

Three Cheers for

Bowling



Alli Cohen, Darienne Majeske & Patrick Branch



Emma & Jack Langan

Genevieve Nantais & Mary Beth Langan

Sibshops



Jordan Sutherby and Natalie Nantais

Jordan and Natalie have a few things in common, brothers with FX and they participate in Sibshops, a support group for kids who have siblings with special needs. It's a unique program which enables them to network with other kids who truly understand what it's like to have a sibling who is "special". There's not enough space to cover every thing they do at Sibshops, a detailed description of the program can be found at: www.thearc.org/siblingsupport. The program Jordan and Natalie attend is through Oakwood's Program for Exceptional Families. Contact Sally Nantais for additional information.

Parent's Venue

Navigating Your Way Through Individualized Educational Plans (IEPs) by Kim Young

Kim and Andrew



Spring is usually a time when parents are looking forward to summer and a little less "running around" in their schedules. It's usually a time when they're anticipating the end of the school year and some relaxation. For a parent of a child with special needs this couldn't be further from the truth. The end of the year means anxiety, worry and dread. Although some districts spread them out during the year, for many parents, the end of the year means attending a meeting regarding their child's IEP.

For anyone who has embarked on this journey already, you know what I'm referring to and this is a refresher course. If this is all new to you, if this will be your first IEP in the spring, then hopefully this will provide some insight.

As a parent of a fully included, third grade boy with Fragile X, our journey began like most, in a PPI preschool room (Pre-Primary Impaired). However, the real struggles didn't begin until Kindergarten.

From the President's Desk

By Laureen Majeske

When we enrolled Andrew in Kindergarten, we were met with open arms. The school staff was aware of his Special Education Certification at the time of enrollment. As the school year progressed, it became apparent to the staff that Andrew was not functioning on the same level as the other students. Something they didn't feel equipped to handle. I think this is a common roadblock that we all encounter. But it's one that can be resolved with the right tools. Hopefully some of the tips I'm including will help make your experience less overwhelming and more successful.

- First and foremost: decide what the ideal future for your child looks like -- the future twenty years from now. That is what should be guiding your decisions regarding placements and IEP goals. *What do we do now that will eventually lead us there?*
- Next: don't go it alone. Bring someone who has experience with the IEP process, someone who is not emotionally attached to the situation and who can be objective. (Before you know it, *you* will be the one playing this role for someone else at their IEP!)
- Do your homework. Learn your legal rights. Research the different tests that the staff is administering to your child. Two web sites that are great resources are fragilex.org and wrightslaw.com.
- Make notes ahead of time to help keep you on track. It's amazing how walking into a room with the whole "team" amassed can make you feel like a deer caught in the headlights.
- One of the most important things to remember is that your goal is not to win. Your goal is to bring that "team" over to your side. You're not only looking to get everything that you want for your child, but really to make the people working with your child believe that what you're proposing *is* what is best for your child.

The success that we are now enjoying with Andrew is the result of a combination of many things-- friends and family that have been a tremendous support, advocating tirelessly for our son, and finally convincing the staff that Andrew truly belongs and has a right to have every door in life open to him. 

Things have been very busy lately at the Fragile X Association of Michigan.

In February, our speaker, Dr. Pamela McCaskill, brought along her husband, Dr. John McCaskill, to help answer our questions about stress. It was a much anticipated subject and we had a large crowd in attendance. I have tried to incorporate the breathing techniques she taught into my "drive time" as was suggested. They really are helpful. I encourage all of you who learned them to give it a try!

March brought Dr. Sandra McClennen, licensed psychologist, speaking about *Educational Strategies* at our monthly meeting. She has always been a helpful resource in the Detroit area and we appreciate her insights into fragile X syndrome.

FXAM sent treasurer Kim Young as our representative for the second annual Advocacy Day – held March 16 in Washington, D.C. Kim reports that FX advocates were well received on Capital Hill. Thank you to Jeffrey Cohen, Public Policy Chair for NFXF, for setting up Advocacy Day and working to gather FX advocates from across the United States.

March also included our bowling fundraiser at Langan's in Farmington Hills. It was a great opportunity to be with family and friends and enjoy bowling and pizza with our children.

We are moving along with plans for our conference to be held Saturday, October 15, 2005, at Beaumont Hospital in Royal Oak. We currently have two confirmed speakers: Marcia Braden, Ph.D., P.C. and Kelley Geddes, M.A. The conference, for family members and professionals, will focus on *Managing Behavior, Education and Stress*. Marcia and Kelley are two *eXperts* on fragile X syndrome and it promises to be an important and informative event!

