

**Improving Care for MRKH Through
Comparative Effectiveness Research
Workshop**

Friday, April 21st
from 4:00 PM to 6:00 PM

**North American Society for Pediatric
and Adolescent Gynecology Meeting**
Renaissance Chicago
Downtown Chicago, IL, USA



THE AGENDA

Improving Care for MRKH Through Comparative Effectiveness Research

Friday, April 21st from 4:00 PM to 6:00 PM

North American Society for Pediatric and Adolescent Gynecology Meeting

Opening Remarks

- 4:00 *Anne-Marie Amies Oelschlager, MD, Seattle Children's Hospital*
Amy C. Lossie, PhD, Beautiful You MRKH Foundation and Global MRKH
An MRKH Perspective
- 4:05 Janay Cook, person with MRKH
Accepting MRKH
- 4:10 *Alison Hensley, Sisters for Love MRKH Foundation and Global MRKH*
Creating a Fulfilling Life
- 4:15 Kay Berry, person with MRKH and retired social worker
Lessons from a Lifetime
- 4:20 **Panel 1: Diagnosing MRKH—Making the Best of a Difficult Experience**
- 4:22 Diane Merritt, MD, St. Louis
What Can Clinician's Do Better?
- 4:25 *Vinson Pan, MD, Affiliation*
MRKH: A Chinese Perspective
- 4:28 Susan Carroll, person with MRKH and PhD candidate in Health Psychology/Trainee Health Psychologist, King's College London
Mental Health Care During a Difficult Diagnosis: Lessons from Health Psychology
- 4:31 *Gale Hadaway, Mother of a child with MRKH and Founder, Her Health Matters*
Finding the Right Physician for your Child
- 4:34 Renee Gough, Mother of a child with MRKH
Advocating for your Child
- 4:37 *Meredith Brookes, Mid-Atlantic MRKH Foundation*
Diagnosis in Young Patients
- 4:40 Discussion
- 4:55 **Panel 2: Treating MRKH—It's More than Creating a Vaginal Canal**
- 4:57 Marc Laufer, MD, Boston Children's Hospital
A Patient-Centered Approach
- 5:00 *Elisabeth Quint, MD, The University of Michigan*
When Parents and Patients Disagree
- 5:03 Candice Norcott, PhD, The University of Chicago
Integrating Mental Health Care into Treatment
- 5:07 *Kristy Siiankoski, person with MRKH and Finding a Healthy Sexuality*
- 5:10 Julie Reinhart, Mother of a child with MRKH
When Your Daughter is Denied Access to MRKH Experts
- 5:13 *Laura Mufson, Mid-Atlantic MRKH Foundation*
Finding the Right Care
- 5:16 Discussion
- 5:30 **Panel 3: Priorities for Comparative Effectiveness Research**
- 5:30 **Improving Diagnosis**
Facilitated by Anne-Marie Amies-Oelschlager, MD and Amy C. Lossie, PhD
- 5:38 **Improving Treatment**
Facilitated by Anne-Marie Amies-Oelschlager, MD and Amy C. Lossie, PhD
- 5:46 **Improving Sexual Health**
Facilitated by Anne-Marie Amies-Oelschlager, MD and Amy C. Lossie, PhD
- 5:55 **Wrap Up**
- 6:00 Adjourn

SPONSORS

Global MRKH is to improve the health and wellbeing for all who are touched by MRKH. Global MRKH is an international collective of Health Care Specialists, Researchers and Advocacy groups dedicated to improving patient care, biomedical research and the psychosocial needs of affected individuals and family members. The Founders of the Global MRKH are Alison Hensley, Amy C. Lossie, PhD, Christina Ruth and Jaqi Quinlan. The Founders act as independent members of Global MRKH, forming the first official international consortium of MRKH organisation leaders, community representatives, health care professionals and adults who have been diagnosed with MRKH. The Administration of Global MRKH is shared equally by the Sisters for Love MRKH Foundation (SFL) and the Beautiful You MRKH Foundation, Inc. (BYMRKH), who jointly established Global MRKH on 1 June, 2015. Sisters for Love MRKH Foundation, Founded by Alison Hensley and Jaqi Quinlan, is based in Australia. The Beautiful You MRKH Foundation, Founded by Amy C. Lossie, PhD and Christina Ruth, is a 501(c)(3) charity based in the United States. The vision of Global MRKH is to foster collaboration amongst clinicians, psychologists, researchers and patient advocates to: 1. Provide support to those diagnosed with MRKH; 2. Increase awareness of MRKH; and 3. Improve outcomes for all who are affected by MRKH.

