not become transgender adults. Gender-variant youth make up a smaller but important subset of children, who consistently identify or express differently than their natal assigned gender. This subset of children benefits from early identification and support as they negotiate developmental milestones and the tasks of adolescence.

Table 1. Terminology and definition

Terms related to Gender Identity and Expression	Terms related to Sexual Identity and Expression
<p>Gender - characteristics culturally associated with femaleness or maleness</p> <p>Gender Expression - how a person expresses one's gender identity; external characteristics and behaviors</p> <p>Gender Identity - how a person perceives and feels gender; internal self-perception as masculine, feminine or other</p> <p>Gender Binary - concept of only two genders - male/female or man/woman, with persons strictly gendered as either/or</p> <p>Gender Non-conforming, Variant, or Diverse - person who does not conform to cultural or normative gender expectations</p>	<p>Biologic, anatomical or natal sex - usually determined at birth by external genitalia, but also includes chromosomes, hormones, internal and external reproductive organs</p> <p>Sexual Attraction - gender that a person is attracted to; attraction may be gynophilic, androphilic, both or neither</p> <p>Sexual Behavior - what one does for sexual intercourse and sexual satisfaction</p> <p>Sexual Identity or Orientation - how one labels his/her emotional, physical, and/or sexual attraction to others</p> <p>Straight - used to refer to people whose sexual orientation is heterosexual</p>
<p>Transgender (Trans, Transsexual) - person's gender identity and natal gender are incongruent; umbrella term referring to a group of people whose gender identity and/or expression does not conform to cultural norms</p> <p>Cisgender - person's natal gender matches asserted gender identity</p> <p>Transman (Female to Male, FTM) - identity label for natal females who transition to male identity and expression</p> <p>Boi - natal female who does not identify as, or partially identifies as female or feminine</p> <p>Butch - having what are conventionally considered masculine traits (physical, mental or emotional)</p> <p>Transwoman - (Male to Female, MTF) - identity label for natal males who transition to female identity and expression</p> <p>Femme - Feminine traits or identified person of any gender/sex</p> <p>Intersex - umbrella term for a variety of congenital conditions in which chromosomal, gonadal, genitals and internal sex organ development is atypical. Also known as Disorders of Sex Development (DSD)</p> <p>Androgynous - person appearing and/or identifying as neither male nor female</p>	<p>Homosexual - person primarily emotionally, physically, sexually attracted to same sex</p> <p>Heterosexual - person primarily emotionally, physically, sexually attracted to opposite sex</p> <p>Bisexual - person attracted to and has sexual relationships with both female- and male-identified persons</p> <p>Gay - a homosexual male or female</p> <p>Lesbian - a homosexual female</p> <p>Pansexual - someone who is sexually attracted to all or many gender expressions</p>

GENDER DEVELOPMENT

Understanding gender development from infancy through adolescence provides a framework and holistic perspective that can promote person-centered approaches to gender-variant and sexually-diverse patients. Early on, infants begin to learn about masculinity versus femininity through cues such as dress, hairstyle and even scents of caregivers. Gender identity begins to shape in the second year of life and can be relatively stable as early as 3–4 years old. Children

unconsciously perform gender-stereotyped activities based on social cues promoting socially acceptable behaviors. Most preschool children play with toys and games that are in alignment with their assigned birth gender.¹ A gender non-conforming child preferentially and consistently chooses non-sex-typed toys, games, activities, and appearance. Early gender nonconformity does not necessarily cause the child distress in and of itself, but can be challenging for some parents and families.

CASE 2: Patient M. is an 11-year-old genetic and anatomic female whose father says “was always a tom boy.” Her father says, “In the last year, she has become moody, and seems depressed. She is having more trouble at school.” Patient M. says, “I hate having a period.” On further questioning without her dad present, M. wonders if she is a lesbian, but also thinks she might be transgender after seeing a show on TV recently.

As children move into grade school, they understand and embrace more static concepts of established gender roles and sex differences.^{2,3} Most children, however, will explore some gender non-conforming behaviors in childhood as passing short-lived phases lasting several weeks to several years. Gender non-conforming children more typically engage in *consistent, persistent, and insistent*^{4,5} cross-gender play, activities, appearance and even body modification. Gender non-conforming children can also be differentiated from children experiencing a passing phase or experimentation by an expressed or unexpressed desire for alternative genitals or by expressing that they feel they are in the wrong bodies. In these school-age years, both parents and children may try to reshape and redirect gender non-conforming interests and expression into more socially acceptable norms for the child's natal gender.⁶ Youth who feel pressure to conform to a gender that they do not feel is their own may experience negative developmental outcomes such as low self-esteem, internalizing and externalizing symptoms, and isolation from peers and family.⁷

As childhood may be a more “gender neutral” time, for most gender-variant youth, puberty is a time of new and additional stressors such as the development of unfamiliar and unwanted secondary sex characteristics.⁸ The additional stress of negotiating the physical, social and emotional changes of adolescence in a body that does not fit with one's gender identity can contribute to poorer health outcomes. Gender dysphoria and variation is linked to isolation, anxiety, depression and suicidality. In addition, this dissonance and stress can lead to self-injurious behaviors such as cutting, burning, drug use and unprotected sexual activity. Many gender non-conforming adolescents have difficulty functioning academically and socially as puberty ensues. The prevalence of suicide attempts among transgender adolescents has been reported in some studies to be as high as 40%.⁹ It is important for health care providers to associate these health-risk behaviors and mental health concerns with gender nonconformity, as they may trigger providers to assess gender identity and sexual orientation.

EARLY DIAGNOSIS AND INTERVENTION

It is important that all healthcare providers have some understanding of gender variance and can recognize children who are struggling with non-conforming gender identity. Primary care providers, especially advanced nurse practitioners, pediatricians, and family doctors are often the first stop for parents with questions or concerns about gender non-conforming behaviors. As many gender-variant children exhibit mental health sequelae of experiencing this dissonance in natal versus identified gender, school nurses and counselors, social service professionals, and psychiatrists should also have a familiarity with features of gender non-conformity for early identification, early intervention, and support services.¹⁰

Evaluation of gender non-conformity has traditionally taken place within the discipline of mental health, with a focus on body and gender dysphoria. Currently gender non-conformity is captured in the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV), as “gender identity disorder (GID)”. At present, core components necessary for the diagnosis of GID in children include: “A strong and persistent cross-gender identification...persistent discomfort with his or her sex or sense of inappropriateness in the gender role of that sex, the disturbance is not concurrent with a physical intersex condition, the disturbance causes clinically significant distress or impairment in social, occupational, or other important areas of functioning.”¹¹ While these criteria may offer some insight into the experience of some gender non-conforming persons, there are many reasons why a pathologic approach does not suffice, nor does it promote understanding or acceptance to a range of diversity and expression of gender and sexuality.

It is important to make clear to parents and families that there are currently no accurate ways to “diagnose” which gender non-conforming pre-pubertal children will consider themselves transgender in adolescence. Studies report continuation rates range from 15% to 40%, with most gender non-conforming natal males going on to become homosexual identified men in adulthood.¹² While some gender non-conformity in prepubertal years is linked to later homosexual orientation, other studies show that as many as one third to one half of children referred to a gender clinic continued in adolescence with their gender non-conformity.¹³ The more

long standing the non-conformity, the more intense the body dysphoria, and the more assertive patients are about identity as opposed to activities, the more likely they will be to continue into adolescence as transgender.¹³

When working with families with prepubertal children who are non-conforming, the primary focus is to support the parents and recommend that children be supported for who and how they are.^{18,20} It is critical that parents



VIDEO Dr. Michelle M. Forcier recently appeared on the Katie Couric show to speak on transgender issues.

work through their own concerns and processes of confusion, loss, shame, guilt and fear with a mental health provider. Children who are not supported by their parents risk increased distress, trauma, anxiety, isolation, and other psychosocial challenges.¹⁴ Data from the California Family Acceptance Project demonstrates all sexual minority youth enjoy protective benefits with parental love and support. Even if parents do not understand or fully accept their child's gender identity or sexual orientation, family support offers tremendous protective effects in terms of depression, suicidality, and substance use.¹⁵

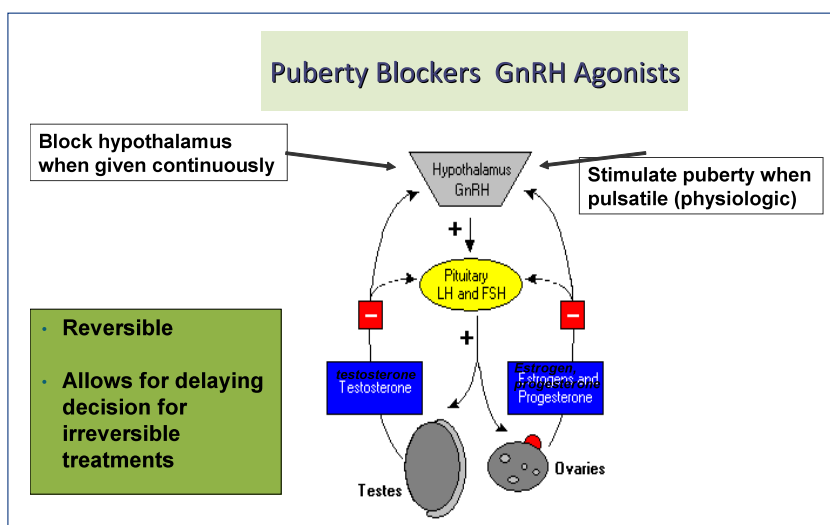
Mental health clinicians have an important role in the assessment and treatment planning for transgender youth. Mental health personnel can assess and differentiate between cross-gender interests and play versus transgender identification and gender dysphoria; evaluate identity in the context of the child's family and psychosocial environment; educate children and parents about gender identity and sexual health; model acceptance of gender non-conformity; evaluate and treat coexisting mental health concerns; and help children and families create safe, healthy and supported transition plans.^{16,5} Moreover, mental health clinicians can act as a liaison and advocate for children by working with schools, the legal system and medical providers.¹⁰

Creating a positive and successful transition plan includes: helping children and parents plan for disclosure to family, friends, school or playmates and other social contacts; educating staff and students within the school system; providing supportive documentation for name and gender change. Many families request a "safe letter" to provide to social and legal entities that explains their child is in the process of transitioning and under the care of health professionals. Most importantly, if there are any concerns about persons and environment as potentially harmful to a child and her/his disclosure, or social transition, guardians may want to consider containing gender non-conforming expression to the home until a safer plan is developed. Finally, medical and mental health providers should communicate frequently, especially if there are mental health concerns such as depression, anxiety, suicidal ideation, eating disorder, and/or substance abuse.¹⁶

MEDICAL INTERVENTIONS

During early childhood and up until pre-puberty, children who exhibit gender non-conformity should be encouraged to be themselves and explore a variety of gender interests and expressions. Parents should be reassured that the trajectory and outcome for gender non-conforming children is unpredictable. Many gender non-conforming children will become adults who are heterosexual (cisgender – when a per-

Figure 2. Puberty Blockers for Transgender Youth



son's anatomical gender matches a person's expressed gender identity) or homosexual (cisgender). Persistent, insistent and consistent non-conforming gender behaviors and expression may be more likely to lead to a future transgender identity.¹ When gender non-conformity continues unabated or newly emerges during puberty, these youth are more likely to identify as transgender.

Early identification allows medical providers to offer anticipatory guidance and proactive medical care. Most guidelines now recommend the use of gonadotropin releasing hormone agonists (leuprolide, triptorelin, gosreltin, or histrelin) as puberty blockers for gender non-conforming youth starting puberty, and addition of cross sex hormones later in adolescence (Figure 2). Blocking the progression of endogenous puberty allows youth to avoid developing unwanted secondary sexual characteristics and provides time and opportunity to more fully explore gender identity.^{10,17} Additional time allows parents and families to adjust their understanding of their child and their imagined future life; support parents and child in developing resiliency and social skills to better navigate successfully through adolescence; and to create a plan for transition that is safe and healthy for that teen.

Puberty blockers are completely reversible, allowing children to return and develop in the puberty of the natal gender without known adverse sequelae. Puberty blockers started at the very beginning of puberty, with the start of breast budding or testicular enlargement as well as initial pubic hair growth (Tanner 2 sexual maturity staging) maintain adolescents in temporary and reversible prepubertal state, with no further development of secondary sexual characteristics. Puberty suppression for transgender adolescence may reduce symptoms of depression and other emotional problems, in turn enhancing overall functioning.¹⁸ Eliminating development of secondary sex characteristics of the adolescent's natal, but not identified gender, allows for more congruent development of identified secondary sex characteristics when

cross-gender hormones are started and eliminates the need for many future cosmetic surgeries. Puberty blockers can make it easier for persons to “pass” in their identified gender as they mature into adulthood. Most continuing gender non-conforming adolescents desperately want to go through puberty in their identified gender and are both relieved and excited when they start puberty blockers and/or cross-gender hormones.

It is important to remember that some gender non-conforming youth do not desire complete phenotypic transition, and are content with their endogenous hormones, hormone-only treatment, partial surgical gender confirmation surgeries (i.e. mastectomy but not phalloplasty, breast implants but not penis or orchiectomy). Youth who identify as gender queer or androgynous may or may not want to take cross-gender hormones or take low doses that do not fully suppress their own endogenous hormones. Youth who can provide informed consent do not have to choose one binary end of the gender continuum over another. Furthermore, gender non-conforming persons may experience a more fluid identity and may change their transition goals and requests for treatment over time.

CONCLUSION

While most children explore various aspects of gender and sexuality as children, consistent, persistent, and insistent gender non-conformity or gender dysphoria is important to screen for and identify in the pre- and early pubertal years. Most gender non-conforming prepubertal children do not identify as transgender later in life but rather may identify as homosexual. Those whose gender non-conformity persists into adolescence are most likely to identify as transgender. Blocking pubertal development at Tanner stage 2 for prepubertal transgender children is a relatively new but highly beneficial strategy to delay puberty and decrease unwanted and distressing secondary sexual characteristics while supporting chosen puberty development. Early identification, collaborative support from healthcare providers and mental health clinicians, and supportive interventions for both children and families grappling with gender variance may improve social and mental health outcomes for what has traditionally been considered a high-risk, vulnerable population.

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Disclosures

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Preschool-Aged Wheezing

NICO W. VEHSE, MD

ABSTRACT

Wheezing is a common physical finding in the pediatric age group 0-4 years and can have multiple diverse causes. Infectious causes are the most common culprit and lead to bronchiolitis or preschool asthma. The identification and understanding of these causes is fundamental in the appropriate treatment of our patients. The differentiation and underlying pathologies of these 2 conditions can be confusing and complicated. A systemic review of these conditions attempts to alleviate some of this confusion and tries to provide some clinical guidance for the treatment of these patients.

KEYWORDS: wheezing, bronchiolitis, asthma, airway inflammation

INTRODUCTION

Infants and children younger than 6 years of age have frequent healthcare needs related to respiratory symptoms. The primary reason for seeking help is related to respiratory viral infections, as some children may present with lower airway obstruction and severe symptoms.¹ These symptoms may be difficult to treat due to multiple mechanisms causing lower airway obstruction in children ages newborn to preschool years. Airway malformations have been excluded as it necessitates a separate discussion.

Bronchiolitis

The first time an infant presents with wheezing – defined as a high-pitched expiratory chest auscultation sound – can be challenging. The differential diagnoses are extensive and objective data are very limited. The most common reason for these symptoms is bronchiolitis, but the use of the diagnostic term is variable. Some providers consider any patient with wheezing and an age younger than 2 years as bronchiolitis, whereas other providers may diagnose only infants younger than 6 months of age presenting with a first-time occurrence of wheezing. On review of the published research on bronchiolitis since 2005, most authors defined bronchiolitis by ICD-9 code, clinical diagnosis or included only first episodes of wheezing in various age ranges. Some authors included recurrent wheezing patients and some did not give any clear definition of bronchiolitis at all.



Nico W. Vehse, MD

The use of a positive respiratory syncytial virus (RSV) test was also used as part of the definitions. Therefore, bronchiolitis patients are a very diverse population in research and clinical practice.

Bronchiolitis is defined by the American Academy of Pediatrics (AAP) as: “a disorder most commonly caused in infants by viral lower respiratory tract infection (LRTI); it is the most common LRTI in this age group and is character-

ized by acute inflammation, edema and necrosis of epithelial cells lining small airways, increased mucus production, and bronchospasm.”² Bronchiolitis is initiated by an upper respiratory viral infection and numerous viruses cause bronchiolitis in infants, with RSV being the most common. Bronchiolitis is a self-limiting disease with 12 days as the median duration of illness for children <24 months, although 20% of children have a continuation of respiratory symptoms after 21 days. Hospital admission or emergency department assessment for respiratory and nutritional support is sometimes necessary.

Unfortunately the term bronchospasm polluted the definition of bronchiolitis and almost all studies assessing the treatment of bronchiolitis. In cases where patients suffer from bronchospasms due to reversible lower airway obstruction, the inhalation of short-acting-beta-agonist (SABA) bronchodilators will relieve these spasms, and therefore this type of bronchospasm should not be regarded as bronchiolitis. Assessing response to therapy is challenging in the absence of infant spirometry; nonetheless, respiratory scoring systems such as the one used at Hasbro Children's Hospital provide the best practical clinical assessment tool. A response to inhaled SABA on more than one occasion is very unlikely a false positive test and indicates reversible lower airway obstruction and not bronchiolitis. Thus, the respiratory scoring system can help exclude infants with reversible lower airway obstruction from the bronchiolitis population. This tool might help guide providers in clinical practice to more appropriate therapies.

REVERSIBLE LOWER AIRWAY OBSTRUCTION

Another very common reason for first-time wheezing in young infants and toddlers is reversible lower airway obstruction during respiratory viral infections.³ This can only be diagnosed by albuterol trials and clinical impression, as mentioned above. It is challenging to decide which infant might benefit from such a trial and no clear guidelines exist on how this trial should be performed. A trial of albuterol – three consecutive albuterol doses (2.5 mg/3ml) via nebulizer or four separate doses of 100 µg with a metered-dose inhaler (MDI) and a valved-holding chamber (VHC) – may be indicated.⁴ A good candidate for such a trial, but not exclusively, might be an infant with a family history of allergy, atopy, asthma or exposure to tobacco smoke. Many physicians are reluctant to diagnose an infant with recurrent and reversible airway obstructions as asthma and many other names are used to express the child's diagnosis, i.e. reactive airways disease, twitchy airways and others. This reluctance stems from the uncertainty regarding the chronicity of the child's respiratory condition.

Reactive airways disease, asthma, viral wheezing and all other used terms for these patients describe the same physiology of reversible lower airway obstruction from smooth, small-airway muscle spasticity. The etiology of these reversible airway obstructions is very diverse in the discussed age group and increasing diversity continues to be elucidated.⁵ As a result, long-term management of exacerbation prevention becomes complicated and requires very individualized approaches. All these children should be treated with inhaled SABA for symptom relief and the MDI with VHC-delivered method is the most effective and safest way to deliver inhaled medications to the lower small airways.

The prognosis for infants through preschool-aged children presenting with respiratory viral infections and reversible lower airway obstruction remains unknown. The best epidemiological study to date is the Tucson Children's Respiratory Study.⁶ This was a prospective cohort study identifying three distinct groups of children with different natural history of diseases: transient-early wheezers, late-onset wheezers and persistent wheezers. Patients with allergic sensitization had a later onset of symptoms and were most likely to continue with chronic asthma symptoms. Ongoing analyses of the data lead to the development of an "Asthma prediction index" for children with reversible lower airway obstruction during respiratory viral infections. Children with a first-degree relative suffering from asthma, atopy or allergies will have a 75% chance of having asthma symptoms past the age of 6 years. The same holds true for infants and toddlers with atopy or allergies themselves. It is important to remain mindful that nobody can prospectively decide if the patient in question is part of this 75% population or the 25% who will have resolution of symptoms.

The best evidence-based management for children with atopy and recurrent reversible lower airway obstruction is delineated in the 2007 NHLBI asthma guidelines⁷ used in the

United States or the PRACTALL Asthma European Consensus.⁸ These children can be confidently diagnosed with asthma around age 5 years when they can produce repeatable and reliable spirometry results. Prior to this, the provider has to rely on subjective impression of symptom relief from inhaled SABA. This population will be well cared for by their pediatrician or family practitioner by using the 2007 NHLBI guidelines, but might require specialist care if more than mild to moderate asthma control medications are needed.

Non-atopic children with acute, intermittent airway inflammation and recurrent, reversible lower airway obstruction will have respiratory symptoms during the respiratory viral season.⁹ Their exacerbations seem limited to episodes of respiratory viral infections and the season is traditionally from September through April. September and April are also the 2 months of the year with increased hospital admission for children with reversible lower airway symptoms.¹⁰ Therefore, therapy and guidance needs to be focused on this time period.

LOWER AIRWAY INFLAMMATION

Children without chronic lower airway inflammation seem to have very questionable benefits from daily, inhaled corticosteroids (ICS) alone. This can be explained by their acute intermittent lower airway inflammation during respiratory viral infections and the difference in their inflammatory cell profile. The cell profile during acute exacerbations is very different from those of mild, well-controlled asthmatics who derive great benefit from low-dose ICS on a daily basis. Neutrophils, not eosinophils or lymphocytes, are the major culprits during acute symptoms. Basic research has revealed that neutrophils and eosinophils respond very differently to low-dose corticosteroids. Eosinophils become readily apoptotic when exposed to low-dose corticosteroids and are readily taken up by macrophages in the airways. This uptake by macrophages is the essential step towards resolution of inflammation.¹¹ Apoptosis is less likely in neutrophils due to many environmental factors, including IL-8, G-CSF, local tissue hypoxia, low-dose corticosteroids and low extracellular pH.^{12, 13} Unfortunately, all these conditions are prevalent during lower airway obstruction.¹⁴ The prolonged activation of neutrophils results in release of their toxic substances into the airways, causing further acute and chronic inflammation. It is unknown why some children have a tendency to respond to this inflammatory process by developing bronchospasm and prolonged inflammation. Fortunately, treating these children with high-dose pulse systemic corticosteroids (2mg/kg/day) seems to provide acute relief and resolution of the neutrophil-induced airway inflammation.

No evidence exists for effective symptom control of children with intermittent, acute, viral-induced neutrophilic lower airway inflammation and reversible airway obstruction. Many personalized and empirically-derived treatments have been used in the past, but none of these

are evidence-based therapies. Some providers might use intermittent high-dose inhaled steroids, others might hold daily medications and use intermittent systemic steroids plus inhaled SABA. Others use both a moderate-dose ICS and a leukotriene-receptor antagonist (LTRA) during the critical period or for the high-risk patient.

It has been my practice to use the latter plus the addition of a very aggressive inhaled SABA schedule during upper respiratory infections. The rationale is to suppress the acute inflammation with ICS and to block the leukotriene-mediated pathway responsible for lower-airway neutrophil recruitment with LTRAs. In vitro studies have also demonstrated that the combination of corticosteroids and long-acting beta-receptor agonists might be beneficial in decreasing inflammatory markers during viral infections.¹⁵ It is unclear whether the regimens or the frequent close follow-ups are responsible for the provider's perception of efficacy of therapy. More likely, it is a combination of multiple factors.

Few novel anti-inflammatory medications have reached the market since the invention of ICS. LTRAs are one example; however, they are not effective when used as single agents to manage lower airway inflammation. ICS attenuates eosinophilic airway inflammation in asthma and remodeling of airway structures. LTRAs block leukotriene-mediated pathways of asthma. Despite the variety of medications available today, there is still no single safe therapy to manage neutrophilic inflammation in pediatric airways. The discovery of such a therapy would have far reaching impact on the treatment of cystic fibrosis, bronchopulmonary dysplasia, acute asthma exacerbations and viral-induced respiratory symptoms.

CONCLUSION

My practice in caring for the newborn through preschool population with recurrent respiratory problems is based on the physiology, immunology and chemistry of each individual patient. It has come to my realization that asthma is a poor diagnosis and more of a symptom description occurring during a respiratory syndrome. Unfortunately, none of the mentioned conditions have a cure. Preventative treatments are very limited and only symptom-relieving therapies are available for managing acute symptom exacerbations.

