

The Art of Healing

A Collection of Positive Messages written by
Young and Adult Women Living with MRKH



**Boston
Children's
Hospital**

Until every child is well™

Center for Young Women's Health

IN APPRECIATION

The staff of the Division of Gynecology and the Center for Young Women's Health gratefully acknowledges the Boston Children's Hospital League and a grateful family who wishes to remain anonymous for funding this project.

Special thanks to Phaedra Thomas-Kowal, RN BSN and Ashley Guevara, LICSW for having the vision to create this booklet, to Anna Miller and Katy Doughty for designing it and to Susan Carroll, PhD for writing the Foreward.

The team is especially grateful to Dr. Marc R. Laufer for his valuable edits, but most of all for his commitment to helping adolescents and adult women diagnosed with MRKH.

This resource would not be a reality without the content which includes the authentic and genuine responses to our survey questions and words of wisdom from many young and adult women diagnosed with MRKH. They are the authors who deserve your praise and recognition for sharing their inner most feelings so others can process their diagnosis and heal.

FOREWORD by Susan Carroll PhD

Welcome to “The Art of Healing” – a title inspired by the beautiful artwork created by young women at our annual MRKH conference for teens and their families. When you look at the front cover of this booklet, you will see a collage of fifteen individual pieces of artwork that are all connected by one continuous black line. Each young woman painted her own part of the line, representing the unique path that she has taken in her journey through MRKH, and then decorated her path with vibrant patterns and colors, representing her unique personality and personal story. When all of the paintings were brought together, their paths joined to form one free flowing line, representing the shared experience that exists between young women with MRKH, though each young woman experiences MRKH in her own way.

As you read through “The Art of Healing”, you will see quotes and stories from young and adult women about how they felt when they were first diagnosed, some things they have found helpful in coping with their thoughts and feelings, and their experiences of talking to others about their diagnosis. Some of their experiences may be similar to yours, and some may be different. How you feel when you are diagnosed with MRKH, how you cope with your thoughts and feelings, and who you choose to talk to will all be unique to you. Receiving a diagnosis of MRKH can feel overwhelming, so it’s okay to give yourself the time and space you need to figure out what you find most helpful.

We hope that reading the stories and comments individuals have shared will help you to find your way through MRKH, and offer you some comfort and reassurance in knowing that you are not alone. Whenever you decide you’re ready, there are resources available to help you learn about MRKH, and many young women and health care providers who will be there to support you. Our experiences of seeing young women connect at our annual conferences and on our monthly online chats have taught us the value and power of connection and support. You are now at the beginning of your journey, and healing may take time. We hope that showing you the paths of other young women will help you take a step towards painting a brighter picture along the way.

DEDICATION

This booklet is dedicated to all the amazing young women who share a special bond.

Table of Contents

Introduction	2
First Reactions	4
Coping	10
Telling Friends and Family	16
Testimonials	20
Resources	40

Introduction

For more than a decade, the Center for Young Women's Health has hosted an annual MRKH Conference, bringing together patients and their families to learn more about MRKH and find support through new friendships and shared experiences.

More recently, we have begun surveying these young women about their experiences - what they wish they were told when they were originally diagnosed, who they decided to share their diagnosis with and why, what their best coping strategies are, and what advice they have for young women who have just been diagnosed.

This booklet brings together a variety of experiences and is designed to help newly diagnosed patients better understand what it means to have MRKH, and to appreciate that you are not alone.



FIRST REACTIONS

Being diagnosed with MRKH can be scary, frustrating, confusing, and sad. Everyone reacts differently, and all of these reactions are normal. We spoke with some MRKH patients about how they first reacted when they were diagnosed, what they wish they had been told and what their biggest worry was initially. The following section reflects these thoughts.

When I first found out I had MRKH, I...

...was 18 years old. I was nervous and scared and didn't really understand what was going on in my body.

...felt very alone.

...was very upset, angry, and confused. I felt like I lost something.

...cried, tuned out the doctor, told a friend.

...didn't really process it. I was upset at first but then I kinda just blocked it out.

...cried, sobbed with my mom. yelled how unfair it was, and ate a lot of ice cream.

...didn't really know how to feel or what it even fully meant.