GLOBAL MRKH



Beautiful
MRKH Foundation **you**

Christina Ruth and Amy Lossie Founded the **Beautiful You MRKH Foundation (BYMRKH)** on July 31, 2012. BYMRKH's mission is to create a supportive community that partners with health care professionals to increase awareness and empower women of all ages with MRKH to feel beautiful, just as they are. Our goals are to: 1. Support teens, women and families; 2. Advocate for MRKH; 3. Disseminate medically-accurate information about MRKH through our website, Facebook Support Groups and other social media platforms; 4. Partner with medical professionals and researchers to incorporate the patient perspective to improve health care for and research on MRKH; and 5. Support research on MRKH. BYMRKH is the largest non-profit organization devoted exclusively to MRKH in the world.

We promote self-esteem, and empower girls and women with MRKH to embrace their beauty, just as they are. We welcome members from around the world, and believe that through our differences, we will find our greatest strengths. We started the Beautiful You MRKH Foundation because we survived the devastating diagnosis of MRKH; fought hard battles with ourselves and others as we accepted our diagnoses; and emerged as strong, determined, resilient and deeply caring women who understand and accept you just as you are – beautifully, perfectly, exquisitely you.

The **Sisters for Love MRKH Foundation** is the first and only official foundation in Australia and New Zealand, which has been formed to provide support to those who have been diagnosed with MRKH and to extend that support to those close to them. Co-Created by Alison Hensley and Jaqi Quinlan, two women who use their own MRKH experiences, Entrepreneurship and creativity skills, to form a 'place' for women with MRKH. The Sisters for Love MRKH Foundation provides comprehensive information on the condition of MRKH and continues to build strong international connections to bridge the diagnostic gap for all those involved with MRKH advocacy and awareness. The Sisters for Love seeks to improve the journey that a woman will take when diagnosed with MRKH, alongside a sisterhood of women and medical professionals to offer support along the way, one step at a time.



Sisters For Love MRKH Foundation

PANEL ABSTRACTS

Anne-Marie Amies Oelschlager, M.D. is an Associate Professor of Obstetrics and Gynecology at the University of Washington in Seattle, WA. She is the Chief of Pediatric and Adolescent Gynecology and a member of the multidisciplinary Differences of Sex Development (DSD) Clinic at Seattle Children's Hospital. She has **clinical expertise** in the **evaluation, diagnosis, and management of MRKH**.

Amy C. Lossie, PhD is the President, CEO and Co-Founder of the **Beautiful You MRKH Foundation, Inc.** A non-profit organization dedicated to increasing acceptance and decreasing shame of MRKH, a form of congenital infertility. She is also a Co-Founder of Global MRKH, an organization dedicated to **improving holistic care** for all affected by MRKH. She is passionate about **raising awareness of MRKH**, providing **support to all who are affected by MRKH** and improving patient care through partnering with the biomedical community. When she's not advocating for MRKH, you will find her out and about in Maryland with her dog Lola or somewhere in the tropics exploring blue water.

Janay Cook, person with MRKH Janay is an associate news producer in Jacksonville Florida and an alumna of Florida A&M University. A true womanist to the core, she aims to use her platform to **educate and inspire women in the MRKH community** around the world. Janay was diagnosed at 18, three months before graduation. Now eight years later, she's sharing her story. "Happiness came to me in a sad vehicle. **This condition isn't intended for the faint-hearted.** One of the biggest lessons I've learned is healing hurts, but it happens when you allow yourself to break, rebuild and break again. **Just be patient with yourself.**" Janay came out publicly about her condition over social media three years ago. Since then she's shared some of her toughest hardships and struggles as well as the **beautiful side of MRKH** that often goes unnoticed. When Janay isn't online shopping for graphic tees, she's watching natural hair tutorials on YouTube and reading novels. In her spare time you can find her writing short stories and screenplays.