Patients younger than 6 years of age will continue to produce the highest healthcare cost and require frequent healthcare utilization until we are able to identify objectively the underlying mechanisms and control the causes of their respiratory symptoms safely and consistently. For now, we are best served by maintaining a keen clinical eye, providing good patient education and limiting environmental exposures through better infection and allergen avoidance. We should use our diagnostic terms wisely to avoid confounding the true underlying physiology, biochemistry, and biological factors causing our patients' suffering and to also help guide us to appropriate effective therapies for relieving their symptoms.

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Health Care Transition for Adolescents with Special Health Care Needs: A Report on the Development and Use of a Clinical Transition Service

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ABSTRACT

BACKGROUND: A growing population of adolescents with special healthcare needs is aging into adulthood. These emerging adults face the transition challenges of their healthy peers but also potentially heightened risks and challenges related to their conditions. We describe the process of developing a pilot program to support healthcare services for emerging adults with chronic conditions and present preliminary data on utilization.

RESULTS: An outpatient multidisciplinary consult model was developed based on patient, family and physician feedback. Patients with diverse conditions were equally referred from primary care, subspecialists and families and community agencies. Services provided included needs assessments (100%), referral to adult physicians (77%), care coordination (52%) and referrals to adult community services (10%). Clinical billing did not fully support the cost of providing services.

CONCLUSION: The pilot program offered multidisciplinary transition services that were utilized by a diverse patient population. Local and national resources for health care transition are provided.

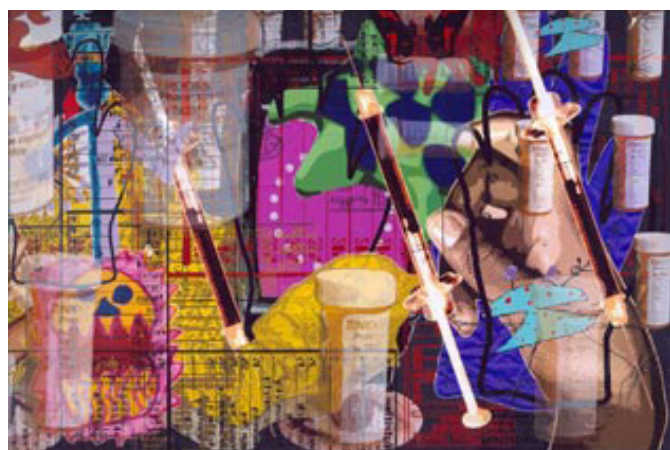
KEYWORDS: transition to adult care; adolescent; young adult

INTRODUCTION

Medical advances have dramatically improved survival rates for many conditions that had once been fatal in childhood. Survival rates in excess of 90% are now realities for children with conditions such as spina bifida, sickle cell disease, cystic fibrosis and cancer. Our success has created a new challenge: How will we care for these emerging adults with chronic conditions?

This article will review current data on transition in Rhode Island and provide results of a pilot program to support healthcare services for emerging adults with chronic conditions. Local and national resources for health care transition are provided.

Although all adolescents need to transition to adult roles in personal, social, educational/vocational and health domains, those with chronic conditions or disabilities can anticipate heightened risks and challenges in this process. Emerging adults with chronic conditions are a significant subset of any primary care practice. In Rhode Island, 1 in



Children in the transition clinic created this mural.

5 children between the ages of 12-17 are reported to have a special healthcare need,¹ defined by the U.S. Department of Health and Human Services as those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.^{2,3} Pediatricians and family practitioners need to prepare patients and families to transition to adult care models (even if continuing care within their practices) and internists need to be aware of issues common in transitioning this group.

Health care transition is defined as “a deliberate shift from pediatric to adult-oriented providers, settings and content of visits to provide comprehensive, age-appropriate care.”⁴ It is a key element of the patient-centered medical home and a core outcome measure for healthcare systems. However, national surveys indicate only 40% of eligible children report transition care. Rhode Island slightly surpassed the national average, but significant gaps included patients who reported a lack of discussions about transition to adult providers, changing health needs and insurance, and a lack of encouragement to assume increased responsibility for care. Adolescents with special healthcare needs (ASHCN) who lacked a medical home, were uninsured or of racial/ethnic minorities were less likely to receive transition services.⁵

Rhode Island Department of Health (RIDOH) surveys have reported a marked lack of comfort among adult primary care providers in caring for ASHCN and reported gaps in care during periods of transfer. Specific needs cited included written

transfer summaries and communication with pediatric care providers.⁶ Fewer than 1 in 5 pediatric practices had a coordinated process for transferring ASHCN.⁷ A survey of pediatric subspecialists practicing within Rhode Island identified availability of adult subspecialists, primary care providers and time within visits to address transition issues as the issues most frequently affecting their adolescent patients. Among options for adding services, the provision of a step-wise process of transition for providers and families, a written medical summary, written transition information and information on non-medical transition resources were priorities.⁸

MATERIAL AND METHODS

The Rhode Island and Hasbro Children's Hospitals Transition Consult Clinic was developed as a resource for health care transition of ASHCN. The structure and content was developed with input from key stakeholders, including RIDOH's Office of Special Healthcare Needs, the Rhode Island Parent Information Network (a family and patient advocacy network), CEDARRS (a pediatric community care coordination program), the Adolescent Leadership Council, adult community services providers, clinical managers (nursing) and subspecialty and primary care physicians. Preliminary needs assessments incorporated state-specific data from the 2009-10 Survey of Children with Special Health Care Needs, RIDOH data, pediatric and adult provider surveys⁸ and the input of patients and families at state forums and as represented by advocacy groups. An outpatient consultation model was proposed and included a multidisciplinary team supported by the hospitals and RIDOH. Interim goals for patient referrals, assessments and interventions were established. Data was collected on referrals, patient needs and interim outcomes, provider hours, services, and billing. Data collection on patient satisfaction and longer-term outcomes is ongoing.

Pre-visit contacts were conducted by the clinical coordinator or physician and sought brief information on condition and anticipated needs and goals from the referral source. Available medical records were reviewed. New patient visits incorporate a broad needs assessment, including a structured transition readiness tool, a review of the medical history and a physical exam. A post-session team meeting reviews the needs assessment and drafts a transition plan. Subsequent visits are scheduled as needed to allow review of emergency plans, medical summaries and written transition plans as well as follow-up of active medical issues and referrals. Summaries are provided to patients, families and primary and subspecialty providers in written and, if preferred, electronic versions. During the pilot period, our clinics adopted an outpatient electronic medical record (EMR). In-house technical support assisted in creating within the EMR a transition template, flowsheet and order set with patient handouts.

Table 1. Prevalence of conditions seen in transition consult clinic:

	N	%
Cognitive disability	9	29
Cerebral palsy	5	16
Metabolic disorder	5	16
Sickle cell disease	5	16
Wheelchair-reliant	5	16
Autism spectrum disorder	4	13
Rheumatologic (lupus, idiopathic arthritis)	3	10
Muscular dystrophy	3	10
Survivor of childhood cancer	2	6
Chronic kidney disease	2	6
Crohn's Disease, Down syndrome, seizure disorder, congenital heart disease	1 each	3

RESULTS

The outpatient consultation model was trialed over a two-year period. Due to limitations of provider availability, 21 sessions were scheduled. Fifty-five patients were referred, 31 patients were seen for a total of 40 patient visits and 11 did not keep appointments or rescheduled. Primary-care pediatricians, subspecialists and families and community agencies each represented ~1/3 of referral sources. One-third of patients not seen following referrals did transition their care to a primary care site providing services to pediatric and adult patients, but did not schedule specific transition consultation visits. Several other families requested specific service referrals but declined on-site consultation visits when contacted by telephone.

Patient characteristics

Patients ranged in age from 16-24 years (mean 19.6). Medical conditions varied, with more than half of patients carrying multiple diagnoses (Table 1).

Needs assessments and transition readiness

Parents identified more needs than adolescents. Adolescents often responded, "I don't know but want to learn to" regarding learning to contact their doctors and arrange visits independently, managing their money and budget, applying for jobs and obtaining financial assistance. Self-management skill needs most often reported included: describing medical condition, identifying risk signs/symptoms for condition, reporting medications and allergies, talking independently with a physician and knowledge of changes in insurance and benefit eligibility with change in age. All patients noted at least 1 skill they performed independently. Of 29 assessed self-care skills, slightly over half (52%) reported: "I am learning to do this"; or, "I have started doing this;" or, "I always do this when I need to." Almost half of families reported earlier discussions with primary or subspecialty physicians regarding a need to change providers as the ASHCN aged into adulthood. All families reported receiving at least one new care or service option when meeting with the advocate/adult services specialist.

Table 2. Transition Services Provided

	#	% of eligible*
Referrals:		
Care coordination	16	52%
Adult community services	3	10%
Adult subspecialist(s)	7	58%
Adult Primary Care	10	77%
Adolescent Peer Group (TALC)	11	84%
Medical Summary:	9	29%
Emergency Care Plan:	9	29%
Transition Plan:	9	29%
Transition flowsheet	7	22%
Transition needs assessment	31	100%
*Some patients were already enrolled in care coordination programs, had adult primary or subspecialists or other pieces of transition in place.		

Patient outcomes

An electronic medical record recording services and recommendations was created for all patients. Discrete elements of services are detailed in Table 2.

Time, effort and charges

Visits ranged from 45-120 minutes. All patients saw the physician, nurse coordinator and advocate/adult service specialist in their initial visit. Interactions with the adolescent peer group coordinator and family therapist were determined by needs assessments and patient and family's willingness. Pre-visit preparation averaged 20 minutes for the nurse coordinator and 20 minutes for the physician. Post-visit follow-up ranged from 15-45 minutes for the physician and 15-120 minutes for the nurse coordinator. The advocate/adult service specialist provided from 15 minutes-5 ½ hours of follow-up. Follow-up efforts ranged from summarizing visits and transition plans to direct contacts with schools, subspecialists and other agencies to home visits for additional needs assessment. Billing ranged from \$107-\$462.

An assessment of patient and family satisfaction with services and longer-term follow-up, including tracking progress through the EMR flowsheet, is ongoing. It remains to be established whether the services are financially sustainable on clinical billing. Transition clinics in other states are often additionally supported by institutional and grant funding.

CONCLUSION

Addressing transition issues in a busy primary or specialty practice is a significant challenge. Minor adaptations of our electronic health record to include flowsheets, timelines and easy-to-access screening tools support incorporating transition discussion into brief visits and monitoring progress on self-management skill development. The introduction of the concept of transition at an early age can allow for gradual introduction of necessary skills and empower patients and families to chart pathways to independence or condition-appropriate supports with guidance from their physicians. Explicit transition policies for practices cue patients and families to expectations and their responsibilities in this process.

(Note: Patients with significant issues or seeking added supports can be referred to the Transition Consultation Clinic at 444-6118.)

Useful online resources

RI DOH transition materials <http://www.health.ri.gov/special-healthcareneeds/about/adolescenttransition/index.php>
 RI Parent Information Network <http://www.startingpointsforriparents.org/transitions>
 National transition website: <http://gottransition.org>

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Health Screening of Newly Resettled Refugees in a Primary Care Setting

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ABSTRACT

Since October 2008, the Medicine/Pediatrics Primary Care Center (MPPCC) has been working with Rhode Island's refugee resettlement agency to coordinate medical care for newly resettled adults and adolescent refugees. The process includes obtaining extensive screening labs and providing immunizations. This review discusses the results of selected screening tests for latent TB, stool parasites, vitamin D, and vaccine-preventable diseases, such as hepatitis, performed as part of the initial intake exam during the first two years of operation of the MPPCC Refugee Clinic.

KEYWORDS: Refugee clinic, TB, hepatitis, Medicine/Pediatrics Primary Care Center

INTRODUCTION

The federal Refugee Act of 1980 provides for a fixed number of individuals seeking political asylum to relocate to the United States each year, and mandates specific health screenings and evaluations as part of the naturalization process. Since its enactment, more than 4300 refugees have resettled in Rhode Island, including 409 individuals in 2009–2010.^{1,2} Refugees are at increased risk of both infectious and non-infectious diseases, which often are not previously addressed, and their vaccination status is typically unknown.³ An intake exam is required within 30 days of arrival in the United States, or within 7 days for refugees who are HIV positive. Refugees are guaranteed Medicaid insurance coverage for only the first 8 months. Disease burden, limited insurance coverage, and vaccination requirements for naturalization increase the importance of timely diagnosis of conditions, initiation of treatment and referrals, and completion of immunizations.

The Medicine/Pediatrics Primary Care Center (MPPCC), an outpatient residency clinic at Rhode Island Hospital, has worked with the International Institute of Rhode Island (the state's primary refugee resettlement agency), to coordinate the medical care of newly resettled adult and adolescent

refugees since October 2008. Most pediatric refugees are seen at the Pediatric Refugee Intake Clinic at Hasbro Children's Hospital. The intake process occurs monthly in two structured clinic visits. The initial patient encounter is a nurse visit: the patient is oriented to the clinic, a tuberculin skin test (TST) is placed, a brief medical history is obtained and a standardized set of labs is drawn. The list of screening labs is comprehensive and includes: complete blood count with differential, malaria blood smear, urinalysis, vitamin D, glucose and cholesterol, lead (for children ages 6 months to 16 years), urine pregnancy test, HIV, rapid plasma reagin for syphilis, as well as urine for gonorrhea and chlamydia. Titers for hepatitis (A, B, and C), varicella, measles, mumps, and rubella are also obtained. Stool collection containers for the ova and parasite exam are provided to patients at this time and are returned at the intake physical examination two days later. At the intake physical, TSTs are read, stool samples are processed, and lab results are addressed by the resident who will become the patient's primary care provider, thus ensuring continuity of care. Immunizations are initiated at this visit as well.

This review discusses the results of selected screening tests for latent TB, stool parasites, vitamin D, and vaccine-preventable diseases performed as part of the initial intake exam during the first two years of operation of the MPPCC Refugee Clinic.

METHODS

Setting/Participants

We performed a retrospective medical record review of all patients who underwent intake exams at the MPPCC Refugee Clinic from October 2008–October 2010.

Analysis

Demographic data and results of screening tests

were collected from electronic medical records using a structured abstraction tool. Descriptive statistics were generated with SPSS software (version 17.0; SPSS Inc, Chicago, Illinois). This study was reviewed and approved by the Lifespan Rhode Island Hospital Institutional Review Board.



HASBRO CHILDREN'S HOSPITAL

RESULTS

During the course of the 23-month study period, 77 patients were seen for care at the MPPCC.

Demographics

Fifty three percent of the patients were female. Median age was 31 years (range: 4 months to 87 years), with 55% of patients between the ages of 20–39 years (Table 1). Country of origin was similar to national trends of refugee resettlement, with the majority of refugees emigrating from Bhutan, Iraq, Eritrea, Burundi, and Myanmar (formerly Burma) (Table 2).

Latent Tuberculosis

TST results were available for 95% of patients. Two patients had a history of pulmonary TB and therefore TST was not placed. Latent tuberculosis (TB) infection was diagnosed by TST > 10 mm in 64% of patients. Chest x-ray results were available in the electronic medical record for all but one of the patients with positive TSTs and were all negative for active pulmonary TB. Due to an increased suspicion for TB, two patients were diagnosed with latent TB infection using QuantiFERON (1 with a negative TST, 1 who did not have a TST placed) (Table 3). The latter test was performed at the RISE Clinic, a tuberculosis clinic sponsored by the Rhode Island Department of Health.

Stool Parasites

Most patients (92%) had their stool examined for ova and parasites. Forty percent of patients had stool samples that were positive for parasites, approximately 2/3 of which were potentially pathogenic. Fourteen patients (18%) had more than one parasite identified (Tables 3 and 4).

Table 1. Sex and Age of Patients

Sex	n=77
Female	41 (53%)
Male	36 (47%)
Age range (years)	n=77
0-19	11 (14%)
20-39	42 (55%)
40-59	16 (21%)
≥ 60	8 (10%)

Table 2. Region and Country of Origin of Patients at the MPPCC Refugee Clinic (October 2008 to October 2010)

Region (Total No.)	Country	No. of Patients n=77
Central Africa (12)	Burundi	10
	Democratic Republic of Congo (DRC)	2
East Africa (13)	Eritrea	11
	Somalia	2
West Africa (8)	Gambia	1
	Liberia	7
Middle East (13)	Iran	1
	Iraq	12
Southeast Asia (31)	Bhutan	22
	Myanmar (Burma)	9

Vitamin D

Ninety-five percent of refugees had their vitamin D levels checked. Vitamin D insufficiency (< 30 ng/ml) was detected in 71% of refugees. A striking 88% of refugees from the Middle East had vitamin D deficiency (< 10 ng/ml) (Table 3).

Table 3. Results of Selected Screening Tests Among Patients by Region of Origin

Screening Test	Region of Origin					No. of Patients
	Central Africa n=12	East Africa n=13	West Africa n=8	Middle East n=13	Southeast Asia n=31	
TST						
≥ 10mm	6	6	7	7	23	49 (64%)
Not performed	1	1 ^a	0	0	2 ^{a,b}	4 (5%)
Vitamin D 25 OH						
Insufficient ^c	6	11	3	9 ^d	26 ^e	55 (71%)
Not performed	0	0	0	3	1	4 (5%)
Stool parasites						
Positive	6	8	4	5	8	31 (40%)
Not performed	0	2	1	2	1	6 (8%)

^a 1 patient with history of pulmonary tuberculosis previously treated

^b 1 patient with positive QuantiFERON

^c vitamin D 25 OH < 30 ng/ml

^d 7 patients with vitamin D 25 OH deficiency w/ levels < 10 ng/ml

^e 1 patient with vitamin D 25 OH deficiency w/ levels < 10 ng/ml

Table 4. Parasites Found in Screening Stool Specimens^a

Potentially pathogenic	No. of Patients
Blastocystis hominis ^b	17
Giardia lamblia	8
Dientamoeba fragilis ^b	4
Hymenolepis nana	2
Hookworm	2
Trichuris trichiura	1
Iodamoeba butschlii	1
Entamoeba histolytica	1
Total	36
Nonpathogenic	
Entamoeba coli	9
Endolimax nana	5
Chilomastix mesnili	3
Entamoeba hartmanni	3
Entamoeba dispar	1
Total	21

^a 14 patients had > than 1 parasite

^b pathogenesis is controversial

Table 5. Results of Hepatitis B Screening

Hepatitis B immune status ^a	Region of Origin					No. of Patients
	Central Africa n=12	East Africa n=13	West Africa n=8	Middle East n=13	Southeast Asia n=31	
Immune						
sAb +, cAb -	4	2	0	0	4	10 (13%)
sAb +, cAb+	1	1	4 ^b	0	5	11 (14%)
Non immune						
sAb -, cAb -	6	8	2	12	17	45 (58%)
sAb -, cAb+	1 ^c	2 ^{b,c}	1	1	4	9 (12%)
Active infection						
sAg +, detectable viral load	0	0	1 ^d	0	1 ^d	2 (3%)

^a sAb = surface antibody, cAb = core antibody, sAg = surface antigen
^b 1 patient with Hep B core IgM consistent with recent infection
^c 1 patient with Hep BeAb positive
^d patient with Hep B core Ab positive, BeAb positive, with detectable viral load

Table 6. Immune Status and Vaccine Documentation of Measles, Mumps, Rubella and Varicella at Intake^a

	Region of Origin					Total No. of Patients
	Central Africa n=12	East Africa n=13	West Africa n=8	Middle East n=13	Southeast Asia n=31	
MMR						n=77
Immune	5	12	6	10	22	55 (71%)
Non-immune	1 ^b	0	0	1 ^c	1 ^d	3 (4%)
Not performed	6 ^e	1	2 ^f	2 ^g	8	19 (25%)
Documented MMR Vaccine at Intake	5	1	0	0	8	14 (18%)
Varicella						
Immune	9	8	8	10	30	65 (84%)
Equivocal	0	1	0	2	1	4 (5%)
Non-immune	2	4	0	1	0	7 (9%)
Not performed	1 ^e	0	0	0	0	1 (1%)

^a immunity defined per Lifespan laboratory guidelines
^b patient not immune to measles, but immune to mumps and rubella
^c patient not immune to measles and mumps, but immune to rubella
^d patient not immune to mumps, but immune to measles and rubella
^e 1 patient's age less than recommended for MMR vaccine
^f both patients empirically given MMR and varicella vaccine on day of intake, without drawing titers
^g 1 patient empirically given MMR and varicella vaccine on day of intake, without drawing titers

Vaccine Preventable Diseases

Seventy percent of patients lacked immunity to the hepatitis B virus (HBV) as demonstrated by negative antibody to hepatitis B surface antigen (anti-HBs). Twelve percent had isolated anti-hepatitis B core antibody (anti-HBc) positivity. Two patients had active HBV infection, (anti-HBsAg positivity) with detectable viral loads and were monitored and referred for additional treatment (Table 5). In addition, patients were screened for hepatitis A and C. No patients had active hepatitis A. Two patients had hepatitis C antibodies, but their viral load was undetectable.

Serologic immunity to measles, mumps and rubella was found in 71% of patients. An additional 18% of patients

had documentation of previously administered MMR vaccine. Immunity was assumed in these patients and thus corresponding serologic titers were not drawn. Serologic immunity to varicella was found in 84% of our patients (Table 6).

DISCUSSION

Refugee health care is challenging because of issues including diverse cultures and languages, burden of infectious and chronic diseases, naturalization requirements, and limited insurance coverage. The CDC provides guidelines for recommended screening for resettled refugees, which has been further expanded by large refugee health programs.^{4,5}

Refugees are often at risk for both the acquisition and secondary transmission of HBV, reflecting the often high prevalence of and under-vaccination for HBV in their country of origin as well as in refugee camps where many have spent years before arriving in the United States. Interestingly, our rates of HBV infection (3%) were lower than those found among refugees resettled in Atlanta (11%) and Minnesota (7%).^{6,7} Our results demonstrate that although many of our patients come from endemic HBV regions, definitive immunity as demonstrated by positive surface antibody was low at 27%. Isolated anti-HBc positivity may indicate occult hepatitis infection (with HBsAg below the detectable limits), loss of acquired anti-HBs, or false positivity. Isolated anti-HBc was found in 12% of our sample and exceeds rates previously documented at 7% among resettled refugees in Minnesota.⁸ However, when specifically looking among sub-Saharan refugees, our rate of 9% isolated anti-HBc was lower than that found in sub-Saharan African refugees resettled in Australia.⁹ Global hepatitis B immunization efforts have focused primarily on infants, therefore adult refugees are still likely to remain unvaccinated and unprotected upon their arrival to the United States. In our clinic, patients lacking anti-HBs-antibody were vaccinated.

Despite high rates of immunity to measles, mumps, rubella and varicella, not all refugees were immune and thus, could serve as source patients or be susceptible in future outbreaks. Susceptibility to a single disease protected by the MMR vaccine was much lower in our clinic (3%) compared to resettled adult refugees in Canada (34%), but similar to measles and rubella susceptibility in refugee children in Boston. Not surprisingly, our adult population had much higher rates of varicella immunity (84%) when compared to this same Boston pediatric refugee population, who showed only a 64% protection rate.^{10,11} Given recent outbreaks of

vaccine preventable diseases both domestically and internationally, it is crucial that refugees and other high risk populations are screened appropriately and receive timely immunization.¹² Some refugee clinics have moved to empiric vaccination without checking serologic titers, however the high rates of immunity to measles, mumps, rubella, and varicella among our patients support our current strategy of checking titers prior to immunization.

Over the past 15 years the rates of TB in the United States have been steadily declining with greater than 60% of cases occurring in people who were foreign-born.¹³ Seventy-eight percent of active TB cases identified in Rhode Island in 2008 were in foreign-born persons.¹⁴ The importance of proper screening and appropriate treatment of latent, active pulmonary, and non-pulmonary TB is critical to curbing the



spread of TB within the United States, especially with increasing rates of multi-drug resistant (MDR) TB worldwide. In our sample, almost all of the refugees diagnosed with latent TB by TST, had documentation of subsequent chest x-rays and proceeded to receive latent TB prophylaxis. This not only decreases individual rates of reactivation TB but also decreases potential secondary transmission to vulnerable communities.