...was 15 years old. I had gone through so many tests including bloodwork and ultrasounds and it was sort of relieving to finally get a diagnosis, but it was hard to accept it naturally and I didn't want to learn anything about it.

...cried. I didn't talk to my mom (or anyone) until weeks later.

...pretended I was fine and refused to talk about it.

...was just about to turn 18. I was happy to finally figure out what was wrong with me."

I wish I was told...

...that I was not alone. There are other people out there going through the same thing.

...everything was going to be okay.

...that it does get easier and just to take your time and not rush into dilation.

...less information. I totally zoned out after I heard I wouldn't have kids.

...nothing. I wish no one said anything. No "it's gonna be ok" blah blah. I knew that, but I needed a hug and someone to let me break down.

...that I wasn't alone.

...that this was something that many people had and there are options and people to help and support you.

...your first doctor is not always the best fit, find who you are comfortable with.

...that it is ok to feel however I want to feel. I also wish I had access to accurate info.

...that connecting with other girls who have MRKH would feel this good/ that conferencing with them would be so beneficial.

...that non-surgical dilation was an option.

...I was told quite a bit but I'm actually glad I wasn't told all of the info initially/all at once.

...where I can find someone else with MRKH.

...there are resources for you and you are not alone! There are doctors that know about your condition and want to help you, but you will have to explain your condition to more medical practitioners than you care to.

My biggest worry was...

...not being able to have sex and a good relationship

...if I was still fitting into my gender norm. Was I still a woman? What does this mean about my plans for my future?

...the cost of everything in the future and trying to stay focused on school and my grades, which I know is minor in comparison but I will need for the future

...dilation

...how to disclose/communicate/share with loved ones

...I would be alone, that nobody would be able to understand how I felt.

...a man would have to sacrifice a normal life/relationship to be with me. That I wouldn't be enough

...not being able to carry children. Also not being able to be happy again. I am now though!

...am I the only one?



COPING

Coping with a new medical diagnosis takes time and skill to learn what is most helpful for you. Everyone is different; however, women who share a diagnosis often have greater insight into effective coping strategies. In the following section, young and adult women offer advice on ways to cope. As you read their suggestions, try coming up with your own personalized list of strategies.

I found the best way to cope is...

Find the positivity in things and to not be afraid to make light of the situation.

To find someone to talk to or find a support group to join.

To meet other people with MRKH.

Talk about it.

Focusing on myself and other things like my school and career. Now I just think about all the positives in my life and practicing a lot of gratitude.

Running/working out

Find positives but also allow yourself to be sad, aggravated and try to go along with happy and sad moments.

journaling every night and asking for support when I need it.

To be honest, I haven't found a good way to cope yet. Oftentimes, I try to push it aside and not think about it as much as possible.

If I could tell a newly diagnosed girl one piece of advice, it would be...

Be strong, don't be scared to speak out, you're not the only one.

Come to the conference!

Wait until you're ready for treatment.

You are a beautiful, normal girl, and there are people just like you out there who are willing to help.

I know it feels like your entire world is caving in on itself, but believe me when I say that you are going to be so much stronger from this, and in many ways, it gets better. There is an entire community of incredible women from all over the world who are there to be with you through all of the highs and lows of your life - MRKH related or not, so get to know them- they are some of the best people I know.

It's okay to cry.

Make sure you find a knowledgeable doctor about this, even if it means traveling.

Take time for yourself, breathe, and know that you are loved by so many people.

Make connections with good friends and people who can support you and understand how you feel without needing to cure the problem! Just to sit in the pain and loss with you Allow yourself to be vulnerable and connect with others. It's the best comfort!

Coping Mechanisms

It's ok if you're not sure how to cope in the beginning. It can take time and "trial and error" to figure out what works best for you. Below are some coping mechanisms that other young women have found helpful. Try coming up with your own list of strategies to help you relax and feel better.



journaling



social support



mindfulness



breathing exercises



physical activity



talking to a therapist



other ideas



TELLING FRIENDS AND FAMILY

When you first learn about your diagnosis, you may not know if you want to share your news with others. Some young women choose to keep their diagnosis private for a while, while others confide in friends and family as a means of support. There is no right or wrong way to deal with this dilemma—just what feels right to you. We talked to patients with MRKH to find out what they thought in retrospect about talking to friends and family members about MRKH. Their responses should serve only as a reference. Everyone is unique so who you talk to about MRKH and when, should be your decision and not someone else's.