Alison Hensley is the proud Co-Founder of **Global MRKH, the recognised International Consortium for MRKH advocacy and the Sisters for Love MRKH Foundation**. The first and official foundation advocating for the unique MRKH community within Australia and New Zealand. In addition to these organisations, Alison is also the President of the **MRKH Support Group** Committee alongside a number of members, including key executive representative's from The Royal Hospital for Women, Sydney established in March 2015. Ally has **always maintained and stood firm to the mission statement** cementing the Australian Foundation, which is to ensure, that in her integral role as a key MRKH leader and representative, she is to remain committed in **reducing any emotional distress, confusion or isolation in the form of face-to-face guidance** both nationally and internationally, with women reaching out for further support, empathy and understanding of MRKH. **By bridging the gap** between those diagnosed and those who diagnose, Ally is able to advocate for multidisciplinary research, best practice health care, psychological assistance and continues to act as a personal mentor to women of all ages, globally. Ally places huge emphasis on ensuring **continual connectivity to all the moving parts of this diagnosis**; the patients, the families, the medical community, and digital media but foremost, never straying too far from her own experiences and sharing those humbly and honestly within the MRKH community. And as 'Ally' continues to work on her **relationship with MRKH**, you will most likely find her on a yoga mat or diving into the waves on Bondi Beach.

PANEL ABSTRACTS

Kay Berry, person with MRKH and retired social worker MRKH does last a lifetime. MRKH is not just figuring out the problem and providing a solution for sex and procreation. MRKH is also on-going care, both physical and emotional. **At 61**, I had an ultrasound that showed a small mass. The plan was a band-aide surgery. When they opened me up, I was full of endometriosis! The band-aide turned into an incision 6 x 7 inches. They found two full uteri located up under my diaphragm and an ovary that was obviously cancerous. I am still here 9 years later thanks to chemo and follow-up care. Emotionally it was even worse. **You need to look at it from an MRKHer's perspective.** When they told me, I was madder than I had ever been in my life. I had a uterus, in fact two of them. But I didn't have a uterus anymore. How could they!!!! How could anyone be so cruel as to not let me have even one second knowing I had a uterus? No one understands what that means to us. I didn't care about the cancer. They had taken away my uteri! **I used this experience to reach out to the MRKH community.** I now help to administer an MRKH support group – MRKH Experiences, Advice, and Support – on face book. We are over 1,300 strong and I have finally overcome my low self-esteem issues. **MRKH is also about on-going care.** What can we expect as we get older? Is there a relationship between MRKH and other illnesses later in life? What will we need to do to keep our vaginas functional for a lifetime? How do we ever overcome the low self-esteem this diagnosis causes? **Please continue research on what MRKH means for a whole life time.**

Diane F. Merritt, MD Washington University in St. Louis Most clinicians are not prepared to provide integrated personal care to address all the clinical needs of women with MRKH. **Advice for the clinician:** Determine if you are able to explain this condition with sensitivity and understanding. If not, by all means take the time to educate yourself, as well as connect and refer to experienced, competent, sensitive and knowledgeable MRKH providers. **Explaining the initial condition:** Many young women would like to receive this information in the presence of their family for support. There is an advantage to informing parents in advance, **allowing parents to have their initial response to the diagnosis** (many moms cry) and enable them to provide a loving, strong and supportive environment when their daughter receives her initial diagnosis. 1) Preface that the initial disclosure may be hard to take in initially; 2) Help the family understand that the condition has a name (MRKH) and explain what that means; 3) Inform your patient that she is not the only one with this diagnosis and **there is an entire community of women who have MRKH** with whom to connect; 4) Create an opportunity to talk privately as there may be topics that she would like to personally discuss without her parents. **Acknowledge the psychosocial impact of this condition** and offer continuing real time opportunities for support as reactions may range from shock and surprise to anxiety, depression and grief. (Will I ever have children? Who will love me? How, when and who do I share this information with?) Counsel that there is no need to rush to decide anything. **Allow time to consider the diagnosis**, complete the workup, and prepare questions. Recommend dedicated return visits to talk with the patient and her designated support people regarding "the next steps". Discuss all options for family building and creation of a neovagina, emphasizing that nothing needs to be done quickly, and **this is a very personal decision**, best timed when the young woman can participate in the decisions and outcomes.