Many of our refugee patients had

potentially pathogenic stool parasites and received parasite-specific treatments. Current CDC guidelines recommend that refugees receive presumptive treatment of intestinal parasites prior to arrival in the United States based on their country of origin. These guidelines were recently changed to include treatment to cover the risks of *Strongyloides* and *Schistosoma* species, which have been shown to be among the most important pathogens with the potential to cause latent and severe infections. However, most of our patients lacked documentation of having received presumptive therapy, and therefore it is unknown whether our

patients benefitted from this intervention. Microbiological examination for ova and parasites has not been shown to be sensitive for *strongyloides* due to varied and intermittent shedding.¹⁵ Serology for *strongyloides* is now recommended by the CDC for all refugees regardless of origin and serology for schistosomiasis for refugees from sub-Saharan Africa.¹⁶ At the time of this review, serology for intestinal parasites was not routinely performed in

our clinic but has now been a recommended change.

Low levels of vitamin D have been described in resettled refugee populations, especially among children and women of childbearing age. Similarly low rates of low vitamin D were noted among Iraqis resettled in both Australia and Massachusetts.^{17,18} The high prevalence of vitamin D insufficiency in our Refugee Clinic supports the continued screening and treatment of this condition.

Establishing a structured refugee clinic enabled us to develop a standardized method to identify and treat infections, immunize against vaccine-preventable diseases, and correct nutritional deficiencies. Additionally we provided documentation of immunizations and/or of immunity which is necessary to access education, employment, and naturalization. This structured refugee clinic also benefited from consistent direct communication between health care providers, patients and resettlement agency staff, all of which facilitate our ultimate goal of providing a medical home. Our study was not designed to look specifically at the impact of a structured clinic on the provision of recommended screening; however, its design likely contributed to the high rates of screening coverage.

Recent refugee research in Rhode Island has focused on immunization status, importance of establishing a medical home, and healthcare utilization among pediatric refugees.^{19,20} This is the first study to document the results of initial screening in adult and adolescent refugee patients in a primary care setting in Rhode Island. Our refugee population is diverse and will continue to change, reflecting larger international trends of conflict and migration as well as the policies of the federal government. Areas of future investigation suggested by our study include an evaluation of the timeliness of delivery of required vaccines and a cost-benefit analysis of empiric immunization as compared to serologic testing prior to vaccination in adult refugee patients.

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Building International Collaborations from the Ground Up: Brown University Partnerships in Haiti and Ukraine

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ABSTRACT

The world is becoming more interconnected with a need for a global approach to healthcare. Brown University has remained a leader in global health through clinical service, education, cutting edge research and dedication to the development of sustainable global partnerships. We describe two programs from the ground up in Haiti and Ukraine, and the important lessons learned in their development.

The path towards the development of global health programs in Ukraine and Haiti both illustrate that although circumstances may vary between global health programs, the recipe for successful collaboration is the same: identifying specific needs, developing strong and sustained partnerships, and addressing barriers by crafting effective solutions to ongoing challenges.

KEYWORDS: Haiti, Ukraine, Global Health, international collaboration, internationalization

INTRODUCTION

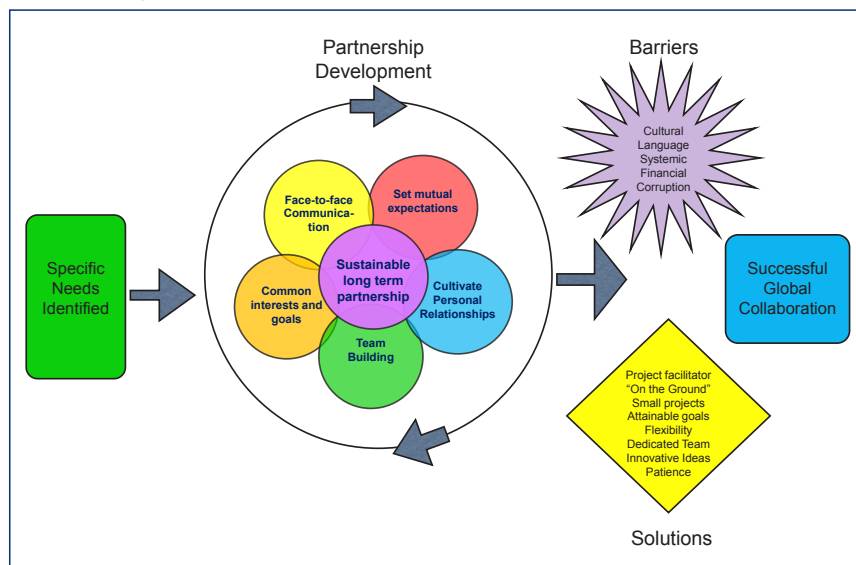
Many academic institutions have increased their focus on global health over the past few years. Migration and increasing foreign travel have mitigated geographic barriers of disease transmission. SARS, drug-resistant tuberculosis, and the 2009 H1N1 influenza epidemic are prime examples of global dissemination of diseases. Global health seeks interconnected solutions to problems of economic development, access to quality health care, and barriers to care. Addressing these issues through a multi-disciplinary approach involving economic, environmental, political, and global cooperation is reflected in the priorities set forth by university global health programs.

Brown University remains engaged in global health through clinical service, medical education, and cutting edge research. Brown faculty and trainees of all levels continue to respond to global inequalities of health and access to care. The most successful interdisciplinary program at Brown is the Academic Model Providing Access to Healthcare (AMPATH) program with Moi University in Eldoret, Kenya. AMPATH has set the standard for long-term sustainable

inter-institutional collaboration by promoting health through high-quality patient care, improving capacity through medical education, and mutually strengthening research programs both in the United States and Kenya.¹⁻²

The creation of new programs in global health begins with identifiable needs and develops through bilateral partnerships aimed at addressing those needs in an equitable collaboration. The goal of this article is to describe two new programs, developed from the ground up, in Haiti and Ukraine and the lessons learned in developing new collaborations (Figure 1).

Figure 1.



DEFINING NEEDS

Haiti

Prior to the earthquake that devastated Haiti in 2010, its health statistics were the most dismal of any country in the Americas. Poverty, malnutrition, pregnancy-related mortality, and mortality of children under five only begin to frame the health issues facing the country.³ Despite the outpouring of international efforts after the earthquake, Haiti's health system remains fractured and failing.⁴ One critical factor is the lack of trained professionals. The target physician density set by the World Health Organization (WHO) is 2.3 per 1000, and in Haiti the density is only 0.25 physicians per 1000 Haitians, compared to 2.67 in the United States, or



Drs. Sybil Cineas, Susan Cu-Uvin, and Timothy P. Flanigan navigate the ruins in Haiti after the January 2010 earthquake.

1.8 in the neighboring Dominican Republic.³ Overwhelmed with the patient load of the hospital and private practices to run on the side, academic physicians have limited time to spend training medical students and residents. The paucity of clinical training opportunities leads to under-investment in trainees who are ill-equipped and unprepared to see patients on their own. Without adequate in-country experiences, many trainees seek international settings to learn, and often do not return.

Drs. Susan Cu-Uvin, Timothy Flanigan, Michael Koster, and Sybil Cineas (Brown clinical faculty) with the support of Patrick Moynihan (president of The Haitian Project), toured several hospitals in the Port-au-Prince area during March of 2010. It was clear that St. Damien, a children's hospital in Tabarre, distinguished itself as a stable institution among the chaos of post-earthquake Haiti. We pursued a long-term partnership with key stakeholders at St. Damien to address the expressed need of providing in-country clinical education through bedside teaching to the medical students rotating from the Université Notre Dame d'Haïti (UNDH).

Ukraine

In 1991, Ukraine gained its independence from the former Soviet Union, but the health system remains a relic of vertically designed systems that are now barriers to quality care, especially for patients with HIV and/or tuberculosis (TB). At the same time, Ukraine has the highest rate of HIV infections in Europe and some of the highest rates of multi-drug resistant TB in the world. The incidence of TB has

increased from 32 per 100,000 in 1991 to 102 per 100,000 in 2009.⁵⁻⁶ This is a marker for not only a high rate of HIV, which has fueled the tripling of TB cases, but also a failure to appropriately address the epidemic on a national level.

Limited resources due to a transitioning health care system have caused intermittent drug supplies and contributed to multiple drug resistance (MDR). In some areas, the level of MDR has surpassed 20% of those patients treated for primary TB and is higher than 40% in those with previous treatment.⁶ Reimbursements and pay are very low for physicians, especially in the treatment of TB, resulting in an aging cohort of doctors all trained in an outdated and nonfunctional system. A patient with a diagnosis of TB and/or HIV may additionally be facing social stigma, economic hardships, and co-morbidities with other illnesses. A strong system of multidisciplinary care within a functional health care system is needed to address these issues. Although change in a system takes time, it also takes motivation and often support from global collaborators to encourage perseverance.

Key physician mentors from Brown, including Dr. Flanigan and Dr. Boris Skurkovich, have been able to work with Ukrainian collaborators to identify specific needs a partnership could address in Ukraine. These needs include improved clinical education for HIV/TB care for women and children and the creation of working multidisciplinary models of care. Some of the factors related to the success and implementation of these models of care are affected by societal perceptions influenced by the media as well as economic feasibility. Therefore our collaboration in Ukraine has

identified needs to include broad topics such as: 1) education to improve accurate and informative media coverage of HIV- and TB-related topics, and 2) research on the economic impact of HIV and TB epidemics on the economy of Ukraine.

DEVELOPING PARTNERSHIPS

Partnerships are the keystone of successful collaboration. They must be mutually beneficial, trustworthy and long-standing to sustain collaboration. Creating partnerships also takes significant investment, being on-the-ground with face-to-face time is essential to establish relationships, mutual trust and confidence.

Haiti

Our first partner in Haiti was with Louverture Cleary School (LCS), a free boarding school for disadvantaged Haitian children. LCS is run by The Haitian Project, a Providence-based nonprofit organization, which supported our logistics (security, transportation, room and board) during the first several visits in 2010, when strained medical institutions could not support volunteers.

During our first meeting with the St. Damien Hospital for Children's administration, there was significant distrust and resistance to involving another partner into a system that was already taxed. Recognizing that foreign aid can be distracting and draining to current systems, we first listened to the needs of the hospital and community. Most of the concern centered around past experiences of groups trying to change operations in one visit, without understanding the context of the economic, political, and cultural milieu. One critical issue identified was health-force shortage, especially well-trained pediatricians. Even within St. Damien's, most physicians lack pediatric residency training. There are barely enough doctors to cover the clinical service, and only a few are able to dedicate the time to teach students. We committed to a long-term partnership, offering to augment rather than change current practices. Repeat visits with the same core faculty demonstrated our dedication to the partnership and strengthened the working relationship both with physician colleagues as well as with administration.

In parallel, we continued to meet with the dean and key administrators at UNDH, including a visit in October 2010, where Dean Edward Wing of Alpert Medical School and Robert Klein, MD, chair of the Department of Pediatrics, traveled to Haiti to negotiate a memorandum of understanding between the universities and hospitals. This support was essential to achieving and maintaining successful negotiations. An LCS graduate attending UNDH medical school, with significant experience at St. Damien after the earthquake, operated as the on-the-ground liaison. This liaison was critical in facilitating communications and coordinating efforts of all partners. Next, during a month-long visit in March of 2011, we worked side by side with our Haitian colleagues and created an academic environment for students,

which was well received from the perspective of the students, as well as key stakeholders at St. Damien and UNDH.

Building on the success of supporting medical student education through lectures, bedside-teaching, and clinical education, we also pursued small research projects with Haitian collaborators at their request. Brown hosted a talented UNDH student, committed to pediatrics in Haiti, for a month-long elective in pediatric infectious diseases during the summer of 2011. At the same time, a faculty physician and social worker from St. Damien also attended the Brown University's Advanced Research Institute (BIARI) for HIV care. These activities again allow for significant relationship building and with their success have solidified the partnership. We continue to pursue further co-partnerships with larger institutions such as the American Academy of Pediatrics (AAP, Section of International Child Health), the Haitian Pediatric Society, and discussions with other U.S. academic institutions now becoming involved with St. Damien.



Dr. Ludmila Berojna and Dr. Natasha Rybak in Ukraine L'viv AIDS Center.

Ukraine

The development of partnerships in Ukraine evolved over a period of years starting as early as 2006. The partnerships began with several small unrelated medical trips by people related to Brown over a period of 5–7 years. Slowly the realization of an interest in the same region of the world was recognized and a group of interested partners coalesced. A collaborator on previous medical projects in Ukraine served as a cohesive source and facilitated several trips to seek out potential collaborators in the field of HIV/AIDS and TB. In parallel, an opportunity arose to fund improved care among women and children affected by HIV/AIDS in Ukraine and Brown University received the first grant to support work in Ukraine in September 2011. This created an opportunity to address many of the issues facing the barriers to care among HIV and TB patients in Ukraine.

The following year was spent making multiple trips to

BROWN



Touring a TB hospital in Kyiv, Ukraine.

Ukraine to meet with potential collaborators. The goal of these meetings was to create a multidisciplinary approach to care that addressed not only the medical care for patients, but also economic and social barriers to excellent care. These factors include the media perception and coverage of HIV and TB, health economics and how health of individuals affects the economy of Ukraine, and how social support and innovative technologies including cell phones can be adapted to make a difference in supporting patients through challenging treatment regimens. By identifying collaborators in these areas we were able to encourage dedicated people to present proposals to address these issues. We then were able to work with them to optimize and finance their proposals through the generous support of the ANTIAIDS Foundation. We are currently in the stages of financing projects and aiding in their implementation in Ukraine.

BARRIERS AND SOLUTIONS

Lack of time to spend on committed projects is the major barrier of collaboration. Usually both parties are working on these projects in "spare time" as these projects are in addition to their full-time responsibilities. Additional barriers include language, cultural differences, financial, social and historical constraints, assessment of benefit, and lack of commitment. Very often there can be a different approach to the normal work day or the standard form of communication from the norms in the United States and recognizing these differences can be critical in maintaining a working collaboration.

Many of these barriers can be alleviated with strong relationships that have weathered multiple projects together

over time. The key is identifying partners that are willing to work towards a common goal, maintain communication with frequent face-to-face visits, and flexibility to address barriers as they arise. The ability to address issues as they appear also greatly improves when a person who serves as a project manager/facilitator is able to be "on the ground." Creating a team of dedicated partners, especially a multidisciplinary team also helps solve problems. Consistent and diligent efforts are needed to continue the collaboration. With consistency over time the approach is more like walking a smooth road rather than climbing a hill. Starting with small projects and attainable goals, and building on success are critical to creating a long-lasting and productive partnership.

One example of a small project with the potential of success is the creation of a journal club. Journal clubs are a common occurrence in U.S. medical education, but unheard of in Ukraine. The introduction of a Skype journal

club between collaborators opened the doors of communication and discussion for new ideas and views of research and allows a safe forum for questions and brainstorming to foster clinical research.

This interactive process will be the cornerstone of a robust partnership, and has the capacity to blossom into a program like AMPATH that provides comprehensive care, improved education, and relevant research through an academic medical model.

CONCLUSIONS

The world is becoming more interconnected with a need for a global approach to not only health care but the multitude of issues affecting health. Understanding the contributing elements to successful collaborations on global health creates building blocks for future implementation of multidisciplinary solutions to global issues. The time and effort that is spent understanding and implementing joint global health projects among nations will enhance medical training and lay the foundation to successfully address any future array of problems such as economic development, cultural barriers and political instability, among many others.

The two programs described here illustrate that although circumstances may vary between global health programs, the recipe for successful collaboration is the same: identifying specific needs, developing strong and sustained partnerships, and addressing barriers by crafting effective solutions to ongoing challenges. Only through this mutually dedicated process can we hope to successfully build capacity and strengthen health care on a global level.

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Neurogenic Detrusor Overactivity: An Update on Management Options

EUGENE CONE; PAMELA ELLSWORTH, MD

ABSTRACT

Neurogenic detrusor overactivity (NDO) affects a variety of patients with storage and voiding dysfunction including those with multiple sclerosis, spinal cord injuries, Parkinson's disease, cerebral palsy, and myelomeningocele, and includes symptoms of urinary frequency, urgency, and incontinence. Primary treatment goals are 1) preventing renal injury, and 2) improving quality of life. First-line therapies include behavioral and anticholinergic agents, with onabotulinum toxin-A as the only FDA-approved second-line therapy, and non-FDA approved second-line therapies including neuromodulation, and intravesical vanilloids. Surgical intervention is reserved for those at risk for upper-tract deterioration and with persistent incontinence. In select individuals an indwelling catheter may be necessary.

KEYWORDS: incontinence, detrusor overactivity, neurogenic lower urinary tract dysfunction

INTRODUCTION

Patients with neurogenic detrusor overactivity (NDO) are a heterogeneous group with storage and voiding dysfunction. Symptoms of NDO include urinary frequency, urgency and incontinence. Neurologic conditions associated with NDO include multiple sclerosis (MS), spinal cord injury (SCI), Parkinson's disease, cerebral palsy and myelomeningocele. Neurogenic bladder dysfunction is present in 80.8% of individuals with MS, 90% with myelodysplasia, virtually all SCI patients with persistent neurologic deficits and 70% of ambulatory SCI patients.¹ NDO affects more than quality of life, increasing risk for urinary tract infection and upper urinary tract damage. The goals of treatment are (1) prevention of upper urinary tract damage and (2) improvement of symptoms to improve quality of life and promote independent living and rehabilitation.

Behavioral therapy is part of the management of NDO, but may be limited by the patient's underlying neurologic condition as well as social factors. The primary therapies for the management of NDO are anticholinergic therapies for patients with detrusor overactivity (DO) and poor compliance, and clean intermittent catheterization (CIC) for those with poor bladder emptying. Although not FDA approved,

neuromodulation (electrical stimulation) has been used in patients who have failed anticholinergics. Intra-detrusor injection of onabotulinum toxin-A is approved by the FDA for the management of NDO in patients refractory or intolerant of anticholinergics. In select individuals, a chronic indwelling catheter may be indicated. Surgical intervention may be indicated for protection of the upper urinary tract in high-risk patients or to achieve continence.

Anticholinergic Therapy

Anticholinergic agents inhibit the binding of acetylcholine to muscarinic receptors in the bladder detrusor muscle, decreasing involuntary detrusor contractions, increasing bladder capacity, and improving bladder compliance (ability of the bladder to accommodate urine at low pressure). Oxybutynin is the only agent currently FDA approved for the treatment of NDO in children; however studies have demonstrated efficacy with other anticholinergic agents in children and adults with NDO.²⁻⁵ Dose flexibility and extended-release delivery systems allow for dose titration and decreased incidence of side effects, particularly dry mouth. Angioedema of the face, lips and mouth has recently been reported with anticholinergics, and they are contraindicated in patients with narrow angle glaucoma. Anticholinergics may be poorly tolerated in the elderly because of memory, behavioral and cognitive side effects. Although anticholinergics are the mainstay in the treatment of NDO, there are few published randomized controlled trials.⁶

Intravesical therapies – the vanilloids, capsaicin, and resiniferatoxin – have been evaluated in the treatment of NDO. These agents increase bladder capacity and decrease urge incontinence by blocking C fiber afferent pathways. A systematic review of the efficacy and tolerability of the vanilloids in neurogenic bladder dysfunction demonstrated that capsaicin-treated patients had a reduction in incontinence episodes per day and a decrease in the number of pads used per day compared to placebo, but 50% of the capsaicin group reported pelvic pain and burning and flushing, compared to 25% with the placebo group.⁷ Currently, their use is investigational.

Onabotulinum toxin-A

In 2011, Onabotulinum Toxin-A (OnaBoNT-A) intra-detrusor injection was approved by the FDA for the treatment of urinary incontinence due to NDO in adults who have an

inadequate response to or are intolerant of an anticholinergic. When injected into the detrusor, the OnaBoNT-A toxin is taken up by the presynaptic cholinergic nerve terminal via endocytosis, binds to the SNARE protein complex, and prevents the binding and subsequent release of acetylcholine from the presynaptic nerve terminal.⁸ This prevents stimulation of muscarinic receptors in the bladder detrusor muscle. The recommended dose of OnaBoNT-A is 200 units, administered as 20-30 separate intradetrusor injections of 1ml each throughout the bladder, sparing the trigone. Treatments are repeated roughly every 10-12 months. The onset of effect is usually within 2 weeks of injection. The maximum dose injected anywhere throughout the body is 360 units over 3 months. A multicenter, randomized, double-blind, placebo-controlled study in patients with MS (154) and SCI (121) with a mean of 33.5 incontinence episodes per week at baseline treated with 200 Units of OnaBoNT-A demonstrated a significant reduction in the number of weekly episodes of incontinence episodes at 6 weeks compared to placebo (-21.8 vs. -13.2, $P = 0.01$). A significantly greater proportion of patients treated with OnaBoNT-A compared to placebo were fully continent at 6 weeks (38% vs. 7.6%). Patients undergoing intradetrusor injection of OnaBoNT must be willing to perform clean intermittent catheterization given the risk of post-procedural retention that may persist as long as the clinical response.⁹ Costs of 200 U of Botox may exceed \$1000 in many locations in the United States, not including cystoscopic or consultation costs.¹⁰

Neuromodulation

Neuromodulation, although not FDA approved for the treatment of NDO has been used in patients with NDO. Sacral nerve stimulation, posterior tibial nerve stimulation and anogenital stimulation have been evaluated.

Sacral nerve stimulation (Interstim, Medtronic, Minneapolis, MN) is approved for the treatment of urinary retention and the symptoms of OAB, but the safety and efficacy of SNS in patients with NDO has not been established. A recent review of the literature found a 92% overall success rate (defined as > 50% improvement in bladder diary variables) with permanent implantation in patients with NDO related to MS, SCI, pelvic surgery, and disc disease, over a mean follow-up of 26 months.¹¹ Chaabane et al noted that 66.1% of patients with neurogenic bladder dysfunction had more than 50% improvement on urodynamic evaluation and bladder diary.¹² A limitation of the use of SNS is the potential need for future MRIs as individuals who have had a permanent implant placed cannot undergo MRI.

Posterior tibial nerve stimulation is a less invasive alternative form of neuromodulation. The mechanism of action is unclear. It is thought to inhibit bladder activity by depolarizing somatic sacral and lumbar afferent fibers. Preliminary studies of PTNS in patients with NDO are limited but promising.

Catheterization

Chronic intermittent catheterization (CIC) is the recommended method for managing emptying problems in patients with neurogenic bladders.¹³ CIC reduces morbidity and mortality, and improves body image and self-esteem. Vandyananthan et al evaluated quality of life in patients with SCI before and during CIC plus oxybutynin. Patients on the CIC plus oxybutynin achieved socially acceptable continence with improved quality of life and enhanced sexuality. To be able to perform CIC, education and support, manual dexterity, and access to the urethra or catheterizable channel is needed. In select patients an indwelling catheter, urethral, or suprapubic tube may be preferred. Patients with impaired use of their upper extremities, obesity, and spasticity may have difficulties performing CIC and may benefit from a suprapubic tube. Suprapubic tubes tend to be better tolerated over the long term, allow for sexual function, and avoid the risk of urethral erosion. Complications related to indwelling catheters include infections, urethral erosion with urethral catheters, stones, and the potential increased risk of bladder cancer.

Surgical Intervention

Surgical intervention is indicated in patients with NDO when conservative therapies fail to protect the upper urinary tracts or don't achieve satisfactory continence. Such procedures are invasive, complex, and often irreversible, and include augmentation cystoplasty (bladder augmentation), urinary diversion, continent urinary diversion, and ileovesicostomy. The choice of procedure varies depending on the individual's bladder and sphincteric function, and ability to perform CIC. Utilization of bowel in urinary tract reconstruction may result in electrolyte abnormalities related to the absorptive properties of the bowel and therefore requires monitoring and treatment. Metabolic acidosis is the most common and may require treatment with alkalinizing agents.