I'm _____ that I talked to my friends about having MRKH

happy because
it's gotten stuff
off my chest

GLAD. I ONLY TOLD
ONE PERSON, WHOM
I FULLY TRUST AND I
COULDN'T LIE ABOUT
WHY I WAS COMING
TO BOSTON.

SO HAPPY
AND FREE

I haven't talked
about MRKH with my
friends, but I feel relieved,
happy, and reassured to
talk about it with other
girls with MRKH.

I haven't
told many...

GLAD

happy &
regretful

glad -- with my friends at home they
didn't know how to react and that made me
feel worse. However some adults reacted well
and did research and showed me my options
and that meant a lot. I am very thankful.



TESTIMONIALS

The following pages are authentic reflections of young and adult women diagnosed with MRKH. The collection includes: stories and experiences, college essays, and a conference presentation. Some of the stories or parts of them may resonate with you, and others, not so much. Keep in mind that the authors of this amazing collection have had time to process their feelings and, in some cases, even embrace MRKH. Accepting a new diagnosis takes time and is very individualized. As one author notes, “not all girls that have MRKH can speak openly about it—which is completely understandable.” We hope that knowing you are not alone and that others care about you and your well-being will provide you with strength and the knowledge that it will get better.

To My Teen Self:

Everything is going to be alright. Right now, it may be a little scary, but don't worry...everything works out for the best!

The day I got diagnosed with MRKH it was very emotional. My initial reaction, was that I didn't feel like a human being, and that my life was over. I thought that no one was going to love me, and there was going to be no one around me that cares. It was all a nightmare, that I couldn't believe was true. When I heard that I only had one kidney, I thought it was a death sentence, but, learning more about the syndrome helped me understand what the rest of my life was going to endure.

The turning point, in my diagnosis was when I was able to talk to more people about my condition. I realized that there are tons of people in the world that love me for who I am. Its all about finding the right people in your life, to inspire you to better yourself.

Not being able to have kids seems like such a devastating point, until you find someone that accepts it. I can proudly say now, that I have a boyfriend who loves me, and absolutely loves the fact that I can't have kids. In the future, we have discussed the possibility of adoption which is just as amazing as having children on your own.

The last two years have changed my life for the better. The more people around me that know and support me makes me more confident as a person! My advice, is to find someone, or a group of people that bring out the best in yourself.

- Caitlyn

My Story

When I was 16, I was diagnosed with MRKH.

This journey to my diagnosis started several months prior. When I was nearing my 16th birthday and hadn't started my period yet, my mother took me to the doctor to figure out why.

One of the first things they did was a pelvic exam. The exam lasted about two minutes, because when the doctor attempted to insert the speculum (the instrument they use to separate the walls of the vagina), it was blocked. She was not able to insert it at all. This put an end to the examination, and the doctor informed us that my vagina was abnormal and referred us to another hospital for further testing.

This hospital did various blood work and imaging, most importantly an MRI. The blood work was to verify that I am, in fact, female. The results came back with the normal chromosome of XX (100% female!)

Then came the results of the MRI. Through the MRI, they discovered that my uterus is completely absent. They were only able to locate the right ovary, which is "abnormally located". They were not able to see a left ovary (although I will note that another doctor found it 4 years later).

The doctor called my mother and told her the results, and she struggled with how to tell me. It took her a few days, but she finally sat me down and explained the little bit that she knew and what the doctors had told her.

We went back to the same hospital 4 more times after my diagnosis, and each time we left more and more frustrated. The doctors just didn't seem to know anything about MRKH, and did not have any answers for us. One doctor did mention, vaguely, that there might be surgery I could do to fix the "not being able to have sex" issue, but he didn't know anything about what the surgery entailed and never told us where we could go for more information. And after those 4 visits, where we left with no answers and more questions, the doctor visits stopped.