The FXAM family has several new members. While we know it's difficult to receive a diagnosis of FX for a family member, we will continue to help you learn about and understand FX. We welcome all of you to our FXAM family.

Please note: The calendar of events in eXtra, eXtra lists upcoming meeting times. Please transfer these times to your home calendar as we will no longer be mailing reminder postcards. Those of you on our e-mail list will continue to receive an electronic reminder. To add or update your e-mail address, contact Mary Beth Langan, our corresponding secretary.

As always, thank you to all of the individuals and families who work so hard to make our group something special.

Good luck to everyone on their upcoming IEPs! ✕✕

Quote for the Quarter

"A strong positive mental attitude will create more miracles than any wonder drug." Patricia Neal

We need your help!

The Directory – it's time for updates, do we need to make changes to your information?

Publicity – Does your paper list local support group meetings? Is FXAM listed? If it isn't, we need to have it added.

Please contact **Mary Beth** at 313-881-3340 or mblangan@hotmail.com

Through the Maze

Featured Website

Wrightslaw

www.wrightslaw.com

OT
IEP
ECD
IDEA
SLT

After a diagnosis, one of the most challenging jobs you may encounter will involve understanding special education law. Special education law is a world filled with acronyms and critical information that may determine the services available for your child, services to meet your child's unique needs.

Parents, advocates, educators, and attorneys come to Wrightslaw for accurate, up-to-date information about special education law and advocacy for children with disabilities.

You will find articles, cases and resources about dozens of topics in their Advocacy Libraries and Law Libraries.

In addition, you will find a wealth of information on Individualized Education Plans (IEPs), everything from how to write measurable goals and objectives to understanding accommodations or modifications. "8 Steps to Better IEP Meetings: Play Hearts, Not Poker" is a must read for novices or experts.

Their free online newsletter, The Special Ed Advocate, can be delivered directly to your e-mail inbox. You can subscribe at www.wrightslaw.com/subscribe.htm.

Wrightslaw.com is a website that needs to be added to your list of favorites. ✕✕

Additional Links for IEP and Advocacy Information

www.causeonline.org - Citizen Alliance to Uphold Special Education (CAUSE)

www.cesa7.k12.wi.us/sped/index.html - School website which has won numerous awards related to website design and information provided for special education.

www.wash.k12.mi.us/perform/Index.asp - Project Perform

www.mpas.org - Michigan Protection and Advocacy Services

Between the Lines

Featured Book

From Emotions to Advocacy

by Pete and Pam Wright

Pam & Pete Wright are a dynamic husband-wife team who seem to have a goal of educating the entire country about special education law. Most folks are happy this is their goal. Pete is an attorney who represents children with disabilities. Pam is a psychotherapist who writes about advocacy for children with disabilities.

Their main goals in this book include teaching parents how to plan, prepare, organize and get quality special education services for their child, though it's also a book for special educators.

It's a very easy book to read and includes great tips, cross-reference alerts and applicable internet resources. You will learn simple, yet important, advocacy skills. These are important skills as, according to the Wrights, you need to act as your child's special education project manager. Not an easy job, but the Wrights try to make it much easier.

This couple has a lot of great information to share. Their other books include Wrightslaw: Special Education Law, Wrightslaw: Smart IEPs, and No Child Left Behind. Wrightslaw: Special Education Law is especially a great book. It's a user-friendly legal reference book designed to improve your knowledge of the law.

Read more about Wrightslaw in this newsletter's feature Website column. Visit the site for a listing of their conference circuit, which – luckily for us – includes stops in Michigan. ✕✕

Reminder

Support meetings take a vacation during the summer months.

Stress Management for Parents

Pamela A. McCaskill, Ph.D.

Stress is a normal part of life and affects all of us in some way or another. Some stress is actually good in that it can motivate us to make changes or get things moving in a positive direction. One type of stress, often referred to as chronic stress, occurs in the context of a long-term, ongoing situation. Parents of children with special needs are particularly at risk for experiencing chronic stress. The impact of chronic stress is intensified for those parents who are also experiencing their own physical or mental health difficulties and perceive themselves as having little or no support. Chronic stress plays a role in many health problems, but has a particular negative impact on the cardiovascular system, nervous system, and immune system. It can lead to clinical depression and anxiety, concentration difficulties and relationship problems.

One of the good things about stress is that it is easy to identify in that our body often gives us very direct cues if we know what to look for. The following is a list of some of the signs of stress.