Augmentation cystoplasty (AC) increases bladder capacity and decreases bladder pressure by augmenting the bladder with a "patch" of detubularized intestine, typically ileum or colon. A catheterizable abdominal stoma can be created for individuals who are unable to access the native urethra or in whom the bladder neck is surgically obstructed to promote continence. A meta-analysis by Campbell et al found complete continence rates ranging from 69%-100% at medium (1+ year) follow-up, and subjective improvement of symptoms in 78%-100% of patients.¹⁴ Complications of augmentation cystoplasty include persistent leakage, bladder perforation, bladder stones, vitamin B12 deficiency, mucus production causing catheter obstruction, and increased risk of bladder cancer. Urinary diversion utilizes a short segment of intestine to which the ureters are anastomosed, typically terminal ileum, to serve as a conduit for urine which is brought to the abdominal wall as a stoma with a collecting device placed over it. Complications include ureteroenteric strictures, stomal stenosis, parastomal hernia, and bowel

obstruction from adhesions, renal calculi and infections.

Urinary diversions can also be made continent via creation of a “pouch” of intestine that stores urine and is emptied by catheterizing an abdominal stoma. Indications are the same as for urinary diversion. Patients with a continent diversion report a significantly higher quality of life versus incontinent diversion patients. Risks related to continent urinary diversion include ureteroenteric stricture, stomal stenosis, conduit and renal calculi, infections, and bowel obstruction. Cutaneous ileovesicostomy is one such procedure whereby a short segment of ileum is anastomosed to the bladder and brought to the lower abdominal wall with a stoma.

CONCLUSION

NDO occurs in individuals with a variety of neurologic conditions. First-line therapies include behavioral therapy, anticholinergic agents and CIC. Onabotulinum toxin A is FDA approved for the management of NDO in patients with an unsatisfactory response or tolerance of anticholinergics. Neuromodulation, sacral nerve stimulation and posterior tibial nerve stimulation are not FDA approved for the treatment of NDO but may have some benefit. Surgical intervention is indicated when other therapies fail to protect the upper urinary tract or provide continence.

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Metachronous Cancer

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ABSTRACT

Metachronous cancer (multiple primary tumors developing at intervals) will appear more commonly as cancer patients live longer lives. In this report, we use data from the Rhode Island Cancer Registry to look at commonly occurring metachronous cancers, their frequency over time, and the implications for cancer survivorship. Sequence two (refers to the chronologically second primary tumor diagnosed for a given patient) and higher primary malignant neoplasms were identified in cancer case reports made to the Rhode Island Cancer Registry, 1987-2009, and used to construct annual, age-adjusted, sequence-specific incidence rates for all cancers combined, and age-adjusted, site-specific incidence rates for common second and higher-order primary malignant neoplasms over the entire observational period. During the period of observation, the proportion of all cancers diagnosed as sequence two and higher primary tumors among males increased steadily from 11.5 to 20.3 percent, while the proportion of all cancers diagnosed as sequence two and higher primary tumors among females increased from 12.8 to 20.7 percent. A mere four cancer types – lung (and bronchus), colon (and rectum), breast, and prostate – account for over half of all sequence two and higher cancer diagnoses (54.3 percent). The average interval between first cancers and second cancers is 6.5 years for men and 4.8 years for women. Such is the “career” of a cancer survivor today that he or she has about a one in four chance of developing a second cancer. This statistic suggests the need for strong and lasting social support networks. Furthermore, the average interval between first and second cancers is substantial, and suggests opportunities for interventions (prevention and screening) that might reduce the burden of sequence two and higher cancers.

KEYWORDS: cancer, metachronous cancer, survivorship

INTRODUCTION

Metachronous cancer (multiple primary tumors developing at intervals) will appear more commonly as cancer patients live longer lives. Second (and higher order) primary tumors

may occur simply as a result of aging, or as a consequence of previous cancer treatments. Patients who have been treated successfully for breast or prostate cancer (representing more than 40% of cancer survivors in Rhode Island), for example, may continue to smoke, may continue to enjoy unmitigated sun exposure in favorite outdoor activities, or may continue to have limited access to colonoscopies. As well, successful cancer therapy has been known to cause new primary cancers. For instance, after chemotherapy for pediatric cancers became successful (about 1970), many young cancer survivors went on to have second primary cancers 10 or 15 years after the conclusion of life-saving treatments.¹

In this report, we use data from the Rhode Island Cancer Registry to look at commonly occurring metachronous cancers, their frequency over time, and the implications for cancer survivorship.

METHODS

Sequence two [refers to the chronologically second primary tumor diagnosed for a given patient] and higher primary malignant neoplasms (stage 0 [refers to *in situ* tumors] and higher for cancer of the urinary bladder, stage 1 and higher for all other cancers) were identified in cancer case reports made to the Rhode Island Cancer Registry from January 1, 1987 through December 31, 2009. Cases thus identified were used to construct annual, age-adjusted, sequence-specific incidence rates for all cancers combined, and age-adjusted, site-specific incidence rates for common second and higher-order primary malignant neoplasms over the entire observational period. Data from the U.S. Censuses of 1980, 1990, 2000, and 2010 were used to construct age-and-sex-specific populations-at-risk, and the U.S. standard population of 2000 was used to effect age-standardization.

Note that sequence zero (0) and sequence one (1) are equivalent. Both represent the first cancer diagnosed for an individual patient. Sequence zero indicates the first and only cancer diagnosed. Sequence one indicates the first among two or more cancers. When a patient is diagnosed with cancer for the first time, the tumor is assigned *zero* as its sequence number. If the patient is later diagnosed with a second cancer, the sequence number of the first tumor is changed from *zero* to *one*, and the second tumor is assigned *two* as its sequence number.

RESULTS

Annual, age-adjusted, sequence-specific incidence rates for all cancers combined are listed in Table 1 and in Figures 1 and 2, by sex. During the period of observation, male age-adjusted, all-cancer incidence rates for tumors of all sequences increased from 522.9 per 100,000 in 1987 to a high of 661.7 per 100,000 in 2001, then decreased to 524.5 per 100,000 in 2009 (Figure 1). Meanwhile, the proportion of all cancers diagnosed as sequence two and higher primary tumors among males increased steadily from 11.5 percent in 1987 to 20.3 percent in 2009, almost doubling (Figure 3). Rates for females increased from 382.0 per 100,000 in 1987 to a high of 476.7 per 100,000 in 1999, then more or less plateaued through 2009, settling down to 452.3 per 100,000 at the end of the period of observation (Figure 2). Meanwhile, similar to the sequence-specific trend for males, the proportion of all cancers diagnosed as sequence two and higher primary tumors among females increased from 12.8 percent in 1987 to 20.7 percent in 2009, not quite doubling (Figure 3).

Over the entire period of observation, nine cancer types account for three-fourths (75.2 percent) of all sequence two and higher cancer diagnoses (Figure 4). A mere four cancer types – lung (and bronchus), colon (and rectum), breast, and prostate – account for over half of all sequence two and higher cancer diagnoses (54.3 percent). The average age of cancer diagnosis is 67.1 for males and 66.1 for females. Similarly, the average age of a first cancer diagnosis (sequence zero or one) is 66.0 for males and 65.2 for females, but the average

Table 1. Age-adjusted cancer incidence rates, RI residents by sex, sequence of cancer, and year of diagnosis, and percent of all cancers that are diagnosed as sequence two or higher cancers

Diagnosis Year	Male All Seq Incidence Rate	Male Seq 0 or 1 Incidence Rate	Male Seq 2+ Incidence Rate	Male Seq 2+ / All Seq Percent	Female All Seq Incidence Rate	Female Seq 0 or 1 Incidence Rate	Female Seq 2+ Incidence Rate	Female Seq 2+ / All Seq Percent
1987	522.9	460.5	62.4	11.5%	382.0	335.8	46.2	12.8%
1988	558.9	485.6	73.3	12.3%	422.2	369.4	52.8	13.0%
1989	531.5	465.3	66.2	12.3%	410.9	354.3	56.6	14.4%
1990	557.2	493.6	63.6	11.0%	413.5	361.8	51.7	13.1%
1991	590.8	512.5	78.3	12.5%	428.1	379.9	48.2	11.8%
1992	614.6	534.7	79.9	12.7%	438.9	385.2	53.7	12.9%
1993	625.3	544.0	81.3	12.9%	437.2	380.8	56.4	13.6%
1994	607.0	527.9	79.1	12.7%	446.2	389.6	56.6	13.5%
1995	615.6	532.3	83.3	13.5%	450.2	390.7	59.5	13.9%
1996	636.6	545.2	91.4	14.2%	455.8	392.2	63.6	14.6%
1997	636.4	542.8	93.6	14.4%	462.9	394.8	68.1	15.5%
1998	624.6	529.9	94.7	15.1%	450.6	381.4	69.2	16.4%
1999	633.7	530.2	103.5	15.9%	476.7	396.7	80.0	17.6%
2000	650.4	534.3	116.1	17.6%	459.4	381.4	78.0	17.9%
2001	661.7	543.7	118.0	17.2%	443.8	378.3	65.5	15.7%
2002	645.4	527.8	117.6	17.8%	460.2	387.8	72.4	16.6%
2003	608.9	492.7	116.2	18.5%	442.1	367.9	74.2	17.7%
2004	627.3	507.1	120.2	18.5%	465.4	387.2	78.2	17.3%
2005	585.5	469.2	116.3	19.1%	448.8	374.6	74.2	17.3%
2006	607.0	484.5	122.5	19.5%	467.5	378.7	88.8	19.7%
2007	606.7	482.4	124.3	19.8%	471.6	375.1	96.5	21.0%
2008	568.7	444.0	124.7	20.8%	457.9	371.8	86.1	19.8%
2009	524.5	411.7	112.8	20.3%	452.3	362.3	90.0	20.7%

age of a second cancer diagnosis (sequence two) is 72.5 for males and 70.0 for females. Thus the average interval between first cancers and second cancers is 6.5 years for men and 4.8 years for women.

When cancer sequences are examined in detail (Table 2), two patterns emerge. Some cancers tend to follow cancers of the same type – e.g., lung and bronchus, colon and rectum, breast, and melanoma of skin – while others tend to follow cancers related to a common risk factor, such as tobacco use – e.g., lung cancer following bladder cancer or kidney cancer.

Figure 1.

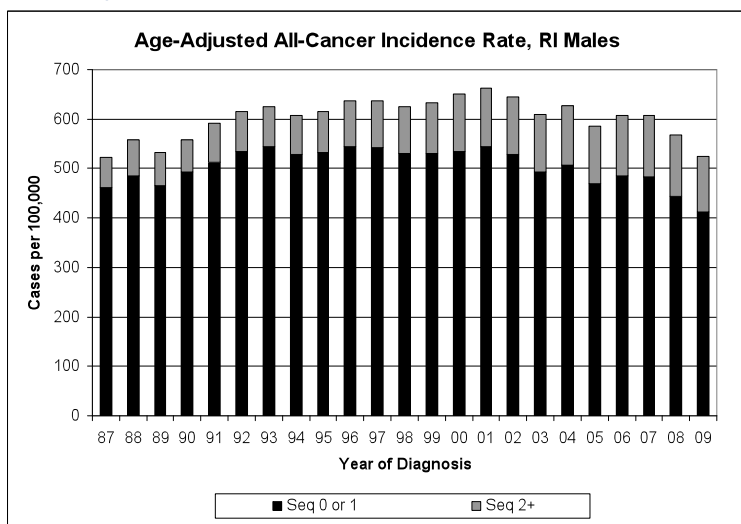


Figure 2.

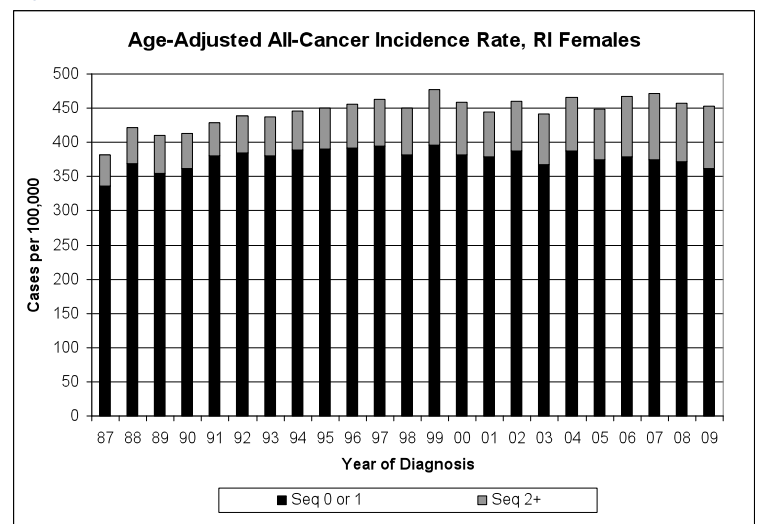


Figure 3.

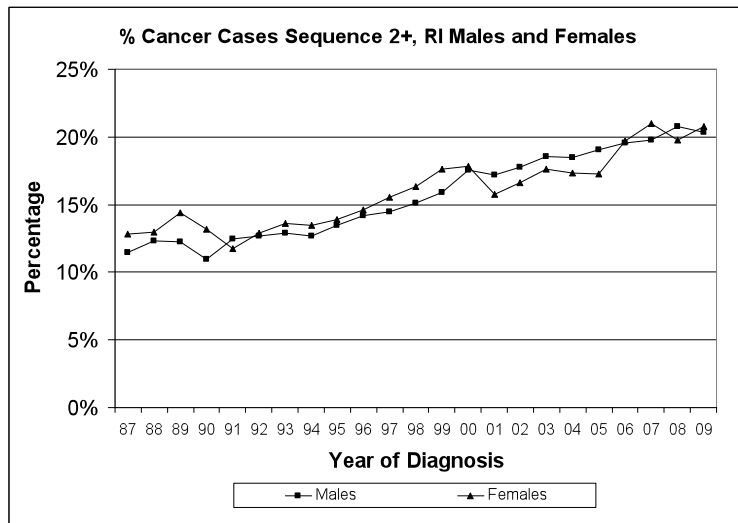
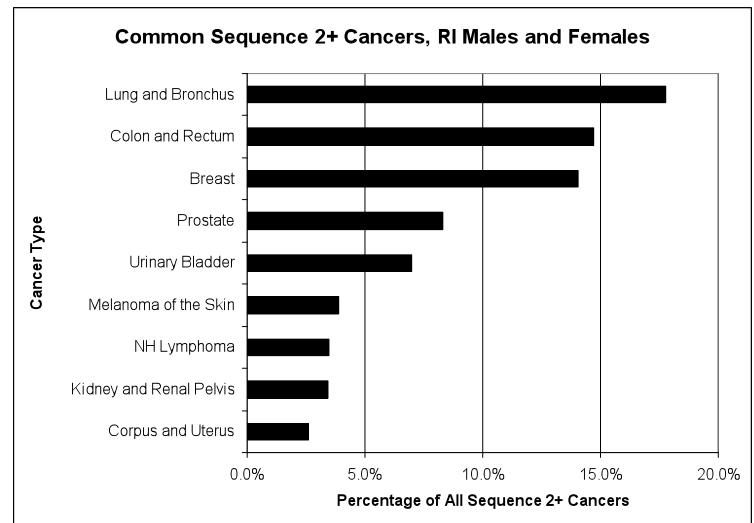


Figure 4.



DISCUSSION

At the present time, one out of five cancers newly diagnosed among Rhode Island residents is a metachronous (sequence two or higher) cancer. This proportion has increased over time, almost doubling over the 23 years of observation – for both men and women – with no sign of abatement. Among metachronous cancers, the most common (in order of frequency) are cancers of the lung and bronchus, colon and rectum, breast, prostate, and urinary bladder, melanoma of the skin, non-Hodgkin's lymphoma, and cancers of the kidney and renal pelvis and corpus uteri. The average interval between first and second primary cancers is not trivial: 6.5 years for men and 4.8 years for women.

In the present study we chose to confine our observations to those cancer cases that, by long-standing convention, are used to compute cancer incidence rates, namely all invasive neoplasms (excluding common basal and squamous cell carcinomas of skin) and *in situ* neoplasms of the urinary bladder. Doing so results in a moderate under-count of both first (sequence zero and one) and second (sequence two) *in situ* tumors, primarily of the female breast (about 16% of female breast cancers between 1987 and 2009, inclusive), but assures that our results are consistent with published incidence statistics from other jurisdictions. The bias thus introduced in calculating the proportion of sequence two and higher tumors is negligible. (For example, if *in situ* cancers of the female breast are used in calculating the proportion of sequence two and higher female cancers from 1987 through 2009, the proportion increases only slightly: from 16.1 to 16.3 percent.)

Table 2. Proportion of sequence two cancer types following each major sequence one cancer type, Rhode Island residents of both sexes, 1987–2009.

		Sequence-2 Sites											
		1	2	3	4	5	6	7	8	9	10	11	12
		LU	CO	BR	PR	UB	ME	NHL	KI	CU	OT	Total	(N)
	Sequence-1 Sites												
1	LU - Lung and Bronchus	0.37	0.09	0.08	0.08	0.05	0.03	0.02	0.03	0.00	0.26	1.00	788
2	CO - Colon and Rectum	0.13	0.31	0.09	0.14	0.04	0.02	0.04	0.02	0.02	0.19	1.00	1677
3	BR - Breast	0.10	0.10	0.42	0.00	0.01	0.03	0.03	0.02	0.07	0.20	1.00	1898
4	PR - Prostate	0.21	0.19	0.00	0.00	0.09	0.05	0.06	0.06	0.00	0.33	1.00	1717
5	UB - Urinary Bladder	0.20	0.09	0.03	0.36	0.01	0.01	0.03	0.07	0.01	0.19	1.00	692
6	ME - Melanoma of Skin	0.11	0.07	0.07	0.19	0.03	0.29	0.02	0.03	0.01	0.18	1.00	444
7	NL - Non-Hogkins Lymphoma	0.16	0.12	0.08	0.11	0.04	0.05	0.11	0.03	0.01	0.28	1.00	378
8	KI - Kidney and Renal Pelvis	0.17	0.10	0.05	0.18	0.09	0.02	0.05	0.15	0.01	0.19	1.00	288
9	CU - Corpus Uteri	0.11	0.13	0.23	0.00	0.03	0.02	0.02	0.03	0.01	0.43	1.00	396
10	OT - Other Sites	0.19	0.10	0.09	0.11	0.03	0.03	0.04	0.04	0.04	0.33	1.00	2114
11	All Sequence-1 Sites	0.17	0.15	0.13	0.09	0.04	0.04	0.04	0.04	0.03	0.26	1.00	10392
12	(N)	1818	1569	1398	965	418	418	418	418	279	2691	10392	

Such is the “career” of a cancer survivor today that he or she has about a one in four chance of developing a second cancer. This statistic suggests the need for strong and lasting social support networks. Not only must we avoid the word “cure” in describing an apparently cancer-free state, but we must avoid giving the impression that cancer is a once-in-a-lifetime phenomenon for those who must experience it. If we do not, we are doing a disservice to patients, one-fourth of whom will be diagnosed with a “new” cancer. Furthermore, this simple statistic (one in four) underestimates what we might call “the burden of survivorship,” because many patients who experience a once-only cancer do not live long enough to contribute many “person-years-of-survivorship.” Thus, the survivors who *do* contribute significantly to this risk pool are at higher risk – higher than a one in four chance – of being diagnosed again.

The average interval between first and second cancers is substantial, and suggests opportunities for interventions that might reduce the burden (morbidity, mortality, disability, and the costs of health care and lost opportunity) of sequence two and higher cancers. For example, were patients to adopt preventive behaviors or to comply with recommended cancer screenings, might not *some* second cancers be prevented entirely? Might not *some* lives be saved? Consider, for example, Rhode Islanders diagnosed with cancer for the first time (sequence zero or one) between 1 January 1995 and 31 December 2009 who were at least age 50. Among them are 513 men and 354 women who were subsequently diagnosed (sequence two) with colorectal cancer. The average duration between the first diagnosis of cancer (of any type) and a diagnosis of colorectal cancer was 2.7 years for these men and 2.8 years for these women. Might some of the colorectal cancers in question have had a better prognosis, if, after successful completion of treatment for the sequence one tumor (in a majority of cases, first course of treatment is completed within four months of diagnosis), patients had been screened promptly for colorectal cancer? Might some of these sequence two colorectal cancers have been prevented entirely (by the removal of pre-cancerous polyps)? The possibility is intriguing, and deserves further consideration.

Considerable attention has been paid over the past several decades to the development of metachronous cancers in childhood cancer survivors, and more recently, to malignancies of sequence two and higher among older adults.² Much of this attention has focused on iatrogenic malignancies caused by cancer treatments, and thus on the etiology and early identification of second primary tumors among patients who have received particular treatment regimens. But the effects of aging must also be given their due. Age and all it entails – duration of exposure, loss of immune-system function, accumulation of DNA replication errors, etc. – is the dominant risk factor for cancer. And one of the great ironies of our “wins” in the war on cancer is that patients are exposed to additional cancer risks as they age. The woman whose breast cancer is treated successfully with breast-sparing surgery in her mid-fifties may have three or even four decades of additional breast cancer risk – at ages when the risk of breast cancer is exceedingly high. Similarly, the fortunate man whose colon cancer is arrested at a very early stage may, later in life, be diagnosed with prostate cancer. Indeed, the risk of prostate cancer is so high among older men that such a scenario is quite probable. Thus we need to go beyond the questions we have asked about iatrogenic malignancies, and contemplate the wider significance of multiple cancers for increasing numbers of patients, caregivers, and healthcare providers. Will we reach a stage when cancer care is no longer considered episodic? Certainly, ever-lengthening treatment plans for specific types of breast cancer belie the traditional “episodic” cancer management paradigm already. What planning needs to be done – now – to address the implications of ever-lengthening cancer “careers?”

Fortunately, Rhode Island has a solid infrastructure from which to address these questions. All 11 private acute-care hospitals in the state have ACOS-approved cancer programs, with solid, data-based quality assurance processes in place. Hospital cancer registry data, contextualized by cancer statistics from the state’s central, population-based registry (a long-standing collaborative effort of the Rhode Island Department of Health and the Hospital Association of Rhode Island) have done yeoman’s service in the planning of new cancer services at big and small hospitals alike. And, after years of organizing, Rhode Island has a robust (and growing) cancer control coalition, the Partnership to Reduce Cancer in Rhode Island, in which all of the above, *and* many community-based agencies and many individuals from all walks of life have come together to address the state’s “cancer problem” and all its subsidiary issues. Notably, the focus of the Partnership has moved from the old bread-and-butter cancer control issues (smoking, sun exposure, cancer screening guidelines, and enrollment in clinical trials) to a greater interest in issues of “cancer survivorship.” On the basis of trends in survivorship and second cancers, the Partnership’s new focus would appear to be a wise one.