And to be honest, we just left it at that. Because the doctors had obviously never experienced this before, we felt that what I had must be very rare. We didn't know where to go for help, and didn't even know where to start. The doctors we had seen didn't have any answers for us, and I felt like a freak. I just wanted to forget about it... I felt so alone in the world and I didn't want to dwell on something I couldn't change.

It wasn't until I did my own research, years later, that I began to understand MRKH better and realize that it was nowhere near as rare as I thought it was. And after so long of feeling so many different emotions about living with MRKH and having nobody to relate to, it was an amazing discovery.

A lot of my diagnosis process was frustrating. The lack of knowledge from my doctors was a big issue... I had so many misconceptions about MRKH and what it was due to their inability to really explain it to me, and I really didn't know how to describe it to people. I mostly kept my diagnosis to myself, firstly because I wasn't sure how to explain it and secondly because I was ashamed and embarrassed about it.

It was my own irritation at my lack of knowledge that drove me to start researching it, and discovering how many women were really out there that were struggling with the same things I was. I recalled the past ten years of my life as I started building relationships with MRKH women all over the world, and realized how much easier everything would have been for me had I known that there were so many women out there to speak with.

It was because of this that I decided to be open up about MRKH, and to share my story with as many people that would listen. Not all girls that have MRKH can speak openly about it, which I fully understand and can sympathize with. However, there are a few of us that feel comfortable speaking up and we will continue doing so with the goal in mind that nobody with MRKH should feel alone.

- *Kristen*

How you become a parent doesn't matter

I'm from London in the UK, and I have MRKH. At 17 I was told I had no uterus and I knew something else wasn't quite right. I was sure I had the condition. I was diagnosed with MRKH at age 20, during my second year of University, after having a lot of tests done including two ultrasounds and an MRI. Luckily, I got through the second year of my degree with amazing support from my friends and a lot of talking, some crying, and figuring things out with them.

I was referred to University College Hospital London in the summer of 2013 where I spent some time with a psychologist who helped me deal with some of the emotional aspects of the condition. I was also given dilators and taught how to use them during a three-hour appointment at the hospital. It was difficult, but I managed to get used to it quite quickly.

I'm still going back to the hospital for follow-ups and to see my psychologist as I am far from finished with dilation yet, but it feels good to be taking control of my future. As for children, I plan to adopt. While I would love to be able to carry a baby myself, it was always my plan to adopt children too. I feel that there are many children born into this world without parents to love them, so if I can be that person then that's more than enough for me. I'll love my child just the same. Sometimes it still hurts that I can't carry my own baby, but then I think about the difference I want to make in a child's life when I adopt them, and that makes me very happy.

I'd like to end on something my friends and my psychologist have instilled in me over the past year: "It's not how you get to be a parent that matters – it's how you are a parent when that child comes into your life, whichever way it happens."

- *May*

What do you want to do with your life?

You don't really realize, that as you grow up your surroundings are causing you to subconsciously configure your future. You watch as everyone grows up, goes to college, falls in love, gets married, has kids, and lives happily ever after. Keep in mind, this scenario is seen through a child's eyes where everything is fantastical. This young child was definitely me. It is most likely a lot of people. The fact of the matter is, life doesn't often happen that way and I quickly learned that mine certainly won't look anything like it.

At the age of 16 I was diagnosed with a rare syndrome that only affects 1 in 4500 women. Its correct medical name is Mayer-Rokitansky-Kuster-Hauser syndrome, but it is commonly known as MRKH because that is far easier to pronounce. Other than my ovaries, my reproductive organs either didn't develop properly or didn't bother showing up at all. I cannot carry a child and I cannot have proper sex until I choose to go through some form of treatment. This is when it hit me that I had been subconsciously planning to become pregnant after falling in love and making love with a vagina I was born with. Who would have thought it was even possible not to have one? It certainly hadn't ever occurred to me.

Learning about my condition made me rethink my entire future. There were so many new things to consider now. How will I have a child if I truly want one bad enough to go through the long legal process of adoption or the major cash of the procedure for surrogacy? And even before that, how will I find a man that will accept me for what I am? I could barely accept myself.

It has taken a lot of thought and a long process of healing that will never truly end. MRKH has become a major part of my life and some people say not to let it take over my life, but to be honest, it already has - right from the start. Not many people understand and so it's easier to explain it in a context that they can relate to better: it's like losing a loved one and thinking of them multiple times every single day. With me, it's the fact that I lost a dream that never even existed.