Physical Signs of Stress:

1. Headaches
2. Stomachaches
3. Muscle Tension (stiff neck or shoulders)
4. Backaches
5. Teeth clenching or grinding
6. Sweaty Palms

Emotional and Behavioral Signs:

7. Sleep disturbance – difficulty falling asleep, frequently waking up
8. Feeling tired all the time
9. Overeating
10. Loss of Appetite
11. Irritability
12. Losing temper more often, yelling
13. Concentration difficulties
14. More disorganized than usual, losing things
15. Excessive worrying
16. Difficulty making decisions
17. Reliance on alcohol, nicotine, or illicit drugs

The intensity and duration of the above symptoms is important to consider. The more symptoms you have at the same time, the worse the stress may be. Typically, the symptoms worsen over time which gives you a chance to intervene and do something to manage the stress before it becomes life-threatening.

Managing stress takes time which can be a problem in and of itself for parents. However, if you don't take the time to manage your chronic stress, your children may find themselves alone in a world without you. I suggest that **everyday** you make a commitment to doing at least 5 of the things below.

General strategies to reduce the impact of chronic stress:

1. Set a realistic daily "To-Do" list (anything else you get done is icing on the cake)
2. Organize things the night before as much as possible
3. Don't be afraid to ask for help from family, friends, sitters, etc.
4. Don't over-commit yourself
5. Get enough sleep (8 hours per night recommended for the average adult)
6. Drink 8 – 10 glasses of water per day
7. Eat healthy foods (fruits, vegetables), balanced diet
8. Find humor in things throughout the day

Strategies to Immediately Alleviate Stress:

1. Read
2. Exercise
 - a. Aerobic exercise – walking, bicycling, swimming
 - b. Stretching – relieves muscle tension
3. Breathing Exercises
 - a. Slow deep breath in to the count of 3 seconds, hold for 1 second, then release slowly to the count of 3 seconds.
 - b. Fast deep breath in, hold it, release breath quickly
4. Say positive things to yourself. Change negative thinking to positive thinking.
 - a. "I can handle this."
 - b. "I've done this before."
 - c. "What is the worst that could happen and is that so bad?"
 - d. "Slow down"
 - e. "This is not the end of the world."

5. Take a bath or shower
6. Listen to music
7. Take a drive
8. Get a massage
9. Writing/ Journaling (10 –15 minutes/per day)
10. Talk to someone
11. Find a hobby – scrap booking, gardening, crafts, woodworking
12. Play with a pet

Managing stress, much like diet and exercise, it a lifestyle choice. Quick fixes rarely, if ever work. If you have been experiencing symptoms of stress for more than 2 weeks and the techniques listed above or in the self-help references listed below are not helping, it might be time to consider professional help. Taking the step toward seeing a counselor is not a sign of weakness, but rather a sign of strength in that you are using resources available to you to solve a problem.

Recommended Reading:

1. Don't Sweat the Small Stuff... And It's All Small Stuff by Richard Carlson
2. Relaxation and Stress Reduction Workbook, 5th Edition by Martha Davis, Matthew McKay, and Elizabeth Robbins Eshelman
3. Feeling Good Handbook by David Burns, M.D.
4. Instant Stretches for Stress Relief by Mark Evans
5. Learned Optimism by Martin Seligman, Ph.D. (also available on Compact Disc)
6. What you can Change and What you Can't: The Complete Guide to Successful Self-Improvement by Martin Seligman, Ph.D.

Dr. Pamela McCaskill is a Licensed Clinical Psychologist in private practice with a specialization in stress management and working with parents of children with special needs. She has extensive training in the evaluation and treatment of children, adolescents, and families with a variety of clinical presentations, including behavior problems, school difficulties, ADHD, anxiety and depression. Dr. McCaskill is currently practicing in Plymouth, MI and can be reached at 734-416-9098. ✨

Mark Your Calendar

Support Meetings:

When: May, June; First Saturday of the month.

Time: Business Meeting: 6 – 7 p.m.
Support Meeting: 7 – 9 p.m.

Where: Beaumont Hospital, Royal Oak
Admin Building, Private Dining Room

Guest Speakers/Special Events:

May 7: What it's like growing up with
Fragile X – Alli Cohen

May 26: Comedy for a Cause!
Joey's Comedy Club, Livonia, Michigan

Jul 24: Picnic, Fort Fraser
Steffens Park, Fraser, Michigan
586-294-0450
www.ci.fraser.mi.us

Aug 27: Annual Golf/Dinner Fundraiser
Westburn Golf & Country Club
South Rockwood, Michigan

Oct 15: Conference: X-pert Advice
Fragile X and Autism Spectrum Disorders
Managing Behavior, Education and Stress

Contact Information:

Phone: 313-381-2834

E-Mail: fraxmich@hotmail.com

Web: www.fragilex.org/html/michigan.htm



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