Hongxin Pan MD, Gynecologist and Director, Female Genital Tract Congenital Malformation Research Center China is a country of very large population, with an estimated 100-150 thousand patients suffering from MRKH. Our group has developed a novel technique - the Luohu technique, demonstrated shorter operative and recovery time, and reduced intraoperative bleeding, as an effective and safe surgical option for vaginal reconstruction. **During the last decade, more than one thousand patients of MRKH for Luohu technique vaginoplasty were treated successful**, that made our center for congenital anomalies of the reproductive tract became the largest referral center for MRKH patients in China. **There're some key points for treatment of MRKH:** 1) Timing of surgery, operation is generally performed for adults after 18 years of age. 2) Luohu technique vaginoplasty is highly recommended as the most effective surgery therapy. 3) Consultations are necessary throughout the entire treatment period. **As the largest referral center for MRKH patients in China**, we are making great efforts in the exploration of the background of disease-associated genes. Furthermore, we would like to cooperate with you and participate in the international clinical study.

PANEL ABSTRACTS

Susan Carroll, person with MRKH and PhD candidate in Health Psychology/Trainee Health Psychologist, King's College London

Receiving a diagnosis of MRKH can be very distressing and difficult to process for a young woman and her family. Though **every person responds differently to MRKH**, there are a number of common themes that arise when women recall their experiences of diagnosis, such as feelings of sadness, anger, loss and confusion. Among these reactions, **young women often feel very alone in their diagnosis** as they have likely never heard of MRKH, and are often unaware of the psychological support that is available to them. At the time of delivering the diagnosis, **integrating psychological care** into practice is **imperative to fostering positive adjustment to MRKH**, and the challenges that it brings to those whose lives it affects. In this talk, Susan will draw on her personal experience of her own MRKH diagnosis, and her work in the field of health psychology, in discussing the provision of **psychological support** to newly diagnosed patients and their families.

Gale Hadaway, Mother of a child with MRKH and Founder, Her Health Matters

Objective: To determine how to best find appropriate diagnosis and treatment for adolescent girls presenting with symptoms of MRKH. Secondly, to have diagnosis and follow up **treatment be a comprehensive pathway** that includes both physical and emotional needs so that additional pain is not injected into an already aggrieved situation. **Method:** Analyze responses from parents and patients to survey questions regarding initial diagnosis of their MRKH. Review testimonials on web support sites. What was remarkable in those first encounters that were positive for the patient and families? Outline commonalities used by the health care provider in each case. **Results:** Approach and presentation of **diagnosis can contribute immensely to patient reaction**. Compassion, sensitivity and education from the healthcare provider are key to patient's feelings of self worth, dignity and hope for the future. Teaching hospitals may provide a starting point in finding care and referrals for MRKH directive healthcare providers. **Conclusions:** Quality of life for MRKH patients, at such a vulnerable age, can be protected and enhanced with the appropriate support from the medical community. **Universal education of the medical community**, especially primary care physicians, pediatricians, and gynecologists is imperative. MRKH standard of care pathways are **needed to share with patients and families**.

Renee Gough, Mother of a child with MRKH

MRKH is an opportunity for growth. But that isn't how it started. It started with a hunch. It grew into a discovery. It bottomed out in grief. **Grief for what I wished for my daughter**. Grief for what I thought she needed to be happy. Grief that our family couldn't change this news. In times like these, angels come into your life. Dr Melissa Gilliam showed me that **nothing was broken, nor did it need repair**. The doctor fixed her eyes on the patient's - and gave her her dignity. Dr Amy Lossie & Christina Ruth showed me that broken hearts make a beautiful mosaic when they **come together** to form the whole of The Beautiful You MRKH Foundation; our only single resource after a few years in total isolation. Every mother I reached out to became another extension of that continuum of angels. We may be a freaked out bunch of mommas, but we are a determined bunch. Through networking, texting, Facebook and phone calls, **we carried the word around this world** like some sort of primitive patchwork of healing power, grabbing bits of science and love, and hoping to give a bit of oxygen to the bereft international collective psyche that is the MRKH community. We are a weary bunch. **But we are never broken**. Never in need of repair. We want only to join in the collective care of the rest of the fractured pieces of the biological puzzles that join us all. When a need this deep runs through so many countries, **the potential for growth is enormous**. What will we find when we ask our girls what they need? What will we find when we ask their families their stories? What will we find when we put these tiny pieces of the puzzle together and join the larger jigsaw? **This opportunity is ours to seize**.