Since being diagnosed, MRKH has made me stronger as a woman. It makes me want to reach out to other girls like me and unite with them because we are the only ones that truly understand what it's like to have MRKH. We are a hidden species it seems... it is a topic nobody addresses because of how taboo its subject matter is. I was once ranting to a few close friends about how stupid it is that nobody is comfortable talking about vaginas and I busted out saying "I don't get it, all women have one!" I realized as soon as it escaped my mouth how mistaken I was and corrected myself: "Well, most people do." My point is that we all have a body so why are certain parts off-limits to talk about?

In my future I want to be an advocate for MRKH. I want to break down the boundaries of taboo topics because that is what causes so many girls to be extremely ashamed of themselves. I want to be proud of what I have overcome as a woman second-guessing what womanhood is. I don't care if others know about my syndrome because the more people who learn about it, the better they'll understand and the less likely it'll be such a taboo topic.

In my future I want to have a child or two. I'd love for one of them to be biologically mine so people can say we look alike. I know how proud I am when people say I "look just like my mother." If I choose to have a second child I'd like to adopt because I can't help but find sense in how some woman with MRKH believe that we cannot have children because we were put on this earth to save the children that do not have loving parents. I mean, who is more loving than someone that doesn't take a child for granted and truly wants to be a mother?

Our futures are chosen for us in a small sense, but overall, we can control what we do with what we're given. Like the old phrase about lemons and lemonade you have to make something good out of what you've got and that's what I plan to do.

- Ashley

A Defining Moment

There have been a few defining moments in my high school career, but so far none compare to what happened during my sophomore year. The defining moment I'm going to tell you about wasn't when I found out I had celiac disease and couldn't eat wheat, but rather, when I found out something else just a few months later.

I'm familiar with being a patient. I was just two years old when I had major surgery and also found out I had only one kidney. Unusual, but it's not the first time it's happened to someone. I've always had a cataract on my left eye, and when I was maybe seven, I found out that I have scoliosis and a few extra ribs. Then in high school my period never came. My doctor said that it was late because I'm tiny and athletic, no biggie... but when I was 15 my mom decided to take me to a specialist.

I had an ultrasound test which wasn't a new experience having grown up with one kidney that needs to be checked every now and again, but this time was different. I remember feeling claustrophobic in a tiny dark room with my mom and a technician. I recall the technician staring at her computer screen with a concerned expression on her face. She was moving the ultrasound probe on my stomach and didn't say a word. She left the room several times, made muffled phone calls, and consulted with someone on the other side of the thick door. We asked what was going on, but she brushed it off and said that she would summarize at the end of the test. What was meant to be a 45 minute appointment turned into 2 hours. That's when the technician walked out again, but this time she didn't come back like she had promised. Instead another technician came in and had us move out of the tiny dark room. My mom and I had so many unanswered questions.

The next part I remember as though it happened yesterday. We were at my Nana's house when my mom answered the phone. At first I didn't know who it was, but after a while I figured out it was someone from the hospital. I was in the kitchen watching as my mom sat solemnly at the table, listening intently while staring at me. Then her hand went over her mouth, and she started crying. I didn't even hear what she said to the

person on the other end because I was preoccupied with the thoughts that were racing in my head. When my mom hung up the phone, she continued to stare at me. I asked her with tears in my eyes, "Am I dying?" She shook her head no. My mom then brought me into a tight embrace, and began crying hysterically as she told me that I couldn't have kids.

There's a reason why pregnant women and babies occasionally bring me sadness. The reason is called MRKH. You can look it up if you want, but I won't get into the specifics now. The fact is that my insides or female organs didn't form correctly when I was still developing in my mother's womb, and in the long run it creates roadblocks on my way to start a family. Also, one of the side effects isn't really something I want to share with other people. In fact, only a few people in my school know, and that's just because I'm including my guidance counselor and the nurse (both of whom I never talk to because they never make it better).