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Gestational Diabetes in Rhode Island

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Gestational diabetes mellitus (GDM) is a condition characterized by the onset or first recognition of glucose intolerance during pregnancy. In the United States there was a consistent increase in GDM prevalence of 46%-95% between the years 1990-2002.¹ Gestational diabetes occurs in approximately 7% of pregnancies, resulting in more than 200,000 cases each year, although the prevalence varies by population based on risk factors and diagnostic criteria.²

Gestational diabetes increases the chances of maternal and perinatal health complications during pregnancy. The unborn child or newborn is at risk for macrosomia, injuries at birth such as bone fractures and nerve palsies, hypoglycemia, shoulder dystocia, and respiratory distress syndrome. Maternal risks associated with GDM include hypertensive disorders, hyperbilirubinemia and preterm births. In order to reduce the complications of GDM, mothers are more likely to undergo cesarean section.³

In addition to the increased risk of adverse pregnancy outcomes, GDM may also lead to other serious long-term consequences. Among mothers with GDM, 5% to 10% develop type 2 diabetes immediately after the pregnancy. In the following 10 to 20 years after pregnancy, the risk of developing type 2 diabetes significantly increases to a range of 35% to 60%.⁴ Children born to mothers affected by GDM are more likely to have impaired glucose tolerance, obesity and impairment in neurobehavioral development.⁵⁻⁷

The symptoms of GDM are often overlooked, and therefore undergoing screening is very important in determining whether an expectant mother has GDM. Early detection allows the expectant mother to take the necessary precautions to manage the condition. There is evidence that the management of GDM reduces birth-related complications and future health risks.⁴

Certain populations are more prone to developing GDM than others. Risk factors include having GDM with a previous pregnancy, having delivered a newborn over 9 pounds, being overweight or obese, being age 25 or older, being

Table 1. PRAMS Phase 6 (2009–2010) population characteristics of women by diagnosis of GDM

	Women with self-reported GDM 12.3%, n = 313	Women without self-reported GDM 87.7%, n = 2233	Adjusted OR (95% CI) of self-reported GDM
Age (%)			
<20 years	5.0 (13)	8.8 (192)	—
20-24 years	10.7 (28)	21.6 (445)	—
25-29	32.3 (95)	28.1 (609)	—
30-34	28.7 (102)	24.7 (568)	—
≥35	23.3 (83)	16.8 (411)	—
Level of education (%)			
< High school	15.7 (45)	14.3 (290)	1.76 (1.11-2.79)
High school graduate	28.7 (73)	29.0 (552)	1.35 (0.94-1.94)
>High school graduate	55.6 (179)	56.7 (1211)	1.00
Ethnicity (%)			
Hispanic	24.7 (83)	22.5 (493)	1.34 (0.96-1.88)
Not Hispanic	75.3 (232)	77.5 (1684)	1.00
Race (%)			
White	63.3 (186)	65.1 (1349)	1.00
Black	5.7 (18)	7.2 (171)	0.91 (0.50-1.66)
Asian	5.8 (23)	3.5 (90)	1.82 (0.97-3.40)
Others	25.2 (80)	24.2 (539)	1.30 (0.92-1.85)
Income level (%)			
<\$50,000	64.0 (178)	57.8 (1174)	1.00
≥\$50,000	36.0 (117)	42.2 (869)	0.54 (0.39-0.74)
Medicaid Status (%)			
No	52.6 (172)	51.7 (1165)	1.00
Yes	47.4 (149)	48.3 (1053)	1.33 (0.97-1.83)
Previous live birth (%)			
None	38.3 (128)	46.5 (1085)	1.00
≥ 1	61.7 (191)	53.5 (1123)	1.18 (0.88-1.59)
Weight gained during pregnancy (lbs)	28.1 ± 0.96	33.1 ± 0.34	-0.0032 (-0.0046-0.0018)
BMI (%)			
Underweight (<18.5)	3.4 (9)	3.6 (91)	1.91 (0.82-4.42)
Normal (19.5-24.9)	33.6 (102)	55.1 (1159)	1.00
Overweight (25.0-29.9)	30.5 (99)	25.1 (506)	2.00 (1.40-2.85)
Obese (≥30)	32.4 (99)	16.2 (365)	3.28 (2.28-4.72)

*Adjusted for age

treated for HIV, and having a family history of diabetes. There are also racial and ethnic disparities in gestational diabetes with African Americans, Hispanics, American Indian, Alaska Native, Native Hawaiian, or Pacific Islander having higher risks relative to white women.⁸

In this study, we examined the prevalence of gestational diabetes, risk factors and outcomes associated with gestational diabetes specific to Rhode Island using data from the Pregnancy Risk Assessment Monitoring System. Identifying risks, consequences and disparities specific to Rhode Island is important for tailoring interventions.

METHODS

The Pregnancy Risk Assessment Monitoring System (PRAMS) is a collaborative surveillance project of the Centers for Disease Control and Prevention (CDC) and 37 state health departments.⁹ Data from 2009 and 2010 were collected from the ongoing, mixed-mode, cross sectional Rhode Island PRAMS survey. The survey was administered to mothers who recently gave birth to live-born infants, identified through the state's birth file. Information was collected on the attitudes and behaviors before the pregnancy, during the pregnancy and shortly after the pregnancy. Between 2009 and 2010, PRAMS collected data from a total of 2,576 mothers, yielding a 68.8% response rate. After removing observations with invalid information for GDM the final analytic sample consisted of 2,546 participants.

Gestational diabetes was assessed using the self-reported question "During your most recent pregnancy, were you told by a doctor, nurse, or other health care worker that you had gestational diabetes (diabetes that started during *this* pregnancy)?" To determine the demographic and socioeconomic profile of women with GDM, we compared women with GDM to women without GDM adjusted for age (Table 1). Additionally, we used chi-square tests to examine potential adverse outcomes, including large for gestational age, cesarean delivery, preeclampsia, labor complications,* preterm births and postpartum depression. To determine if the association between GDM and adverse outcomes differed by baseline body mass index (BMI) we used logistic regression to determine the odds of selected adverse pregnancy outcomes for women with GDM compared to women without GDM adjusted for age and stratified by BMI category. All analyses were performed using StataSE, version 11.1 to apply the appropriate weights and account for complex survey

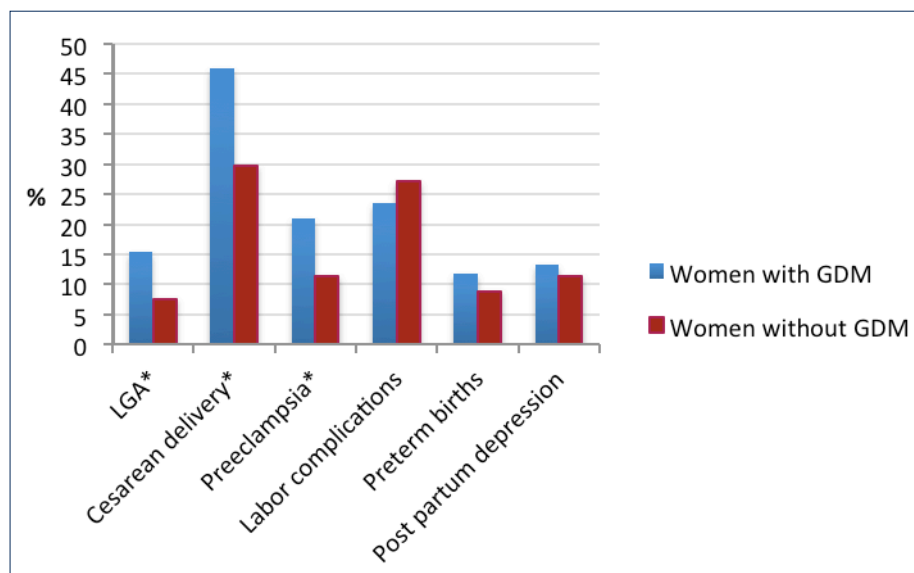
design. The percents and population estimates reported are adjusted to represent live births in Rhode Island.

RESULTS

In this study, 321 women [12.3%, 95% confidence interval (CI) 10.8–13.8] who had a live birth in 2009 or 2010 had self-reported GDM with their most recent pregnancy. Women with GDM were older (23.3% with GDM were ≥ 35 years old compared to 16.8% without GDM), more likely to have had at least one previous live birth (61.7% with GDM compared to 53.5% without GDM) and more likely to be overweight or obese prior to pregnancy (62.9% with GDM compared to 41.3% without GDM). When adjusting for age in independent logistic regression models, women with less than a high school education had higher odds of GDM compared to women who had at least some college (AOR 1.76; 95% CI 1.11–2.79). Women with high-income levels had about half the odds of GDM compared to their low-income counterparts (AOR 0.54; 95% CI 0.39–0.74). Compared to women with normal BMI, overweight women had increased odds of GDM (AOR 2.00; 95% CI 1.40–2.85) and obese women had even greater odds (AOR 3.28; 95% CI 2.28–4.72). After adjusting for age there was no significant association with ethnicity, race, Medicaid status or previous live birth (Table 1).

Women with self-reported GDM had a statistically significantly higher percent of adverse health outcomes such as large infants for gestational age, cesarean delivery, and preeclampsia but not labor complications, preterm births or postpartum depression (Figure 1). After adjusting for age, all women regardless of weight category prior to pregnancy

Figure 1: Table 3. Prevalence of selected health outcomes in women with self-reported GDM and without self-reported GDM



*Significant at 0.05 level

Table 2. Adjusted odds ratio of selected health outcomes in women with self-reported GDM vs. without self-reported GDM^a

	Underweight and normal BMI OR (95% CI)		P-value	Overweight and obese BMI OR (95% CI)		P-value
	Women with GDM	Women without GDM		Women with GDM	Women without GDM	
Large for gestational age	0.72 (0.17-3.01)	1.00	0.669	2.36 (1.20-4.62)	1.00	0.012*
Cesarean delivery	1.71 (1.06-2.76)	1.00	0.029*	1.93 (1.32-2.83)	1.00	0.001*
Preeclampsia	1.87 (0.95-3.65)	1.00	0.068	1.49 (0.94-2.35)	1.00	0.090
Labor complications	.67 (.39-1.15)	1.00	0.147	0.90 (0.59-1.37)	1.00	0.628
Preterm births	0.44 (0.31-0.63)	1.00	<.001*	2.04 (1.31-3.16)	1.00	0.002*
Post partum depression	2.20 (1.12-4.30)	1.00	0.021*	0.72 (0.40-1.32)	1.00	0.287

*Significant at 0.05 level

^aAdjusted for age

were at increased odds of cesarean delivery compared to their peers who did not have GDM (AOR 1.71; 95% CI 1.06–2.76 among women with BMI < 25 and (AOR 1.93; CI 1.32–2.83) among women with BMI ≥ 25). (Table 2) There were also statistically significant inverse associations between preterm births and GDM based on BMI status prior to pregnancy. Overweight and obese women with GDM had greater odds (AOR 2.04; 95% CI 1.31–3.16), whereas underweight and normal weight women with GDM conversely exhibited lower odds (AOR 0.44, 95% CI 0.31–0.63) compared to their peers without GDM. Among the overweight and obese women, those with GDM have 2.36 (95% CI 1.20–4.62) times the odds of having a large for gestational age child compared to those without GDM. A statistical significance in the relationship between GDM and postpartum depression was only observed in underweight and normal weight women (AOR 2.11, 95% CI 1.08–4.12). There were no significant associations between preeclampsia or labor complications and GDM in either BMI group.

CONCLUSION

The prevalence of GDM in Rhode Island was significantly greater than the estimated national average of 7%, comparisons with other states is difficult since different methods are used for determining GDM. Michigan rates range between 4.0 (based on birth certificates) to 8.6% (based on self-reported responses from PRAMS), while Massachusetts reported 6.9% (based on self-reported responses from PRAMS and birth certificates).^{10, 11} The prevalence of GDM in Rhode Island is greater than the prevalence of 9.3% self-reported GDM in Oklahoma, where obesity and diabetes type 2 are greater than the rates in Rhode Island.¹² Oklahoma's obesity rate in 2011 is 31.1% and percentage of existing cases of diabetes adjusted for age is 10.1% among adults, whereas Rhode Island has comparatively

lower rates of 25.4% for obesity and 6.8% for diabetes.¹³

The high prevalence in Rhode Island may be due to two factors other than an actual higher prevalence. A possible explanation for the high prevalence is that Rhode Island may have more complete assessment of gestational diabetes compared to other states. Another factor is the difficulty in discriminating between preexisting undiagnosed type 2 diabetes and hyperglycemia induced by pregnancy. Many women of childbearing age are not usually screened for diabetes; thus women with preexisting diabetes who are screened for the first time for diabetes during pregnancy may be mistakenly diagnosed as having GDM. Data from the 2009 Rhode Island Behavioral Risk Factor Surveillance System indicate that only 55% of women between the ages of 18 and 44 have been tested for diabetes in the past three years.

Currently, Rhode Island's Birth Medical Worksheet provides only one general option of 'Diabetes' for physicians to select. Two separate options, one for existing diabetes and one for GDM will be implemented starting with 2014 births. To address the issue of only having one diabetes option, secondary analyses were performed. First, women who self-reported previous diabetes were removed from the analyses, the resulting prevalence estimate was 12.0% (95% CI 10.5–13.5). Second, women for whom a physician indicated diabetes, either GDM or pre-existing type 1 or 2 diabetes, were removed from the analyses. The resulting prevalence estimate was 9.1% (95% CI 7.7–10.4), which is likely an underestimate since women with gestational diabetes would also be excluded.

The study has several strengths. PRAMS has a population-based sample, rather than clinical-based sample and thus reduces the bias of recruiting subjects that are more likely to attend clinical visits, to be more health-aware or have more comorbidities. Another strength of PRAMS is that although it is made up of primarily self-reported data,

the PRAMS survey data is linked to the birth file, thus allowing validation of medical information such as adverse pregnancy outcomes.

Despite these strengths, the study has two limitations. First, the self-reported measures of diagnosis of GDM and BMI before pregnancy are collected 2 to 6 months after delivery. This may lend to recall bias and reporting error, and thus may result in inaccurate measurements of the variables. Second, only women with live births were surveyed in the study. Therefore, the findings cannot be generalizable to all pregnancies, including women with stillbirths.

It is important to further explore the risk factors that are unique to Rhode Island that contribute to the high prevalence of GDM.

Footnote

* Labor complication includes one or more of the following conditions: febrile (>100 F), meconium (moderate/heavy), premature rupture of the membrane, abruption placenta, placenta previa, other excessive bleeding, seizures during labor, precipitous labor (<3 hours), prolonged labor (>20 hours), dysfunctional labor, breech/malrepresentation, cephalopelvic disproportion, cord prolapse, anesthetic complications, fetal distress.

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Rhode Island Monthly Vital Statistics Report

Provisional Occurrence Data from the Division of Vital Records

VITAL EVENTS	REPORTING PERIOD		
	OCTOBER 2012	12 MONTHS ENDING WITH OCTOBER 2012	
	Number	Number	Rates
Live Births	981	11,692	11.1*
Deaths	757	9,487	9.0*
Infant Deaths	8	72	6.2#
Neonatal Deaths	7	61	5.2#
Marriages	669	6,397	6.1*
Divorces	266	3,310	3.1*
Induced Terminations	239	3,619	309.5#
Spontaneous Fetal Deaths	16	466	39.9#
Under 20 weeks gestation	14	384	40.5#
20+ weeks gestation	2	77	6.6#

* Rates per 1,000 estimated population

Rates per 1,000 live births

Underlying Cause of Death Category	REPORTING PERIOD			
	APRIL 2012	12 MONTHS ENDING WITH APRIL 2012		
	Number (a)	Number (a)	Rates (b)	YPLL (c)
Diseases of the Heart	202	2,381	226.1	3,487.0
Malignant Neoplasms	175	2,199	208.8	5,594.5
Cerebrovascular Disease	46	415	39.4	535.0
Injuries (Accident/Suicide/Homicide)	61	744	70.6	9,564.5
COPD	40	510	48.4	380.0

(a) Cause of death statistics were derived from the underlying cause of death reported by physicians on death certificates.

(b) Rates per 100,000 estimated population of 1,052,567 (www.census.gov)

(c) Years of Potential Life Lost (YPLL).

NOTE: Totals represent vital events, which occurred in Rhode Island for the reporting periods listed above.

Monthly provisional totals should be analyzed with caution because the numbers may be small and subject to seasonal variation.

Paget's Disease of the Breast

ANA P. LOURENCO, MD; MARTHA B. MAINIERO, MD

CLINICAL HISTORY

A 61-year-old female presented to dermatology with history of a scaly, red lesion on her left nipple which had not resolved over several months. A skin biopsy of the area revealed Paget's disease of the nipple, which was estrogen receptor negative and progesterone receptor focally positive. She was then referred for breast imaging to evaluate the extent of disease.

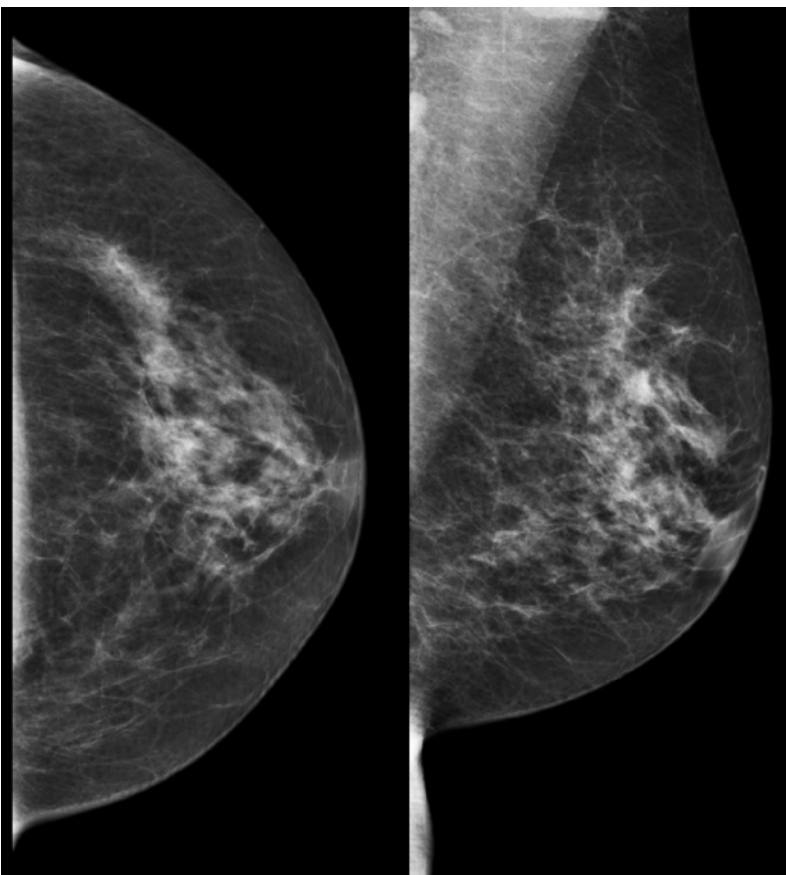


Figure 1 A and B. Left CC (A) and MLO (B) views from a digital mammogram show heterogeneously dense breast tissue with no suspicious masses or calcifications.

IMAGING FINDINGS

Digital mammogram shows heterogeneously dense tissue without evidence of suspicious mass or calcifications (Figures 1A and B). Ultrasound of the retroareolar left breast was also negative (Figure 2). Contrast enhanced breast MRI (Figure 3) was obtained and showed asymmetric left nipple enhancement, as well as segmental, non-mass enhancement in the retroareolar left breast extending into the upper central breast, measuring 5cm in greatest dimension. The findings were highly suggestive of ductal carcinoma in situ (DCIS). MRI-guided biopsy of the abnormal enhancement



Figure 2. Ultrasound of the retroareolar left breast is negative.

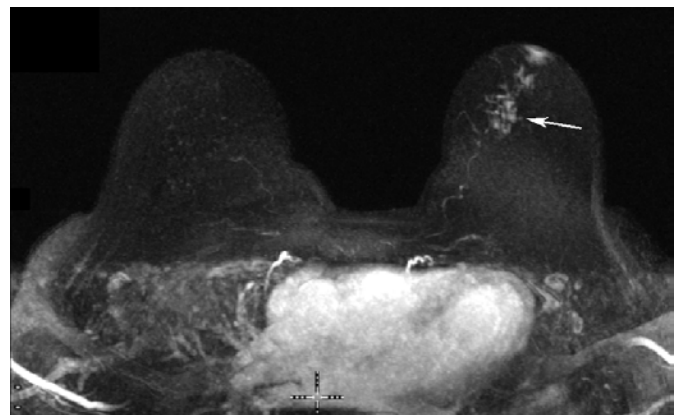


Figure 3. Maximum intensity projection image from a contrast enhanced MRI of the breasts shows suspicious, segmental enhancement in the left breast (white arrow).

yielded high grade DCIS with necrosis. Due to the extent of disease, the patient underwent mastectomy and sentinel lymph node biopsy with final pathology result showing high grade DCIS with microinvasion and no evidence of lymph node involvement.

PAGET'S DISEASE OF THE NIPPLE

Paget's disease of the nipple is an uncommon presentation of breast cancer, comprising <5% of breast carcinomas.¹⁻⁴ It classically presents with an erythematous, scaly rash on the nipple, and must be distinguished from other nipple dermatoses. The diagnosis of Paget's disease is made from skin biopsy of the lesion, and it is associated with an underlying breast malignancy in greater than 90% of cases.⁵ The majority of the associated breast carcinomas are DCIS, but invasive carcinoma can also be found. Traditional treatment for Paget's disease of the breast is mastectomy because clinical breast exam, mammography and ultrasound often cannot localize the underlying malignancy. However, up to 68% of patients have localized disease at final excisional pathology, and may be able to undergo breast conserving therapy.⁵ Multiple studies⁵⁻⁷ have shown that breast MRI can successfully identify an underlying primary breast malignancy in cases of Paget's disease of the nipple with negative mammogram and ultrasound. The largest series⁵ found that an underlying breast malignancy could be identified in 94% of patients with Paget's disease of the nipple, and that breast MRI had increased sensitivity over mammography. Preoperative breast MRI can help select those patients with localized disease who may be candidates for breast conservation.

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Medical School, PA Program at JWU Seek to Collaborate

PROVIDENCE – Brown University and Johnson & Wales University (JWU) have signed a memorandum of understanding to explore collaborations between the Alpert Medical School and the new physician assistant program at JWU.

The agreement, signed in March, outlines several areas for potential cooperation including sharing training facilities, jointly arranging lectures, pursuing educational grants, and engaging in cost-sharing.

“The collaborative training of physicians, physician assistants, and other members of the interprofessional health care team is an evolving national educational initiative,” said Dr. George Bottomley, director of JWU’s Center for Physician Assistant Studies.

“The new model of health care is patient-focused, IT-driven, and team-based,” said Dr. Edward Wing, dean of medicine and biological science at Brown. “Alpert Medical School is fortunate to partner with JWU to explore interdisciplinary training opportunities with its physician assistant program.

This new collaboration makes good sense as we work toward expanding the entire health care workforce in Rhode Island and beyond.”

The debut of the JWU PA program, the first in Rhode Island, comes amid greater recognition across the state that interprofessional education will better prepare health care workers for the future of care delivery.

Alpert Medical School, for example, holds interprofessional workshops twice a year that team its medical students with students from the University of Rhode Island’s nursing and pharmacy colleges, and Rhode Island College’s nursing and social work schools. Acting as a cohesive care team, the Brown, URI and RIC students diagnose and develop treatment plans for actors playing the role of patients in Alpert Medical School’s simulated doctors’ offices or

“clinical skills suites.”

Recognizing the increasing patient care responsibilities being placed on physician assistants, Johnson & Wales has developed a curriculum that emphasizes academic and clinical excellence.

JWU is renovating an 18,000-square-foot building at 157 Clifford St. that it bought last year for the new PA program, a mere 1,000 feet from the medical school. v



Johnson & Wales’ new physician assistant program will be housed in this building on Clifford Street in downtown Providence, in close proximity to the Alpert Medical School.

Rhode Island Hospital opens COBRE Center for Stem Cell Biology

PROVIDENCE – Rhode Island Hospital is expanding its research space in the city’s bio-med-focused Knowledge District with the opening of a new hematology-oncology laboratory, the COBRE Center for Stem Cell Biology in Lifespan’s Coro building.

The new 11,000-square-foot hematology-oncology research lab was made possible by a grant from the National Institutes of Health (NIH). The NIH conferred more than \$300,000 to Peter Quesenberry, MD, director of hematology oncology at Rhode Island and The Miriam hospitals, specifically for the construction of the new lab.

“This new lab space will help us to further study the use of stem cells for the treatment of many illnesses – various forms of cancer, tissue and organ damage and much more,” Dr. Quesenberry said. “By working closely with the physicians, we are developing new studies that stem from the patient – essentially, creating research in reverse, from the bedside to the bench, in an effort to develop new treatments for all-too-common and debilitating illnesses.”

The cancer studies being conducted are directed toward revising drug resistance in prostate cancer, chronic myelocytic leukemia and breast cancer.