PANEL ABSTRACTS

Meredith Brookes, Mid-Atlantic MRKH Foundation A diagnosis of MRKH at an early age, is often precipitated by an acute medical condition. The acute issue requires immediate action while the “usual” symptoms of MRKH need to be monitored until the patient is ready for treatment. For me, the medical emergency that led to the **MRKH diagnosis** was Intestinal Malrotation, a medical condition where the bowels are twisted; this can prove fatal if not surgically corrected. Unfortunately, an acute situation for a young patient may lead many doctors to take on a patriarchic **attitude** toward the patient, at best. At worst, some doctors **believe** only they know what's best for the patient's care. Even for the best parent advocates, there's a learning curve and, faced with an acute medical emergency, someone who knows what is needed can be very reassuring, **inspiring a high level of trust**. While initially it **may be comforting** to have a doctor who acts like they believe they have all the answers, making unilateral medical decisions for the patient and family, it is **extremely problematic** in terms of patient advocacy and eventually can lead to a situation where patients feel they have no say in the decisions made about their own bodies. If those issues aren't troubling enough, it can lead to catastrophic emotional issues for both patient and family when the doctor, makes a decision that isn't in the **best interest of the patient** or makes the wrong call. The loss of trust between the patient, family and the doctor can be world shattering. It can affect all future interactions that the patient has with medical professionals. **The doctor- patient/family relationship needs to be a partnership from the get go**, even with early diagnosed cases. I hope to use my personal MRKH journey to illustrate the issues of concern in this important relationship.

Marc R Laufer, M.D, Chief of Gynecology, Boston Children's Hospital, Gynecologist, Brigham & Women's Hospital, Professor of Obstetrics, Gynecology, and Reproductive Biology, Harvard Medical School, Co-Director Center for Young Women's Health [youngwomenshealth.org] Providing each and every patient with an individualized evaluation, educational resources, guidance, treatment, and support, that is both **respectful of, and responsive to, their distinct preferences, needs and values**, are some of the principles of patient centered care of girls and women diagnosed with MRKH. As clinicians we must ensure that the **patient is involved in all aspects of her care** and the patient's readiness or reluctance for treatment should guide all clinical decisions. Clinicians must remember that MRKH affects each member of the patient's world differently. While the primary goal is to **support young and adult women diagnosed with MRKH**, clinicians should also aim to provide resources for parents, other family members and significant others. A parent or guardian may feel that they want to “fix” their daughter as soon as possible” but it is our job to support and **guide the family** to age appropriate patient centered care and provide interventions if and when the client desires such interventions. A team approach is necessary to **provide an accurate diagnosis**, specific cultural and age appropriate health information, and psychologic/social work support.

Elisabeth Quint, MD, The University of Michigan Adolescence can be a tumultuous time for many families. The teenage brain is still developing, hormones are surging and communication in families are often difficult. **Having to face a complicated diagnosis like MRKH during this time is hard:** the topics are sensitive and require thoughtful discussions, teens are looking to their parents for guidance as parents themselves also need support. The timing and method of vaginal creation can be a source of disagreement: the parents may want to take action and help their daughter get started, while **the daughter does not feel ready for any decision yet**. Vice versa: the MRKH-er really wants to work with her care team on this and the parents are not ready for her to even think about vaginas and sex. The parents may prefer one method for vaginal creation over the other, be it surgery (parents have to sign a legal consent until age 18) or dilations and the MRKH-er may not agree. Disclosure, who to share medical information with, can also lead to differing opinions. **Having MRKH is not a secret, but it is personal information** and parents and adolescents may not agree who gets to share in that. Through discussions with each other, the medical care team, mental health providers or others, families often find ways over time to develop solutions, while **the MRKH-er always has the final word**.