Some of the people who've found out I can't become pregnant say "That's okay, just adopt". Yeah, right. That's easy for someone to say who doesn't have to worry about it. They aren't thinking what I am. Sure childbirth is painful, but what about the other parts of being pregnant? Having your first ultrasound, carrying a life, feeling your baby kick, listening to the heartbeat... none of that will ever be mine, and I think about it every single day.

However, there are other girls like me, as I found out at a conference for teens with MRKH and their families in Boston in 2012. The conference is sponsored by the best MRKH doctor there is, Dr. Marc Laufer. He happens to be my doctor. I'm so grateful that I live so close to Boston. At this conference I met many other girls who also have MRKH. In fact, people attended from all around the United States. One girl came from Ireland, and another came all the way from Dubai.

The opportunity to meet other young women was amazing. At the end of the day I knew I couldn't wait another year to talk to these girls, so before the conference was over, I took the initiative to make sure that all of the girls could keep in touch. I found a blank piece of paper, set up columns for name, phone number, email and Facebook name. I passed the paper around the room so that girls could add their contact

information (they could opt out if they didn't want to participate). Next, I photocopied the information so that everyone could have a copy of the list before they left. A few days after the conference, I created a private Facebook group titled "Fighters". I'm so happy to tell you that we now have over 300 members! My group has people from Canada, Mexico, Poland, India, Ireland, England, Nova Scotia, and all over the United States. The group is now connecting girls diagnosed with MRKH from around the globe so they never feel alone, and to me, this is a huge accomplishment.

- Dani

Weeds

Life, and growth,

The vines that weave the earth and its inhabitants together.

One and a half decades I spent sprouting,
But that fateful afternoon stung my eyes and blurred my vision,
Left me empty like desiccated soil

As I wondered why growth flourished everywhere
The oak trees in my parents' backyard,
The blooming wildflowers that grow trailside,
The tall grass in my childhood park,
The ivy that scales the freeway overpasses and hangs down like fringe,
The sprouts that peek through cracks in the pavement

But would never bloom from within the pit of my own stomach.

It would be many long and barren years
Before I realized that creation of life has more than one meaning.

More than conceiving

Flesh and bone.

-Olivia

A College Essay

I have every qualification that any young woman has. Like many young women I can balance my social and family life. I can create beautiful art. I can balance being on a Varsity team and keep up with my school work. There are many girls who share these same qualifications as me, what sets me apart is what I am missing. I might seem like every other young woman my age, acting and learning like everyone else, but I know that I am different.

I just turned 16 when I first went to my gynecologist wondering why I hadn't yet had my period when all of my female peers did. After hours of various tests and months of waiting, I got the diagnosis. The doctor and I finally understood what we saw, or rather, what we couldn't see. I finally had a name for what was happening to my body but didn't understand what that meant. I am missing something key that would traditionally help with my path to womanhood.

I was diagnosed with Mayer-Rokitansky-Kuster-Hauser syndrome. MRKH is a condition in which females are born without a uterus. About 1 in 5,000 women have this syndrome. I learned that I am not alone, I have learned that I am not a freak of nature but I am truly a part of a quiet, yet strong, community of women.

When my doctor was explaining this condition to me, she was handing to my mother and father various packets of information. I remember feeling overwhelmed with the amount that I had to learn about myself, I remember feeling numb all over. I kept on asking myself, "Why?" I couldn't speak, I couldn't make eye contact or move. They all stared at me expecting a reaction but I couldn't give them anything, I felt empty. I struggled with the diagnosis and the feeling of not being a complete woman is devastating. On top of getting a tough diagnosis, I was expected to also continue on with regular life--and that was the hardest.

It took my a year to pursue going to the Boston Children's Hospital for a further understanding of my diagnosis and treatment plan, but it also has taken me a year to start opening up about it. I overcame the problem of figuring out how to balance my real life and my life with MRKH. I learned

through video conferences with women like me, as well as keeping track of medical advances for new treatments. I have a whole team of supporters and other women who are just like me. Before I started opening up to some of my close friends and family I felt isolated but now the world has shown me that I shouldn't be afraid to hide the fact that I don't have a uterus.

I am a young woman who is confident about who I am, and have surrounded myself with women who have inspired me. Coming to terms with my MRKH showed me that I am stronger than I think I am, that I can cope with difficult situations, and that I can always find a community to help me when I need it most.