Additionally, cutting-edge studies to develop better treatments for prostate and breast cancer are being conducted, as are studies of mesenchymal stem cells for their ability to reverse pulmonary hypertension. The laboratory also will support research in novel anti-cancer treatments for pediatric and adult malignancies, and will continue to examine therapeutic mechanisms underlying refractory leukemia and lymphoma. The new lab space can accommodate 14 laboratory benches, and can accommodate 10 funded investigators, as well as their technicians and students. v

Jay Publishes Research on New OA Prevention Treatment



PROVIDENCE – Researchers have found that adding lubricin, a protein that our bodies naturally produce, to the fluid in our joints may reduce the risk of or even prevent osteoarthritis (OA). The findings, in a paper by Gregory D. Jay, MD, PhD, of the department of emergency medicine at Rhode Island Hospital, is published online in advance of print in the journal *Proceedings of the National Academy of Sciences*.

The discoveries were made in part by studying the knees of mice, which genetically lack lubricin, causing an aggressive arthritis in spite of high levels of hyaluronic acid in the synovial fluid. A lack of lubricin, resulting in higher friction, leads to cartilage cell death - even in the presence of high

levels of hyaluronic acid, a viscous fluid that cushions the joints. This discovery appears to challenge the practice of injecting hyaluronic acid alone into a patient's joints.

"The lubricant is a protein, not hyaluronic acid, and currently, there are no disease-modifying treatments for osteoarthritis," Dr. Jay said. "Patients suffering from this degenerative joint disease either go through a total joint replacement, or are forced to live with pain every day. This discovery, however, supports that adding a lubricin replacement to the fluid in joints may in fact prevent osteoarthritis in those who have a genetic predisposition to the illness, or who have suffered significant trauma to the joints."

He added, "We are working to create a replacement for natural lubricin that we hope will significantly improve the treatment options, and ultimately prevention measures, for those with early osteoarthritis, or those with joint injuries."

The study was funded by a grant from the National Institutes of Health.

Other researchers involved in the study are Kimberly A. Waller of Brown University; Ling X. Zhang of Rhode Island Hospital; Khaled A. Elsaid of the Massachusetts College of Pharmacy and Health Sciences; Braden C. Fleming of Rhode Island Hospital and Brown University; and Matthew L. Warman of Boston Children's Hospital v



PHOTOS: RHODE ISLAND HOSPITAL

Brown, Whiteley Receive \$1.5M Grant

Researchers will study mobile app to engage young adults with HIV

EAST PROVIDENCE – Larry Brown, MD, and Laura Whiteley, MD, adolescent behavioral researchers from the Bradley Hasbro Children's Research Center, have been awarded a \$1.5 million grant to improve antiretroviral treatment (ART) adherence in HIV infected youth and young adults.

The study, funded by The Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD), will explore the use of a mobile phone app/game to better inform youth about their health needs and improve their adherence to treatment.

"Optimal outcomes in the treatment of people living with HIV require consistent attendance to medical appointments and high compliance to antiretroviral

In the study, young adults between the ages of 14 to 24 who are HIV positive will have access to an action-adventure smartphone based app/game called "Battle Viro."

treatment," said Dr. Whiteley. "Treatment adherence is associated with enhanced CD4+ cell count, reductions in HIV viral load, decreased transmission and an overall decrease in risk of death. Teaching young adults with HIV how to better manage their health is crucial to their long-term wellbeing."



Larry Brown, MD



Laura Whiteley, MD

PHOTOS: BRADLEY HASBRO CHILDREN'S RESEARCH CENTER

In the study, young adults between the ages of 14 to 24 who are HIV positive will have access to an action-adventure smartphone based app/game called "Battle Viro." Tasks within the game are related to common HIV treatment protocols, such as players collecting pills to keep immune level scores high.

While gaming, participants will experience action-oriented adventures with a goal of increasing knowledge about their health (treatment, transmission, adherence), improving players' motivation to manage their personal health, and building skills, such as interacting with physicians.

"Despite the necessity of treatment adherence for optimal health outcomes, youth living with HIV often do not stay

in care and do not consistently take their HIV medications," said Dr. Brown. "There is a great need to find effective interventions to improve treatment adherence for adolescents and young adults infected with HIV. Without adherence to medical care, we are not likely to halt the progression to AIDS."

Pill bottle opening data from each participant's medication bottle cap will be captured using a tracking technology, to measure whether participants are taking their medication regularly. The research team hopes to find more consistent medication adherence among the group that plays the smartphone game. ▽

Bradley Researchers Find Age-Related Changes in How Autism Affects the Brain

Findings come from a first-ever large-scale study of brain activity in children versus adults with autism that could lead to more targeted treatments for autism spectrum disorders

EAST PROVIDENCE – Newly released findings from Bradley Hospital published in the *Journal of the American Academy of Child & Adolescent Psychiatry* have



HASBRO CHILDREN'S HOSPITAL

Daniel Dickstein, MD, FAAP

found that autism spectrum disorders (ASD) affect the brain activity of children and adults differently.

In the study, titled "Developmental Meta-Analysis of the Functional Neural Correlates of Autism Spectrum Disorders," Daniel Dickstein, MD, FAAP, director of the Pediatric Mood, Imaging and Neurodevelopment Program at Bradley Hospital, found that autism-

related changes in brain activity continue into adulthood.

"Our study was innovative because we used a new technique to directly compare the brain activity in children with autism versus adults with autism," said Dr. Dickstein. "We found that brain activity changes associated with autism do not just happen in childhood, and then stop. Instead, our study suggests that they continue to develop, as we found brain activity differences in children with autism compared to adults with autism. This is the first study to show that."

This new technique, a meta-analysis, which is a study that compiles pre-existing studies, provided researchers with a powerful way to look at potential differences between children and adults with autism.

Dr. Dickstein conducted the research through Bradley Hospital's PediMIND Program. Started in 2007, this program seeks to identify biological and behavioral markers – scans and tests – that will ultimately improve how children and adolescents are diagnosed and treated for psychiatric conditions. Using special computer games and brain scans, including magnetic resonance imaging (MRI), Dr. Dickstein hopes to one day make the diagnosis and treatment of autism and other disorders more specific and more effective.

Among autism's most disabling symptoms is a disruption in social skills, so it is noteworthy that this study found significantly less brain activity in autistic



HASBRO CHILDREN'S HOSPITAL

Rowland Barrett, PhD

children than autistic adults during social tasks, such as looking at faces. This was true in brain regions including the right hippocampus and superior temporal gyrus, two brain regions associated with memory and other functions.

Dr. Dickstein noted, "Brain changes in the hippocampus in children with autism have been found in studies using other types of brain scan, suggesting that this might be an important target for brain-based treatments, including both therapy and medication that might improve how this brain area works."

Rowland Barrett, PhD, chief psychologist at Bradley Hospital and chief-of-service for The Center for Autism and Developmental Disabilities was also part of the team leading the study. ▽

HIV Therapy for Treatment-Experienced Patients

Multi-site study, led by Miriam's Tahsima could change treatment strategy

PROVIDENCE – A new multi-site study reveals patients with drug-resistant HIV can safely achieve viral suppression – the primary goal of HIV therapy – without incorporating the traditional class of HIV medications into their treatment regimen. Karen Tashima, MD, director of the HIV Clinical Trials Program at The Miriam Hospital, served as study chair.

The AIDS Clinical Trials Group (ACTG) Network's OPTIONS Trial proves, for the first time, that treatment-experienced patients can leave out this class of medication, known as nucleoside reverse transcriptase inhibitors (NRTI), as part of the regimen. These results could change treatment guidelines, lessen side effects and increase adherence rates, the researchers say.

Dr. Tashima and colleagues presented the results from the 48-week study at the annual Conference for Retroviruses and Opportunistic Infections (CROI) in Atlanta on March 6.

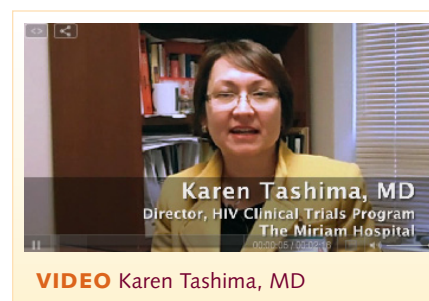
"We are so comfortable clinically with the NRTI class that we think we must always use at least one drug from this class in treatment. However, some patients have developed within-class resistance, making the NRTIs less

effective overall. Therefore, drugs from this class may not be needed if the new treatment plan contains more effective medications," said Dr. Tashima, who also leads ACTG's clinical research site at The Miriam Hospital.

"There were a few new drugs coming out at the same time and we decided to turn the question around. Instead of having patients take their current medications from the NRTI class as well as these new drugs from different classes, we asked half of the study participants to add NRTIs and half of them to leave out NRTIs from their new treatment plan. We were able to take the usual study paradigm and turn it around," she added.

The OPTIONS Trial, also called A5241, included ACTG sites from around the country as well as sites from the International Maternal Pediatric Adolescent AIDS Clinical Trials group and the Adolescent Medicine Trials Network. Study volunteers needed to be at least 16 years old and show treatment experience or resistance to their current HIV medications.

Most of the A5241 participants had been on ART for 10 years or more. Traditional antiretroviral therapy consists



of medications from the nucleoside reverse transcriptase inhibitor class, including tenofovir, azidothymidine and lamivudine. The new medications studied included darunavir and tipranavir from the protease inhibitor class of HIV medications, maraviroc from the CCR5 antagonist class, raltegravir from the integrase inhibitor class, etravirine from the non-nucleoside reverse transcriptase inhibitors class and enfuvirtide an injectable drug from the fusion inhibitor class.

Patients will continue on the study for a total of 96 weeks to ensure virologic suppression is maintained.

"There is no question that the results show what we had set out to prove – a treatment-experienced patient will not lose virologic suppression by omitting NRTIs," said Dr. Tashima. **v**

Women & Infants Launches 'Safe to Sleep' Campaign

Saving infants from accidental crib deaths

PROVIDENCE – Women & Infants Hospital is kicking off a “Safe to Sleep” model of care and educational campaign. Recognizing that one of the biggest dangers for newborns is loose blankets in the crib that can cover the baby’s face and interfere with breathing, all babies born at Women & Infants Hospital are now being placed in a HALO SleepSack. This wearable blanket, also being used at Care New England’s Kent Hospital, replaces the need for any blankets that a baby may be able to kick off,

helping to ensure that baby sleeps safely and comfortably throughout the night.

“We want to be sure that all of our new families are getting off to the healthiest start, right from the very beginning,” said Marcia VanVleet, MD,

medical director of the newborn service team at Women & Infants Hospital. “In addition to modeling a safe sleep environment in the hospital, Women & Infants will now giving all of our new parents a Summer Infant swaddle to take home with them – a safe alternative to blankets that keeps baby warm and comfortable.”

“Safe to Sleep” is an expansion of the original “Back to Sleep” campaign, which was named for its recommendation to place healthy babies on their



Baby Henry in sleep sack developed by a Bill Schmid, a father who lost his infant daughter to Sudden Infant Death Syndrome (SIDS). An engineer, he devoted himself to finding new and creative ways to address these risks in an infant’s sleeping environment, which are primarily centered around loose bedding in the crib.

backs to sleep, the most effective action that parents and caregivers can take to reduce the risk of SIDS. According to the Eunice Kennedy Shriver National Institute of Child Health and Development, since that campaign started the percentage of infants placed on their backs to sleep has increased dramatically, and the overall SIDS rates have declined by more than 50 percent.

SIDS, the leading cause of death in babies one month to one year of age, is the sudden, unexplained death of a

baby younger than one year of age that does not have a known cause even after a complete investigation. Sleep-related causes of death, which are not SIDS, may be linked to how or where a baby sleeps or has slept. They may be due to accidental causes, such as suffocation, entrapment (when a baby gets trapped between two objects, such as a mattress and a wall, and cannot breathe), or strangulation (when something presses on or wraps around baby’s neck, blocking baby’s airway). v



Marcia VanVleet, MD



All babies born at Women & Infants Hospital are now being placed in a HALO SleepSack.

Kent Recognized for 'Keeping it Green'

Miriam receives honorable mention

PROVIDENCE – Rhode Island honored environmental sustainability practices in healthcare through the first Rhode Island Environmental Sustainability (RIES) Awards from Hospitals for a Healthy Environment in Rhode Island, in partnership with Brown University, the City of Providence, the Rhode Island Department of Environmental Management and Health Care Without Harm.

The awards were offered to healthcare individuals, institutions and agencies that have demonstrated leadership in sustainability initiatives and serve as models for their peers.

The awards were presented at the Blue Wrap Blue Jean Ball, a networking

and fundraising event, held on March 21 at the Roger Williams Park Casino.

Kent's 'Keeping it Green' team

Kent Hospital's "Keeping it Green" (KIG) team received the RIES Award for environmental sustainability. The awards committee recognized Kent for its recycling and waste reduction program, green clean program, environmental landscaping program with little to no fertilizer, irrigation, and pesticide use, staff garden, and weekly farmers market in the summer.

"On behalf of Kent Hospital, we are extremely pleased to be recognized with this award for our green efforts," said Joseph Dipietro, Esq., senior vice president & chief administrative officer and legal counsel, who oversees Kent's Keeping It Green team.

"This honor reflects the hard work, dedication and commitment this team and the entire hospital places on the importance of recycling, sustainability and overall corporate social responsibility."

Miriam's 'Greenways Team'

The Miriam Hospital's "Greenways Team" received an honorable mention for their sustainability initiatives in paper and waste reduction, blue wrap



recycling, pharmaceutical waste collection program, and good community relations.

Miriam hired a sustainability coordinator, Monica Anderson, last year, and since then the green team has grown to a 61-member multidisciplinary team that meets monthly. Greenways, following an environmental audit, has kickstarted many recycling projects, and doubled the recycling rate in a year.

Environmental champion

The Environmental Champion Award was given to Sylvia Weber, a nurse, who was honored for her dedication and commitment to environmental health. She formed the RI State Nurses Associations Environmental Affairs Committee and is a strong advocate for environmental legislation. She has testified both at the state and at the national level on countless environmental issues. v



PHOTOS: KENT



Veterans of the 126th Aviation Regiment were given post-deployment health screenings at the Providence VA Medical Center recently.

Providence VA screens returning soldiers

PROVIDENCE – The Providence VA Medical Center recently hosted a Post-Deployment Health Readiness Assessment (PDHRA) for members of the 126th Aviation Regiment, which served a 9-month deployment in Kuwait, where they performed aviation support missions with Blackhawk helicopters in Southwest Asia.

The event was the fifth PDHRA conducted with the Rhode Island National Guard since 2012. It was the first time the new women's health clinic was used for a comprehensive health screening, which examined for physical and behavioral health concerns associated with deployment. The soldiers underwent a primary care screen as well as mental health and traumatic brain injury screens. **v**

Care New England and The Providence Center Announce Affiliation

PROVIDENCE – Care New England (CNE) and The Providence Center (TPC) entered into an affiliation agreement on March 18.

The strategic affiliation followed a Request for Proposal (RFP) process CNE initiated to identify and engage an innovative, high quality community provider of mental health and addiction services which would enhance and expand the mental health and addiction services currently provided throughout CNE.

One way in which the affiliation is leveraging its combined expertise is the creation of a Short-Term Residential Substance Abuse Treatment Program. To be located on the Butler Hospital campus, the program will be managed by The Providence Center and supported by Butler physicians who are experts in addictions. Another way in which expertise will be shared is in the area of emergency services. CNE and TPC are exploring opportunities for TPC's behavioral health care practitioners to provide psychiatric and substance abuse assessment, counseling and follow-up services to patients that present in the emergency departments of CNE affiliate hospitals. **v**



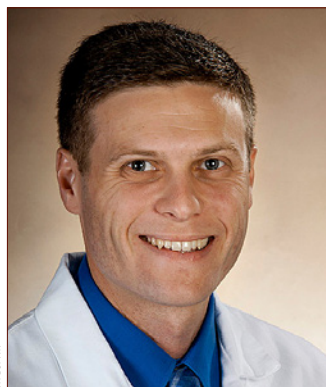
Care New England and The Providence Center announced a partnership on March 18 to strengthen behavioral health services. Signing the agreement between the two organizations were (seated) Dennis Keefe, president and CEO, Care New England; Dale K. Klatzker, president/CEO, The Providence Center; (back row, from left) Walter Dias, COO, Butler Hospital; Patricia Recupero, JD, MD, president and CEO Butler Hospital; and Owen Heleen, chief strategy officer, The Providence Center.

Doctors speak at Humanitarian Assistance Symposium

PROVIDENCE – Adam C. Levine, MD; Selim Suner, MD, and Susan Cu-Uvin, MD, recently spoke at an inaugural symposium at Brown University titled: “Humanitarian Assistance at the Crossroads: Brown University’s Role in Improving Humanitarian Effectiveness.”

The March 2 event brought together state and national academic, medical and humanitarian leaders to emphasize the need for training dedicated professionals in humanitarian aid.

“We know that more and more physicians and nurses are responding to disasters and humanitarian emergencies, and it’s vital that we start working to train and prepare them for the often difficult task of working in austere and sometimes dangerous environments. Having better prepared responders will help protect both them and the people they are going to serve,” said Dr. Levine,



Adam C. Levine, MD



Selim Suner, MD



Susan Cu-Uvin, MD

an emergency physician at Rhode Island Hospital and The Miriam Hospital, and co-director of the Global Emergency Medicine Fellowship at The Warren Alpert Medical School of Brown University.

In summer 2012, Dr. Levine worked to set up a medical clinic in a refugee camp in South Sudan, while engineers organized a water sanitation system,

social workers protected orphans, and business people managed volunteers.

Dr. Suner is director, Rhode Island Disaster Medical Assistance Team (DMAT), and a professor of emergency medicine at Brown.

Dr. Susan Cu-Uvin, director of Brown’s Global Health Initiative, moderated the event. v

Classified Advertising

Office space for sale or lease

Medical office space for lease or sale in Providence, in an established building in a prime location across from Women & Infants Hospital. 1600 sf, first floor, ample parking. Lab and x-ray on premises. \$25/sf. Hines Dermatology Associates, Inc. Please call Cheryl at 508-222-9966, Monday–Friday, 7am–3pm.

Searching for a physician assistant to join your practice?



The Rhode Island Academy of Physician Assistants can help you find a qualified PA. Visit the RIAPA Career Center to advertise

and view the CVs of the best and brightest PAs. Go to www.RhodeIslandPA.org and click on Career Center to start your search. RIMS members are eligible for a 15% discount on ads. For questions and details of how to obtain the discount contact: Megan Turcotte, mturcotte@rimed.org, 401-331-3207.

W&I team travel to Rwanda on medical mission

PROVIDENCE – In February, B. Star Hampton, MD, of the Division of Urogynecology and Reconstructive Pelvic Surgery at Women & Infants Hospital, traveled to Rwanda with the International Organization for Women and Development (IOWD), as part of a fistula repair team.

The team included senior fellow, Nicole Korbly, MD; Jessica Salak, MD, an obstetrician/gynecologist with the Center for OB/GYN, and Edie McConaughy, a certified nurse midwife.

They worked in Kigali for two weeks at Kibagabaga Hospital with a team of American surgeons, anesthesiologists, and nurses, and collaborated with and trained Rwandan physicians, medical students, and nursing staff.

During this trip, Dr. Hampton’s team evaluated more than 200 women with fistula and was able to successfully operate on nearly 50 of these women. “Our team was able to provide basic and advanced care to the women in Africa. We worked hard to tackle difficult surgical cases and to create meaningful results,” said Dr. Hampton. v



B. Star Hampton, MD

Bradley Hospital and Gateway Healthcare Launch Kids'Link RI

24-hour hotline geared for children in emotional crisis

EAST PROVIDENCE – Bradley Hospital, the nation's first psychiatric hospital for children and adolescents, has collaborated with Gateway Healthcare, Rhode Island's largest community behavioral health care provider, to offer a 24-hour hotline for children in need of mental health care.

Kids'Link RI is a hotline that is available 24 hours a day, seven days a week for children in emotional crisis and who are suffering from behavioral problems or psychiatric illness.

"As many parents know all too well, a child can have a crisis or an emergency any time of the day or night. We want to make sure families have access to the care they need," said Henry Sachs, MD, chief medical officer of Bradley Hospital. "With the Kids'Link hotline, we are providing a safety net, so that no matter where or when a child needs help, he or she can receive it."

The hotline – 1-855-KIDLINK – connects parents and caregivers to children's mental health services in Rhode Island, and helps families determine the best place to go for treatment. With this confidential hotline, parents and caregivers can dial a toll-free number, and be connected with emergency service clinicians or receive direction about the appropriate "next step" for managing their crisis.

"We are so pleased to partner with Bradley Hospital to make the Kids' Link hotline available," said Gateway President and CEO Richard Leclerc. "There is nothing more heartbreaking than a child suffering with behavioral health issues, and we want to ensure that access to services is swift and seamless. The Kids' Link hotline will prove to be an important community resource going forward."



Parents and caregivers are encouraged to call the hotline on behalf of any child who is:

- Feeling excessive anger or sadness
- Hurting himself/herself or others
- Lashing out at siblings, friends and adults
- Having behavior problems at school
- Having severe worries

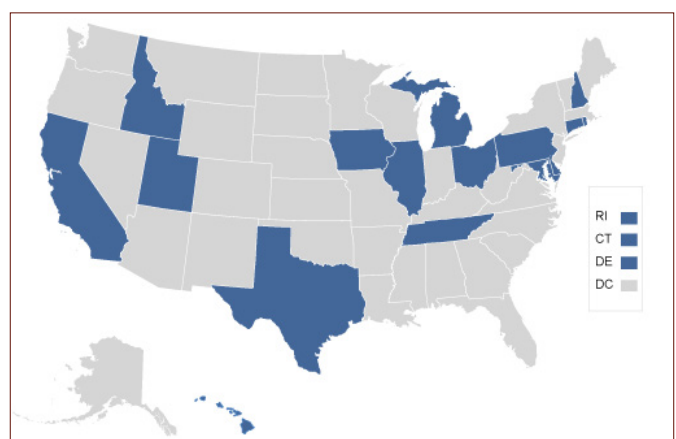
When necessary, evaluations for children are offered at Bradley Hospital and Gateway Healthcare locations. For more information about Kids'Link RI, visit <http://www.bradleyhospital.org/KidsLinkRI>. v

RI Receives \$1.6M Healthcare Innovation Award

BALTIMORE – Rhode Island is one of 16 states to receive a model design testing award from the Centers for Medicare & Medicaid Services (CMS) Innovation program it was announced in late February. Over the next six months, the state will receive up to \$1.63 million to develop its State Health Care Innovation Plan.

According to CMS, Rhode Island intends to develop a model that builds upon the patient-centered medical home initiative and focuses on a community-centered delivery system. The model will leverage the opportunities provided by the state's Health Benefits Exchange and Medicaid initiatives.

Planning activities will facilitate a multi-stakeholder process to review current state payment and delivery system reform initiatives; identify data sources and baseline data for outcomes measures and financial analysis; and identify policy



lever changes available and needed to effectuate the plan. The resulting plan will define strategy and mechanisms for moving Rhode Island's health care delivery system to a value-driven, community-based, and patient centered system. v

Lifespan picks Epic Systems technology platform for electronic medical records

Project expected to cost \$90M

PROVIDENCE – Lifespan has partnered with Epic Systems Corporation, a worldwide leader in health information technology, to transform the way Lifespan hospitals deliver care by emphasizing a patient-centric model.

This model will provide patients with electronic access to their health information 24/7, enable patient communication with caregivers, eliminate duplicative and unnecessary tests, streamline the scheduling process and provide a system that will pull patient information from different caregivers into a single electronic medical record.

“Our decision to partner with Epic is so much more than an IT decision; we are undertaking a fundamental redesign of the way we deliver care throughout the Lifespan system,” said Timothy J. Babineau, MD, Lifespan’s president and chief executive officer. “Once fully deployed, the new Epic system will make it possible to exchange information at the point of care. Patients will be empowered with easy access to their health information, and providers will have exactly what they need to make decisions in real time.”