PANEL ABSTRACTS

Candice Norcott, PhD, The University of Chicago Adolescence is a time of discovery, struggle, and growth. Mayer-Rokitansky-Küster-Hauser syndrome (MRKH) impacts 1 in 5000 females. So, although uncommon, it is not rare. Diagnosis most often occurs in adolescence with girls presenting with amenorrhea. So during this **tumultuous time of growth** girls with MRKH get news that alters the way they think about their futures. There is no uniform reaction to being diagnosed with MRKH, however, girls often are most distressed at being “different” than their peers. Over time, the way a girl **feels about her diagnosis** may change as her developmental needs change. And while traditional treatment has focused on the physical aspects of the illness, less attention has been paid to the **psychological impact**. There is conflicting data about how MRKH impact women. Some data suggest that women are overwhelmingly impacted by this diagnosis while other data suggests that over time women adjust well (Kaplan, 1970; David et al 1975). Research has agreed that when **women are treated** for both the **physical and psychological aspects of MRKH** they fair better. Dr. Norcott will talk about common psychological presentations of adolescents upon diagnosis. The mothers’ of girls diagnosed with MRKH play an important role and must be considered. Important elements to consider as well as **helpful tips** will be discussed.

Kristy Siiankoski, person with MRKH As a woman with MRKH and a Sexologist, I am driven by the question “How do you develop a healthy and happy sex life and individual sexual identity when your sex organs **have been diagnosed** as abnormal, dysfunctional and completely medicalized?” For some this might be straight forward, but for others it may be a **long and challenging journey** which can be made more difficult by the age of diagnosis, cultural taboo, and a lack of awareness and acceptance. Due to these reasons, this issue needs to be treated with **sensitively and openness** throughout the diagnosis and treatment phase. The impact of MRKH on sexual well-being and body image can be treated as a second order issue throughout this process. While the definition of **successful treatment** may be increasing the length of the vagina, sexual well-being does not begin and end with the length of the vagina. A lack of adequate resources and professional medical advice focusing on these issues throughout my own experience led me to create ‘The Happy V’. The Happy V provides an online platform where the variation and **uniqueness** of all women's bodies (not just those with a diagnosis) are appreciated with a focus on awareness, pleasure and **acceptance of one's body** with practical and honest advice. This is an important aspect of the further work which needs to be done to focus on a more **holistic patient experience from diagnosis**, treatment to long-term ongoing care.

Julie Reinhart, Mother of a child with MRKH Julie Reinhart's 16 year old daughter was diagnosed with MRKH in the summer of 2015. Today, Ms. Reinhart will discuss the struggles her family and their primary care physician, Dr. Veronica Rejon, have encountered in their attempt to get the **best possible care** for her daughter. **As of this date** their insurance company has denied four individual referrals to an MRKH specialist from Dr. Rejon.

Laura Mufson, Mid-Atlantic MRKH Foundation Comprehensive care of this particular condition is key for a patient’s physical and mental well being. At the time of diagnosis, patients should be referred to options for **specialists and psychologists that can help them** through the rest of the recovery process. This requires access to physicians and psychologists, both not only with lengthy experience in MRKH, but also **good bedside manner**. The limited number of physicians and psychologists that specialize in the area of MRKH in the United States make it already difficult for patients to access the **right care they need to recover** from their diagnosis and get the right treatment. Inability to access the right doctors and psychologists may lead to adverse effects in patients with MRKH. **Personal experience with some of these issues will be used to demonstrate the effects of “good” and “bad” care.**

HEALTH CARE PROVIDER

MRKH

Project Objective:

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The Team

Amy Lossie
Kristen Peterson
Christina Ruth
Jaclyn Misch

Alison Hensley
Kristy Siiankoski
Kristy Ziemann
Susan Carroll

HEALTH CARE PROVIDER

To better understand the experiences of those effected by MRKH, we designed a survey to capture the voices of Health Care Providers

40.8%

'NAME' Mayer-Rokitansky-Küster-Hauser as type

RESEARCH Genetics, Support and UTx

81% offer Dilatory Therapy for vaginal lengthening

Let's Get Honest!

we asked



83



health care providers voices



"vaginal dilator therapy is a non invasive procedure which creates the most natural vagina"

Support groups can bridge the 'patient-professional' diagnostic gap with useful and relevant information

Over 76%

offer Adoption resources specific to family planning options

2.7%

offer advice on dating and relationships

" To see more PSYCHOLOGICAL support on the ground "

- Health Care Provider

MRKH

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PARENT

To better understand the experiences of those effected by MRKH, we designed a survey to capture the voices of PARENTS



58.3%

YES ... when asked if their child's diagnosis was handled sensitively

83%

discuss FERTILITY options

2.6%

Their child should opt to undergo treatment once in a committed relationship

Let's Get Honest!

we asked

- Diagnosis
- Treatment
- Sex
- Psychology

256 parent voices



"My daughter ended up running away at 17. She was told she was meant to be a boy"

74.3% of parents recognise the impact that MRKH has on sex and well-being

41%

were satisfied with the level of support offered

60.5%

did NOT receive any information about additional supports

Everyone involved showed compassion!