Lifespan expects to begin implementation this spring with the project being completed in 2015. The project is expected to cost \$90 million.

Benefits

Lifespan expects the new system to provide many other benefits, such as:

- A single patient medical record that will be accessible throughout the entire Lifespan system. For consenting patients who travel, their record will be accessible across the country with the patients’ other caregivers who use Epic.
- A portal that will allow patients access to their health information, as well as the ability to schedule appointments electronically and communicate with their caregivers.
- Enhanced chronic disease management under an accountable care delivery model.
- Elimination of duplicate and unnecessary testing.
- Increased ability to perform clinical research and generate research funding.
- Improved patient care through enhanced and standardized processes.

Lifespan will also be making the Epic electronic medical record available to its affiliated community physician practices. ▽

Brown, Hospitals Strike IP Agreements

Services to be provided for discoveries made by hospital-based scientists

PROVIDENCE – Under a recent agreement announced with Lifespan, Brown University’s Technology Ventures Office (TVO) will provide selected IP management and commercialization services to the health care system.

Brown also recently expanded its relationship with Care New England, bringing together in one place much of the licensable life science intellectual property developed by scientists across each institution, University and hospital officials said. The two health care systems and Brown’s Division of Biology and Medicine conducted \$200.3 million worth of biomedical research in fiscal year 2012.

The new agreement with Lifespan calls for Brown to provide the health care system with IP identification, reporting, protection, marketing, licensing, and business development services for selected new discoveries made by hospital-based scientists.

Late last year, Brown expanded a similar arrangement it had with Care New England’s Women & Infants Hospital to cover the other Care New England hospitals – Butler Hospital and Kent Hospital.

“Providence’s collectively growing biomedical enterprise has a lot to offer the world, and Brown has the expert staff and relationships to help connect our state’s scientists with the opportunities their ingenuity creates,” said Brown Provost Dr. Mark Schlissel. “We are pleased to work with Lifespan and Care New England to bring new discoveries to the marketplace where they can help patients in need.” ▽



BROWN

Padbury study featured on cover of *Genomics*

PROVIDENCE – The cover of the March issue of the journal *Genomics* features a study by Brown and Women & Infants researcher and Professor of Pediatrics Dr. James Padbury and co-authors who looked at the genes associated with pre-term birth.

In the United States one in eight women give birth pre-term, and researchers aren't sure why. Informed by a systematic search of the scientific literature, the team then combed through genomic data from nearly 2,000 pre-term and regular term mothers. They identified 19 genetic pathways and networks of interest, encompassing 53 different genes. Their next step is doing deep sequencing of the significantly associated genomic regions in the Brown Genomics Core. [v](#)

CharterCARE signs intent agreement with national company

PROVIDENCE – CharterCARE Health Partners (CCHP), the corporate parent of Roger Williams Medical Center and St. Joseph Health Services of Rhode Island/Our Lady of Fatima Hospital, announced in March that it has executed a Letter-of-Intent (LOI) with Prospect Medical Holdings, Inc. (PMH), a national healthcare services company.

Under the proposed transaction, CCHP and PMH will create a new and innovative joint venture that will maintain local governance and input.

PMH will make a significant capital contribution into a new company, which will be jointly owned by PMH and CCHP. Fifty percent of the Board of Directors of the new company will be appointed by CCHP, thereby maintaining a strong, local governance presence.

Edwin Santos, chairman of the CCHP Board, stated, "We look forward to completing this transaction, which will provide significant capital for our hospitals to sustain and develop clinical programs, acquire new technology, attract physicians and maintain a skilled workforce."

CCHP and PMH will work toward the development of a definitive agreement, at which time an application for approval under the Rhode Island Hospital Conversion Act will be made to the Rhode Island Attorney General and the Rhode Island Department of Health. [v](#)

NEWS BRIEFS

Reduced radiation dose in CT colonography

A new study by a Rhode Island Hospital researcher has found it's possible to maintain high-quality CT colonography diagnostic images while reducing the radiation dose. This is important as the use of CT colonography, or virtual colonoscopy, becomes more widely used for colorectal cancer screenings.

Through his research, Kevin J. Chang, MD, of the department of diagnostic imaging, found that decreasing the tube voltage would not negatively impact the integrity of the CT colonography. His research is published in the current issue of the journal *Radiology*.

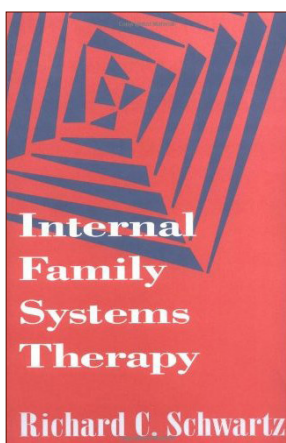
Alpert Medical School reaccredited

The Liaison Committee on Medical Education (LCME) has voted to continue accreditation of The Warren Alpert Medical School of Brown University, Dean Edward Wing announced March 7. After an intensive visit in October 2012, LCME officials found the school to be compliant with all of its more than 120 accreditation standards, noting strengths in areas such as student participation in scholarly programs, financial aid counseling, limiting student indebtedness, and the new medical education building.

Butler to host creator of Internal Family Systems (IFS) at annual lecture

PROVIDENCE – On Monday, April 8, from noon to 3:30 p.m., Butler Hospital will host Richard C. Schwartz, PhD, who will lecture on: “The Treatment of Trauma and the Internal Family Systems Model (IFS),” at the 18th annual Irving M. Rosen, MD, lecture on spirituality and health.

A featured speaker for national professional organizations, Schwartz has published five books and over 50 articles about IFS. Grounded in systems thinking, he developed the IFS model in response to clients’ descriptions of various parts within themselves.



In 2000, he founded the Center for Self Leadership, which offers trainings and workshops in IFS for professionals and the general public, both in this country and abroad.

The lecture will be held at the Ray Conference Center, 345 Blackstone Blvd., Providence. The cost is \$45. It carries three continuing medical and educational credits for physicians, psychologists,

nurses, social workers, teachers and school psychologists, and mental health counselors.

To register, call 401-455-6265.

HEALTH grand rounds: Immunization update with Dennehy

Thursday, April 4

8:30–9:30 am

Public health grand rounds presentation, “2013 immunization update” by Penelope Dennehy, MD. Watch at the Public Health Auditorium, 3 Capitol Hill, Providence or by live webcast. amms.oshean.org/content/DOH/PHGR-4-4-2013

Pre-register online at:

https://apps.biomed.brown.edu/cme_registration/

Bradley Hospital launches conference series for professional training, education

PROVIDENCE – The clinical staff from Bradley Hospital will lead an ongoing series of conference sessions to provide training and continuing education for psychologists, social workers, physicians, nurses, certified counselors, speech/language and occupational therapists, teachers, milieu therapists, and other professionals. Topics cover different behavioral health populations and treatment modalities and are intended to provide practical, state-of-the-art information.

The following are planned for April and May:

Thursday, April 4

“Using Motivational Interviewing with Adolescents”

Speaker: Nadine R. Mastroleo, PhD

This session introduces the use of Motivational Interviewing (MI) by mental health clinicians working with

a wide range of client concerns, with special attention on the use of MI with adolescents who use alcohol or other drugs. Nadine R. Mastroleo, PhD, is a Nationally Certified Counselor (NCC) and assistant professor (research) at The Warren Alpert Medical School of Brown University, who will lead the conference.

Thursday, May 2

“Advanced Tools for Treating Children in a Family Context”

Speakers: Michelle Rickerby, MD, and Thomas Roesler, MD

This presentation focuses on understanding symptoms in a family context and learning how to interview children and their families to further that understanding and intervene systemically. The conference will be led by Michelle Rickerby, MD, from the Department of Psychiatry at Rhode Island Hospital and clinical associate professor at The

Warren Alpert Medical School of Brown University; and Thomas Roesler, MD, from the Department of Psychiatry at Rhode Island Hospital and associate professor at The Warren Alpert Medical School of Brown University.

Where: Squantum Club

947 Veterans Memorial Parkway
Riverside RI

Other: The cost of each program is \$99. Registration deadlines are April 1 and April 29, respectively. Beverages and light snacks are provided at both conferences, and continuing education credits are available. For more information or to register, call the Lifespan Health Connection at 401-444-4800 or 1-800-927-1230, or visit <http://www.bradleyhospital.org/oth/Page.asp?PageID=OTH133142>.

Report from Remote Combat Outpost in Afghanistan

FRED BURGESS, MD

KHILIGAI, AFGHANISTAN — As I walked ducking my head low, the rotating blades of the helicopter spun overhead, sending the drizzling rain in swirls through the air. There was snow on the ground, and steam in the air, but I was already overheating, straining under the load of three overstuffed duffel bags and wearing 50 lbs. of body armor. I couldn't help thinking for the third time this trip, that at age 57, I might be getting too old for this. I had spent the last week bouncing my way across Afghanistan, with stops in Kandahar, Bagram, and Mazar-e-Sharif with little sleep, living much as a homeless person without the shopping cart. At least I had finally reached my "home" for the next three months, Combat Outpost Khiligai, home to the 933rd Forward Surgical Team (FST).

When I had learned that I would be mobilized as an Army Reservist in support of Operation Enduring Freedom, I had contacted the unit commander

'I have not run into any other Rhode Islanders, but did meet a Special Forces soldier wearing a Providence College Friars shirt the other day.'

looking for information on where I would be located. The 933rd FST, based out of Kentucky, had just arrived in theater this past November for a 9-month tour. At the time, she informed me that



Dr. Frederick Burgess, anesthesiologist from the Providence VA Medical Center, stands in front of the 933rd Forward Surgical Team's tent hospital in Afghanistan.

the unit was split between two remote locations, and that I would be joining the team in Khiligai as their anesthesia provider. To my dismay, I could not find Khiligai on any map, or through searching Google. Khiligai was a major Russian tank base during its occupation in the late '90s, and sits along one of the main northern highways leading to Tajikistan and Uzbekistan, mid-way between Konduz and Kabul. The outpost is small by most standards, with fewer than 200 full-time residents, home to a Cavalry unit, American and German

Special Forces, a Hungarian Provincial Reconstruction Team, the 933rd FST, and an aviation Medevac unit, all adjacent to an Afghan National Army base.

Mobile surgical units

FST's are designed to be 20-person, mobile surgical units able to follow the battle, providing Level II care for 30 critically injured soldiers for a period of 72 hours before relief or resupply. During recent actions in Iraq and Afghanistan, FST's have been used as stationary surgical hospitals, often split into two



View from the hospital area.

separate 10-person teams, typically including 1–2 surgeons, an anesthesia provider, 2–3 nurses, surgical techs, and medics. In recent years, there has been considerable variability in the organization of the teams, often encompassing various medical specialties and extended capabilities. Current Army doctrine requires the positioning of surgical teams throughout the combat theater such that any severely wounded soldier can receive surgical care within one hour of wounding.

The FST at Combat Outpost Khiligai is primarily an emergency trauma setup, delivering care for life-threatening accidental and combat injuries, with little elective surgery due to environmental conditions. We do only what must be done to stop the bleeding, and then move patients on to a higher-level facility. During my first three weeks here, we have only dealt with a few minor laceration repairs, and a number of minor medical problems, which included patients with kidney stones and musculoskeletal injuries. Triage occurs at the Battalion Aide Station (BAS) run by 3 medics, who manage most of the minor complaints. With only two phy-

sicians on the post, a general surgeon and myself, we are regularly consulted for anyone requiring medication or higher-level evaluation.

Equipment, logistics

The FST is equipped with a small digital radiograph unit, limited bedside testing equipment to analyze hemoglobin, electrolytes and blood gasses. Our anesthesia equipment is high quality, including a new compact anesthesia machine, high-flow blood warmers, forced hot

air patient warmers, pulse oximetry, and end-tidal carbon dioxide monitoring. Keeping the trauma patient warm and the ability to rapidly deliver blood products are essential in preventing the lethal triad of acidosis, hypothermia, and coagulopathy.

Operating in austere environments, tasks such as blood banking, blood typing, generator maintenance, electrical safety, and medical supply logistics become the responsibility of the 10 members of the FST. Monitoring the blood supply, typing of donors and patients often falls to the nursing and anesthesia staff. Supplies of plasma and packed red blood supplies are maintained in small refrigeration/freezer units in the operating room tents. Given the small supply of blood products, the U.S. military has developed protocols to obtain fresh whole blood from local donors for the management of massive transfusion situations that may occur with one individual, or a mass casualty event. Typically, the FST will stock approximately 15 units of O+/- blood and a similar quantity of type AB, and fresh

frozen plasma. Resupply can be rapid, but weather conditions often delay air resupply, making local blood drives potentially necessary. The availability of fresh warm whole blood is regarded as being advantageous in improving hemostasis in the combat trauma setting.

Daily routine

Much of our time at the FST is spent checking supplies, monitoring and testing equipment, and a constant rearrangement



of the unit's layout. As operational activities escalate or de-escalate, the physical location and arrangement is constantly being relocated and revised. The Taliban fighting season is much like the baseball season. There is little activity in the winter months, but as the weather warms, we are getting ready for the "Fighting Season," which begins near the end of March, peaking in August. Recent changes at the outpost have us relocating, which means I am getting a lot of practice packing and

setting up tents, participating in minor construction projects, setting up satellite dishes, and other physical tasks that medical school never prepared me for. My typical days start with an email or "Skype" home, breakfast, a team meeting, an educational effort twice a week with the camp medics and medical staff, followed by a range of responsibilities. Lunch often includes leftovers from dinner, corn dogs, and frozen pizzas, and then more work in the afternoon, followed by PT. Patients are managed on

an as-needed basis. Evenings are mostly free to watch DVDs; Internet access is very limited. Military units operate on a 24-hour/7-days-a-week basis, but there is down time, and most Sundays are essential work only days. I have not run into any other Rhode Islanders, but did meet a Special Forces soldier wearing a Providence College Friars shirt the other day. We exchanged a few fond memories of Rhode Island. We're both looking forward to a fine meal up on the Hill when we return! v



Medevac helicopter 'dustoff' landing at the outpost.



Why You Should Join the Rhode Island Medical Society

The Rhode Island Medical Society delivers valuable member benefits that help physicians, residents, medical students, physician-assistants, and retired practitioners every single day. As a member, you can take an active role in shaping a better health care future.

RIMS offers discounts for group membership, spouses, military, and those beginning their practices. Medical students can join for free. Earn rewards for referring new members through our "Member-Get-A-Member" campaign.



APPLY FOR MEMBERSHIP ONLINE

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Discounts on Continuing Medical Education

InReach online CME program discounts;
RIMS is an ACCME accrediting agency

Powerful advocacy at every level

Advantages include representation, advocacy, leadership opportunities, and referrals

Complimentary subscriptions

Publications include *Rhode Island Medical Journal*, *Rhode Island Medical News*, annual *Directory of Members*; RIMS members have library privileges at Brown University

Member Portal on www.rimed.org

Password access to pay dues, access contact information for colleagues and RIMS leadership, RSVP to RIMS events, and share your thoughts with colleagues and RIMS



Above: State House press conference on health care, Brown MSS at the AMA, CPT update seminar, bike helmet distribution; Upper right: RIMS staff meets with physicians to discuss concerns.

Make a House Call at the State House!

We invite you to make a "House Call at the State House" this legislative session. For the past several years, members of RIMS leadership have volunteered to spend an early evening at the General Assembly. With our new, online Member Portal, we are now able to welcome all RIMS members to observe the General Assembly in action.

Given the vagaries of legislative scheduling, your House Call you may offer you the opportunity to: attend a committee hearing; assist RIMS with testimony; get a tour of the State House; and hopefully meet your legislators. This has proven to be a worthwhile and informative opportunity for those RIMS members who have attended in the past.

It is impossible to overstate the importance and impact of real life physicians being at the State House. Every year, RIMS' Public Laws Committee puts together a broad legislative agenda and works with allies on health care legislation, and naturally "plays a lot of defense" on behalf of physicians and their patients. Your presence at the State House can truly make a difference in support of RIMS' efforts.

Registration is easy through the RIMS website, rimed.org. Enter the Member Portal of the RIMS website, log onto your account, and click "Events" on the Portal menu. Once you connect to this page, you may select a date on the "Event List" on this page and follow the prompts to complete the process. Should you have questions about your Member Portal log-in information, please email rimed@rimed.org.

You will not need to be at the State House until 4:30–5:00 pm. The registration page will request contact information, both email and a cell phone or pager. We will send you a reminder a few days prior to House Call date along with instructions where to meet Steve DeToy, RIMS' lobbyist, who will be your guide.

Tar Wars® Poster Contest and Bike Helmet Distribution

The Community School will host the annual Tar Wars® Statewide Poster Contest for elementary school students, and RIMS' annual bike helmet distribution for RiteCare children. Join us, volunteers are welcome to help distribute and fit helmets.

Saturday, May 11, 2013

The Community School
15 Arnold Mills Rd
Cumberland

Bike Helmet Distribution
9–11:30 am, school parking lot

Tar Wars® Statewide Poster Contest
10 am–12 pm, school gymnasium



2012 Tar Wars® Poster Contest winners



NEW Share your thoughts on RIMS "Communities" online forum

Members can now share their views on a variety of topics with their colleagues and RIMS staff. The RIMS website offers an exclusive, password-protected Member Portal with access to many convenient features and an online "Communities" forum. This is a unique opportunity to express your opinions with RIMS leadership who work to advocate on behalf of Rhode Island physicians and patients.

COMMUNITIES TOPIC-OF-THE-MONTH

A discussion of the Rhode
Island Department of Health's
RI Primary Care Trust

Save the date! RIMS Annual Banquet & Inauguration of Officers

Saturday, September 21, 2013
Warwick Country Club

Watch for your invitation in the mail.
For more information contact
Sarah Stevens at 401-331-3207.

Stay informed

Make sure RIMS has your current email address or you could be missing out on timely information of interest that most physicians are unlikely to receive as quickly from other sources.

Please contact Sarah Stevens with additions or changes, or visit RIMS' Member Portal to update your contact information.

Recognition

American Academy of Dermatology recognizes Weinstock with its 'highest scientific honor' at 75th annual meeting

PROVIDENCE – On March 3, **MARTIN A. WEINSTOCK, MD, PhD**, an epidemiologist and chief of dermatology at the Providence VAMC, received the Lila and Murray Gruber Cancer Research Award, which is the highest scientific honor that the American Academy of Dermatology confers.

It has been conferred annually by the Academy since 1972; five of the recipients have been awarded Nobel prizes. Dr. Weinstock is the first epidemiologist to receive this award. A professor at Brown in both the Department of Dermatology and in the Department of Community Health, he delivered a plenary lecture, "Public Health Science will cut Melanoma Deaths in Half," at the Academy's 75th annual meeting held March 1–5 in Miami Beach, Fl.

"We need evidence beyond what we have to be convincing to the broadest possible community, including the community that will be putting lots of big dollars

behind these early detection efforts," Dr. Weinstock said in discussing support for melanoma screenings. "We are talking about how, under the Affordable Care Act, if you have a certain level of evidence supporting interventions in health care, they get a huge amount of institutional support to make them happen."



He examined the history of melanoma prevention efforts and the steps needed to prove the value of screenings.

New medications for treating metastatic melanoma have been developed, but many patients who receive these new treatments still die from their melanoma within one or two years after diagnosis, he said, adding, "So, early detection is what we are left with."

"I think we can cut in half the number of melanoma deaths through screening early detection over the next decade. But we have to be able to do it with scientific evidence."

In the United States, researchers have been accumulating more data at a faster pace over the past five years using case control studies and natural experiments, he said. Still, building the case for melanoma screenings will take time.

"This does not happen with one person having an idea, doing an experiment, and kaboom — we have the breakthrough," Dr. Weinstock said. "It's usually teams and people building on each other. That is the way science tends to work."

And in the end, the best way to reduce melanoma deaths over the next decade may depend on old-fashioned observation. "Reducing deaths from melanoma boils down to two words: look and see. People need to look at the skin and see that certain spots on the skin could be potentially dangerous," Dr. Weinstock said. "It's getting the science around those two words that has the potential, after all these years of rising melanoma deaths, to finally reduce melanoma deaths, to cut them in half, or more. But we need to upgrade the science to convince the relevant people and institutions to do what needs to be done to reduce this death toll."

Medical women to honor Rompf, Buckley

PROVIDENCE – The Rhode Island Medical Women's Association (RIMWA) will honor **PATRICIA A. ROMPF, MD**, and **LUCY P. BUCKLEY, MD**, as the 2013 Woman Physician of the Year at the organization's annual meeting. They are being honored in a dual presentation in celebration of RIMWA's 32nd anniversary.

Dr. Rompf, a clinical associate professor in pediatrics at Brown University, is a pediatric cardiologist affiliated with Hasbro, Bradley and Rhode Island Hospitals.

Dr. Buckley is an assistant clinical professor in pediatrics at Harvard Medical School, and over the years she has worked as a cardiologist at the Children's Hospital in Boston and as the director of the Children's Hospital Satellite Clinics in New Bedford and Fall River. She also served as the pediatric cardiac consultant for the Rhode Island Department of Health and is affiliated with Hasbro Children's Hospital.

The event will be held at 6:30 p.m., Monday, May 13, at the Providence Marriott Hotel, One Orms Street.



Lucy P. Buckley, MD



Patricia A. Rompf, MD

PHOTOS: RIMWA

Recognition



Dr. Anne S. De Groot

Tech Collective names first bioscience award winners

PROVIDENCE – **DR. ANNE S. DE GROOT**, director of the Institute for Immunology and Informatics (iCubed) at the University of Rhode Island, is one of six recipients of Tech Collective, Rhode Island's bioscience and IT industry association, inaugural Rhode Island bioscience awards.

DENISE SPERO, PhD, co-director of iCubed, was also a winner. She recently served as guest editor for the *Rhode Island Medical Journal's* bioscience edition in February.

The other winners are: **EDWARD BOZZI**, associate clinical professor and coordinator of the bio-manufacturing program at the University of Rhode Island; **LESLIE COUSENS**, scientific director of protein therapeutics at EpiVax Inc.; **ANDREW P. MALLON**, CEO and director of research at Calista Therapeutics Inc., and **MICHELLE WU**, director of quality services for Ximedita.

The awards ceremony will take place May 2 at Rhodes on the Pawtuxet.

Area Appointments

Brown names associate dean for medical education

PROVIDENCE – **ALLAN R. TUNKEL, MD, PhD**, has been appointed associate dean for medical education at The Warren Alpert Medical School of Brown University reporting to the dean of medicine and biological sciences. He will begin his duties on July 15, succeeding Associate Dean Philip Gruppuso, MD.

Currently, Dr. Tunkel is chair of medicine at Monmouth Medical Center and professor of medicine at Drexel University College of Medicine. He was the senior associate dean for academic campuses supervising Drexel's relationship with its 25 clinical academic campuses throughout Pennsylvania and New Jersey. While in that role he developed new affiliate relationships with hospitals in medical education and residency training. From 2002 to 2005, Dr. Tunkel was the associate dean of admissions managing all activities to recruit a class of 250 students including transfer students and special programs. During his tenure in the Department of Medicine he has served as vice chair, vice chair for education, and residency program director. He has received numerous teaching awards and honors and is passionate about physician training.


An undergraduate of Seton Hall University, Dr. Tunkel later pursued a PhD in experimental pathology followed by a medical degree at the University of Medicine and Dentistry of New Jersey, New Jersey Medical School. He completed his residency and chief residency in medicine at the Hospital of the Medical College of Pennsylvania followed by a fellowship in infectious diseases at the University of Virginia. He is also widely acknowledged as an expert in bacterial meningitis.

As associate dean, Dr. Tunkel will have primary responsibility for the undergraduate medical education programs at Alpert Medical School. He will supervise curriculum planning, evaluation and management for the four-year medical program and Brown's eight-year BA/MD continuum program, the Program in Liberal Medical Education; oversee medical school admissions, financial aid, registrar activities and the Office of Diversity and Multicultural Affairs on student recruitment; and have primary responsibility for medical school accreditation requirements and processes.