Facts

HELP!

-parent



PARTNER

MRKH

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PARTNER

To better understand the experiences of those effected by MRKH, we designed a survey to capture the voices of PARTNERS!

27.9% sexual enjoyment was negatively impacted

UNDERSTANDING for insight

73% "I wanted to do everything I could to HELP her"

Let's Get Honest!

we asked

Diagnosis
Sex
Treatment
Psychology

163 partner voices



"I knew I wanted her even if children are not part of our future."

Disclosing the absence of a uterus is easier than the absence (or shortening) of a vagina

Over 48% feel helpless not knowing how to offer the right support

4% MRKH has positively influenced sexual enjoyment

"The trauma effected her perception of SEX AS stressful!"

-partner



MRKH

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PATIENT

To better understand the experiences of those effected by MRKH, we designed a survey to capture the voices of PATIENTS!

- the most described word .. mentioned over 109 times!
- would opt for Dilatory Therapy
- said YES to Uterine Transplants

Let's Get Honest!

we asked

- Diagnosis
- Treatment
- Sex
- Psychology

835 patient voices



"I was handed a stack of papers and told to educate myself."

Psychological and Social Support OUTSIDE the clinical setting has been well established to assist post MRKH diagnosis

Over 56% have accessed online resources about MRKH

8.6% wanting treatment because their partner wanted to have penetrative sex

" my Doctor drew a PICTURE TO HELP!"
-patient

ACKNOWLEDGEMENTS

The team would like to acknowledge the patients, parents, partners and health care providers who participated in this survey. The responses will hugely contribute to the future of comparative research for MRKH patient care and research. We would further like to thank the organising committee of the The North American Society for Pediatric and Adolescent Gynecology (NASPAG) for the opportunity to host this workshop.

We would further like to acknowledge the support of the Beautiful You MRKH Foundation Inc., the Sisters for Love MRKH Foundation and Global MRKH and their extended network, for use of their online and social media platforms to enable the survey to disseminate internationally.

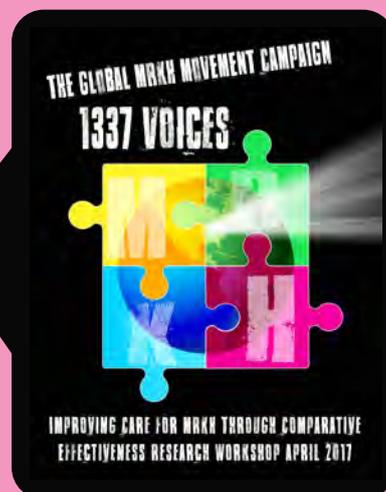
Lastly, the authors would also like to thank all those who are involved with support, advocacy and research of the MRKH Syndrome; to collectively improve the experiences associated with diagnosis, treatment, sex and relationships, psychological and social support, assisted fertility and family planning options.

The Team

Amy C. Lossie, PhD – Project Lead
Alison Hensley – Survey Team Leader
Kristen Peterson- Social Media Team Leader
Susan Carroll - Survey Team Member
Kristy Siiankoski – Survey Team Member
Kristy Zieman – Survey Team Member
Christina Ruth – Social Media Team Member
Jaclyn Misch- Social Media Team Member

To access the full report, titled **Improving Care for MRKH Through Comparative Effectiveness Research**, please email Amy C. Lossie, PhD. at bymrkh@gmail.com

Thank you!



Program designed by Jaqi Quinlan, Founder of **CreativeQ**, Entrepreneur, Doting Mummy & Wonder Wifey



Jaqi Quinlan, Co-Creator of the Sisters for Love MRKH Foundation and Global MRKH is the creative soul behind this program and the original logo supporting the Empowering the Collective Survey campaign, titled A Global Movement in MRKH Patient Care. Jaqi uniquely conceptualises brand messaging frequently for both Australian based and international MRKH inspired campaigns, bringing virtual connectivity off the screen and into our homes. With considered design interwoven with her own MRKH experiences, Jaqi is a unique and tenacious woman in this unique community of MRKH awareness and advocacy.

The Team



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