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Area Appointments

Dudley appointed Chief of the Division of Cardiology at Brown

His research interests include cardiac cell replacement therapy, sudden cardiac death

PROVIDENCE – Samuel C. Dudley, MD, PhD, has been appointed chief of the division of cardiology at the Cardiovascular Institute (CVI) at Rhode Island and The Miriam hospitals and chief of the division of cardiology in the Department of Medicine at The Warren Alpert Medical School of Brown University. In this role, Dr. Dudley will oversee all cardiology services on the two campuses including patient care and clinical research. He is also responsible for the research and educational programs at all the Brown teaching hospitals to further strengthen the program's position as a regional and national leader in cardiac care. His appointment was effective March 1, 2013.

"Dr. Dudley is a unique combination of physician, researcher and entrepreneur," said Timothy J. Babineau, MD, president and chief executive officer of Lifespan. "We are confident that his leadership skills and hands-on approach will serve to strengthen the program and support all cardiac physicians; that his compassion and commitment to the highest quality patient care will be of great benefit to our patients; and that his commitment to cutting-edge research will solidify our cardiac program as one of the best in the country."

Dr. Dudley's research efforts into such areas as sudden cardiac death have resulted in the development of an innovative blood test designed to identify those patients most at risk. His entrepreneurial spirit has led him to receive more than 20 patents and to launch a biotech firm focused specifically on commercializing this blood test.



LIFESPAN

"We look forward to the important contributions that Dr. Dudley will make to education and research in cardiology. His clinical skills and research interests strongly complement clinicians and researchers at the medical school, in the basic science departments and public health," said Edward J. Wing, MD, dean of medicine and biological sciences at Alpert Medical School.

Dr. Dudley comes here from the University of Illinois at Chicago where he served as chief of cardiology and co-director of the Center for Cardiovascular Research. He previously served as chief of cardiology at the Atlanta (Ga.) VA Medical Center and associate professor of medicine and physiology at Emory University in Atlanta.

He earned his bachelor's degree from the University of Virginia in Charlottesville, and his medical degrees from the Medical College of Virginia, Vir-

ginia Commonwealth University. He completed his residency, postdoctoral fellowship and cardiology fellowship at the University of Chicago.

He serves on several editorial boards for publications including the *Frontiers in Cardiac Electrophysiology*; *Journal of The American College of Cardiology*; *Journal of Cardiovascular Pharmacology and Therapeutics*; and *The Open Biochemistry Journal*. He is fellow of the American College of Cardiology and the American Heart Association and is a member of the Association of University Cardiologists, the American Society of Clinical Investigation, Heart Rhythm Society, Cardiac Electrophysiology Society, and the Cardiac Muscle Society, among others.

His research interests include cardiac cell replacement therapy, diastolic heart failure and sudden cardiac death. He has published more than 90 manuscripts and book chapters and is the inventor of more than 20 patents including a blood test to predict sudden death risk, a blood test for diastolic heart failure, a possible treatment for diabetes and obesity and eight novel therapeutics for diastolic heart failure and sudden death prevention. He is chief science officer of ROS Technologies, a company he founded to commercialize the blood test for sudden death risk.

The Cardiovascular Institute (CVI) at Rhode Island Hospital and The Miriam Hospital is a collaboration of cardiovascular services at the two campuses, along with cardiology programs in the community. v



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Area Appointments

Landmark names Fort medical director



WOONSOCKET – **GLENN FORT, MD**, has been named medical director of Landmark Medical Center. Dr. Fort, who has been a member of Landmark's staff since 1989, is now responsible for coordinating and overseeing medical care, and serving as the liaison between medical staff and senior management. He specializes in infectious disease and holds a medical degree from the

University of Valencia and a master's in public health from Boston University.

Whelan joins Westerly staff

WESTERLY – **TARA WHELAN, DO**, a dermatologist, has joined The Westerly Hospital medical staff. Dr. Whelan attended medical school at the University of New England College of Osteopathic Medicine in Biddeford, Maine. She completed her internship, a residency in family medicine as well as her dermatology residency at St. John's Episcopal Hospital in Far Rockaway, NY.



WESTERLY HOSPITAL

Urology, Inc. joins Southcoast group

FALL RIVER, MASS. – Urology Inc. announced recently it has joined Southcoast™ Physicians Group, a network of primary and specialty care physicians and part of Southcoast Health System. The urology practice includes **DAVID BAE, MD**; **JOHN CARROLL, MD**; **JOHN KAISER, MD**; **PATRICK KELTY, MD**, and **DENNIS LA ROCK, MD**. It will now be recognized as Southcoast Urology.



David Bae, MD



John Carroll, MD



PHOTOS: SOUTHCOAST

John Kaiser, MD



Patrick Kelty, MD



Dennis La Rock, MD

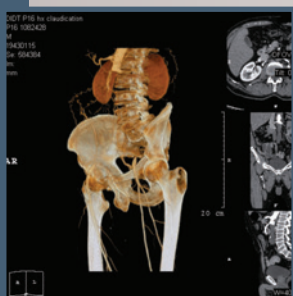


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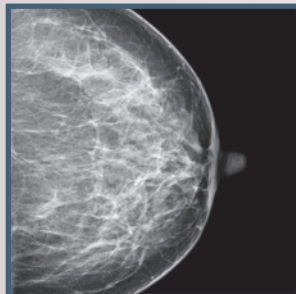
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Area Appointments

PHOTOS: SOUTHCOST



Clyne named director of arrhythmia services

FALL RIVER, MASS. – Southcoast™ Health System has named Barrington resident **CHRISTOPHER CLYNE, MD, FACC**, as medical director of Southcoast Cardiac Arrhythmia Services.

Dr. Clyne is board certified in electrophysiology, cardiology and internal medicine. He brings to Southcoast extensive experience in arrhythmia ablation and pacemaker lead extraction.



Sklar named director of Charlton cath lab

FALL RIVER, MASS. – Southcoast™ Health System has appointed **MITCHEL SKLAR, MD, FACC**, as director of the cardiac catheterization laboratory at Charlton Memorial Hospital.

He is a cardiologist with Southcoast Physicians Group. In his new role, Dr. Sklar will provide leadership to the cardiac catheterization laboratory and interventional radiology suite (peripheral vascular) at Charlton while continuing to maintain his clinical duties.

A Providence resident, he is a clinical assistant professor of medicine at the Warren Alpert Medical School at Brown University.



Gerogiannis to bring robotic-assisted cardiothoracic surgery to Charlton

FALL RIVER, MASS. – Southcoast™ Health System announced in March that **IRAKLIS S. GEROGIANNIS, MD, FACS**, has joined Southcoast Cardiothoracic Surgery, part of Southcoast Physicians Group. Prior to joining Southcoast, he was a cardiothoracic surgeon and medical director at Gulfport Memorial Hospital in Gulfport, Miss.

He was also an assistant professor of surgery at Tufts University School of Medicine in Boston and specializes in robotic cardiothoracic surgery, which he will introduce at Charlton Memorial Hospital this year.

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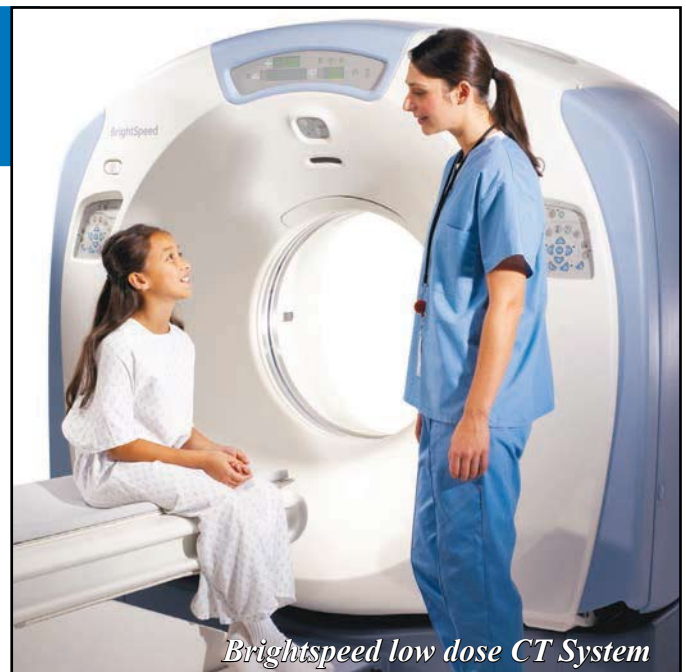
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Obituaries

BARRINGTON – **RICHARD EUGENE KUHN, MD**, 90, passed away on February 19, 2013. Dr. Kuhn was a graduate of Seton Hall College and Hahnemann University School of Medicine (now Allegheny College). He served in both the U.S. Army and the Air Force, retiring with the rank of Captain.



His career as a surgeon spanned more than four decades, during which time he earned numerous awards and accolades. He practiced most recently at Roger Williams Medical Center in Providence.

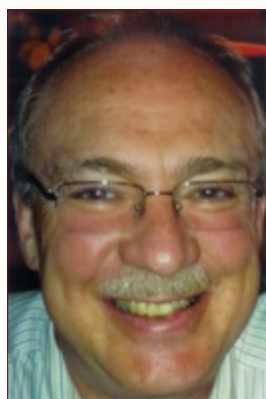
An avid boater, Dr. Kuhn enjoyed time on the water with family and friends throughout his life and spent countless hours on the waters near his home in Barrington and around Cape Cod, MA.

Dr. Kuhn was the husband of the late Elaine Burgess Annable Kuhn, the father of the late Richard Eugene Kuhn, Jr. and the father-in-law of the late Albert K. Antonio. He is survived by three daughters, Karen Elaine Kuhn Antonio, Denise Anne Kuhn Rochlin and her husband Robert Rochlin and Carol Anne Kuhn Ryan and her husband J. Ryan; a grandson, Richard Eugene Kuhn, III, Esq; 12 grandchildren and their spouses and his four great-grandchildren. Private funeral services have been held.

WARWICK – **DR. RAYMOND B. MAXIM**, 53, passed away March 12, 2013. He was the husband of Deborah J. (Hardy) Maxim. Dr. Maxim practiced internal medicine at the Pontiac Medical Group in Cranston.

He was a medic in the Army Reserve in his early career and an EMT in the emergency room at Roger Williams Hospital. He also helped establish the ambulance program at the University of Rhode Island in the early 1980s.

Dr. Maxim was a graduate of Ross University School of Medicine, and completed his medical residency at Roger Williams Medical Center in Providence. He was a Fellow of the American College of Physicians, and director of the Rhode Island State Medicaid Program, while also a teacher and clinical instructor of medical



students and residents of the Boston University Training Program affiliated with the Roger Williams Medical Center.

Born in Middleboro, MA, he was the son of Ronald Maxim and the late Carol (Hopkins) Maxim. Besides his wife and father he is survived by two children, Colin M. and Victoria J. Maxim; siblings Walter Maxim, Donna MacDonald, Holly Madonna, Richard Allen and Susan Chicoine.

Donations in his memory may be made to the American Cancer Society, 931 Jefferson Blvd., Suite 304, Warwick RI 02886.

PROVIDENCE – **MICHAEL J. RYVICKER, MD**, 70, died Friday, March 1, 2013 at The Miriam Hospital. He was the husband of Bonnie (Engel) Ryvicker of Providence. They were married for 48 years. Born in Brooklyn, NY, he had lived in Rhode Island for 38 years.

Dr. Ryvicker, a clinical associate professor of medicine at the Alpert Medical School of Brown University in the Dept. of Diagnostic Imaging, was a diagnostic radiologist at Miriam Hospital and its offices until his retirement in 2012.

A veteran of the Public Health Service, he served at the Staten Island Public Health Service Hospital. He was a graduate of Downstate Medical Center in Brooklyn and interned at Brooklyn Jewish Hospital and was a resident at Montefiore Hospital in the Bronx.

He was the father of Kenneth Ryvicker and his wife, Bonnie, of Needham, MA; Sari Mansheim and her husband, Ben, of Yad Binyamin, Israel, and Miriam Ryvicker of Brooklyn. He was the brother of Alan Ryvicker and his wife, Marcia, of Nesconset, NY. He is also survived by nine grandchildren.

Contributions in his memory may be made to Jewish Family Service, 959 North Main St., Providence RI 02904.



Book by W&I Staff Earns Award from Nursing Journal

PROVIDENCE – A textbook written and edited by members of the medical staff at Women & Infants Hospital recently earned a 2012 Book of the Year Award from the *American Journal of Nursing*. The textbook, *Obstetric Triage and Emergency Care Protocols*, came in second in the maternal child health section.

Editors are Diane J. Angelini, EdD, CNM, of the Nurse Midwifery Section of the Department of Obstetrics and Gynecology, and Donna LaFontaine, MD, FACOG, former medical director of the hospital's Triage (Emergency) Department.

"Obstetric triage has developed into a specialty area/unit within obstetrics with multifunctional aspects. In some institutions, the obstetric triage setting is primarily a screening area for laboring women; while in other settings, it serves multiple functions including labor evaluation, assessment of obstetric emergencies and management of obstetric conditions post viability," noted Angelini and Dr. LaFontaine in the preface.

The handbook, which is organized by subject and stages of gestational development, offers many guidelines using images exclusively from the hospital's Department of Diagnostic Imaging.

Chapters include:

Diane J. Angelini, EdD, "Overview of Obstetric Triage and Potential Pitfalls"

Chelsey Caren, MD, of the Triage Department, and **David Edmonson, MD**, of the Breast Health Center, "Postpartum Breast Complications" and "Common General Surgical Emergencies in Pregnancy"

Catherine Friedman, MD, Center for Women's Behavioral Health, "Substance Use and Psychiatric Disorders in Pregnancy"

Robyn Gray, DO, of the Triage Department, "Vaginal Bleeding in Pregnancy," and, with **Luu Cortes Doan, MD**, a resident, "Pregnancy Loss Prior to Viability"

Elisabeth Howard, CNM, Nurse Midwifery Section, "Labor Evaluation"

Margaret Howard, PhD, and **Rebecca Christophersen**, both of the Center for Women's Behavioral Health, "Psychiatric Complications in the Postpartum Period"

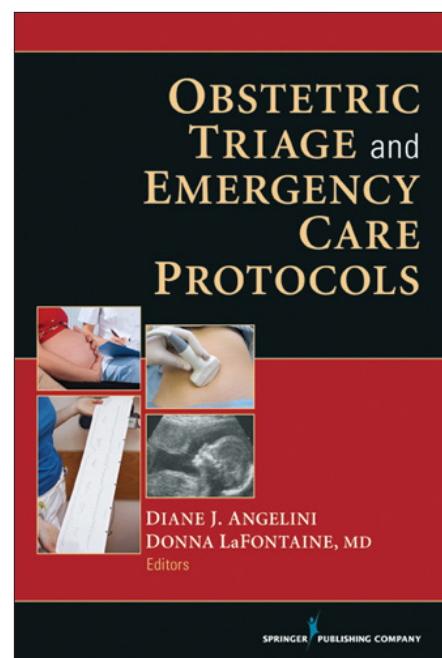
Linda Hunter, CNM, Nurse Midwifery Section, "Preterm Labor"

Julie Johnson, MD, and **Brenna Anderson, MD**, both of the Division of Maternal-Fetal Medicine, "Infections in Pregnant Women"

Dr. LaFontaine, "Sexually Transmitted Infections" and "Intimate Partner Violence and Sexual Assault in Pregnancy"

Edie McConaughy, CNM, Nurse Midwifery Section, "Fetal Evaluation and Clinical Applications"

Martha Pizzarello, MD, Triage Department, and **Dr. LaFontaine**, "Secondary Postpartum Hemorrhage and Endometritis"



The book, which is also available for e-readers, can be purchased through the publisher at springerpub.com.

Moune Jabre Raughley, MD, Triage Department, "Abdominal Pain and Masses in Pregnancy"


Janet Singer, CNM, Nurse Midwifery Section, "Recognition and Treatment of Postabortion Complications"

Amy Snyder, MD, Triage Department, "Nausea Vomiting and Hyperemesis of Pregnancies"

Linda Steinhardt, MS, CNM, Nurse Midwifery Section, "Limited or No Prenatal Care at Term"

Roxanne Vrees, MD, Triage Department, "Management of Ectopic Pregnancy" and, with **Alyson McGregor, MD**, also of the Triage Department, "Trauma in Pregnancy"

Emily White, MD, Triage Department, "Vaginal Bleeding in Early Pregnancy"



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The Names Given to Medical Publications

STANLEY M. ARONSON, MD

PHYSICIANS, AS SCIENTISTS AND PRACTITIONERS, FILL THE PAGES OF COUNTLESS technical publications with contributions expressly designed to question, define or clarify aspects of their healing profession. The numbers of such periodicals increases each year; and many (including the *Rhode Island Medical Journal*) now provide their scientific content in electronic versions. But while the numbers of such periodicals increases, their generic titles seem to keep to a relatively small number.

Historians tell us that the first regularly published tract containing medical contributions appeared in 1665 under the title: *Philosophical Transactions, Royal Society of London*. The word, transactions, has since been used by other scientific societies, especially the computer sciences, for their regularly appearing publications. The word derives from the Latin, *transigere*, and its past participle, *transactus*, meaning to carry through, to accomplish.

To many, ACTA stands for the international Anti-Counterfeiting Trade Agreement, but in a narrower context *acta* is the title of a number of medical journals, especially Scandinavian, and is based upon the Latin, *agere* and its past participle, *actas*, meaning to set in motion, to drive. Acta as a noun also describes laws (acts) passed by Parliament.

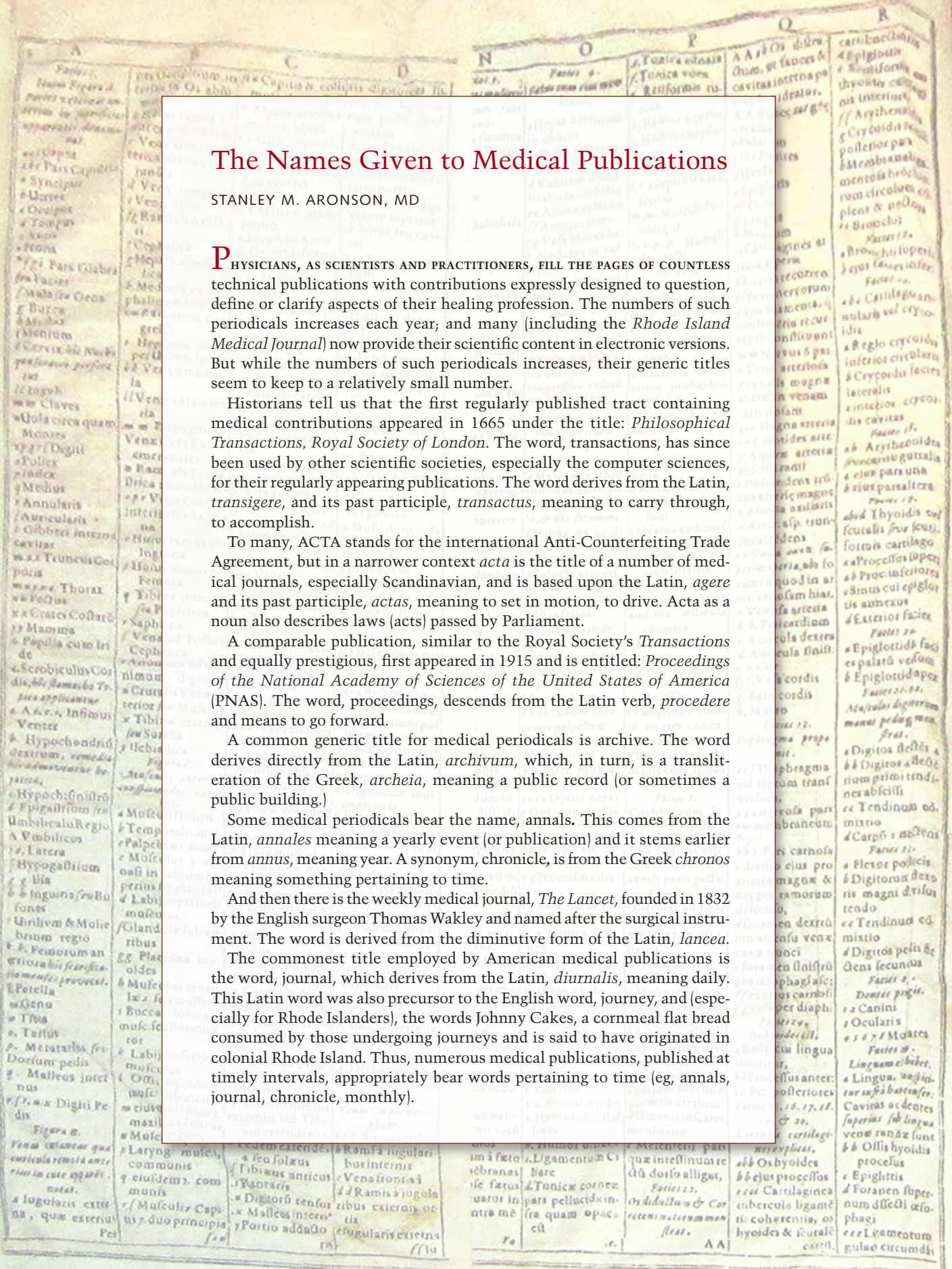
A comparable publication, similar to the Royal Society's *Transactions* and equally prestigious, first appeared in 1915 and is entitled: *Proceedings of the National Academy of Sciences of the United States of America* (PNAS). The word, proceedings, descends from the Latin verb, *procedere* and means to go forward.

A common generic title for medical periodicals is archive. The word derives directly from the Latin, *archivum*, which, in turn, is a transliteration of the Greek, *archeia*, meaning a public record (or sometimes a public building.)

Some medical periodicals bear the name, annals. This comes from the Latin, *annales* meaning a yearly event (or publication) and it stems earlier from *annus*, meaning year. A synonym, chronicle, is from the Greek *chronos* meaning something pertaining to time.

And then there is the weekly medical journal, *The Lancet*, founded in 1832 by the English surgeon Thomas Wakley and named after the surgical instrument. The word is derived from the diminutive form of the Latin, *lancea*.

The commonest title employed by American medical publications is the word, journal, which derives from the Latin, *diurnalis*, meaning daily. This Latin word was also precursor to the English word, journey, and (especially for Rhode Islanders), the words Johnny Cakes, a cornmeal flat bread consumed by those undergoing journeys and is said to have originated in colonial Rhode Island. Thus, numerous medical publications, published at timely intervals, appropriately bear words pertaining to time (eg, annals, journal, chronicle, monthly).



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50 Years Ago:

State Lauds RIMS, HEALTH, Volunteers for Ending Polio Campaign

MARY KORR
RIMJ MANAGING EDITOR

WHEREAS, On Sunday, March 3, 1963 more than 583,000 Rhode Islanders appeared at clinics in the thirty-nine cities and towns of the state and took oral Sabin anti-polio vaccine; and

WHEREAS, The mass immunization project was the first to be conducted in the country on a statewide basis; and

WHEREAS, Under the sponsorship of the Rhode Island Medical Society, with the full cooperation of the State Department of Health, this operation was carried out in an orderly and most efficient manner with the help of approximately five thousand volunteer workers; and

WHEREAS, Dr. James E. Bowes, campaign coordinator, and other campaign officials expressed their pleasure at the cooperation of the various agencies involved in this clinic for which there was no precedent for the scale attempted; now, therefore, be it

RESOLVED, That the general assembly expresses its heartiest congratulations and commendations to the Rhode Island Medical Society, the Department of Health, the individual doctors and other volunteers at the various clinics...


Passed by the General Assembly

Signed by Gov. John H. Chafee, March 8, 1963

In the April 1963 issue of the *Rhode Island Medical Journal*, a resolution of the General Assembly of the State of Rhode Island and Providence Plantations extended congratulations to the Rhode Island Medical Society and the State Department of Health for the "outstanding success of the End Polio Campaign," the first state in the union to immunize the majority of its population at risk.

The Big, Black Telephone

This advertisement appeared in the April 1963 issue of the *Rhode Island Medical Journal*.



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