- Anonymous

A Marathon, Not a Sprint

MRKH Conference Talk, Boston Children's Hospital, March 2016

I was diagnosed with MRKH 9 ½ years ago, and I've been attending the annual MRKH conference almost ever since. As I thought about what to say here today, I spent some time reflecting on how I felt the first time I came here; how it felt to walk through those revolving doors that you all walked through this morning, and to sit here in this auditorium just as you are doing now. I felt scared, lonely, exposed and like I wanted to be anywhere but here. I distinctly remember two conversations I had with my Mam that day. The first happened just outside the hospital as she encouraged me to walk through the door. I was acutely aware that when I did, it would be the first time that I would be in a room full of people who would know that I had MRKH, and that thought seemed to be enough to glue my feet to the ground. She looked at me and said "I feel like I'm torturing you", to which I may have responded "you are". The second conversation happened just at the back of this room where we sat that first year, as we listened to a woman with MRKH share her story. My Mam leaned in and whispered to me "you never know Sue – that might be you one day", to which I responded emphatically "not in a million years". As it turned out, her encouragement to get me through the door that day was life changing, and it took a lot less than a million years for me to feel brave enough to stand up here and share my story. But although I have grown to love it, coming here for the first time was not an easy thing to do. It took a lot of courage, just as I imagine it has taken many of you a lot of courage to be here this morning. So I'd like to welcome you all – both those of you who I've had the privilege of getting to know over the years, and those of you who are here for the first time and might be feeling a bit lost, lonely, nervous or uncertain about what to expect. Or perhaps you might be feeling hopeful, or relieved, or comforted by the knowledge that there is a place like this for you to turn.

Since coming here for the first time, I've met a lot of women with MRKH, and one thing that always strikes me is that MRKH doesn't target any particular type of person. We are all coming from different backgrounds, cultures, beliefs, perspectives and personal experiences, and each of us

has a story to tell. We are also coming from different stages of MRKH in our lives, so we may be trying to navigate our way through different challenges at the moment. However, whether you're here because you're a parent trying to support your daughter, a sibling trying to support your sister, a partner trying to support a partner, or a young woman trying to find support for yourself, we are all here because we are trying; trying to seek out information that will help us to understand a condition that is not well-known, trying to find support for ourselves at a time when we may feel very isolated, and trying to offer support to each other by sharing our own experiences, and listening to those of others. So I hope that by the end of today, you leave feeling informed and supported, and that perhaps you may even find it more difficult to walk back out through those revolving doors than you did to walk in.

So to tell you the story of how a girl from Ireland ended up speaking at a conference in Boston, I'll take you from my diagnosis at 17 right up to now. As I sat outside the doctor's office awaiting the results of my MRI scan, I listened to comforting music on my iPod to help me to stay calm. I promised myself that no matter what the outcome, I would keep it together and stay strong. But when my name was finally called and the music stopped playing, I remember feeling like I was tensing every muscle in my body to try to hold myself together. And when she looked me in the eye and said "your womb didn't develop darling", I fell apart. I was a child being told that I would never have a child. I couldn't breathe, the room started spinning, and I sobbed. I felt suffocated by the realisation that I would never again know what it felt like to not have MRKH. From that day onwards, the world looked different to me. It almost felt like I was living in a parallel world where I could see everyone else, but nobody could see me. I lost a sense of who I was, and felt like I was defined by my diagnosis. MRKH became the first thing I thought about when I woke up in the morning, the last thing I thought about before I went to sleep at night, and the only thing I knew how to think about during every waking moment in between.

I will always remember something that my Dad's aunt Jennie, one of the dearest people in the world to me, said to my parents when she learned of my diagnosis. She said that she had noticed a sadness in me, and that she could see that my "little sparkle" was gone. It broke my heart, because I so desperately wanted to be that person with the sparkle in my eye, both for myself and for those people who cared about me so much, but I

didn't know how to re-engage with a world that I no longer knew how to be in, and I couldn't find a way to re-connect with the person that I used to be. My diagnosis didn't come with an instruction manual on how to cope. The only information I got from my doctor was a post-it note, and on it written, "MRKH".

So in the absence of any helpful information, my Mam did what she always does and advocated for me at a time when I couldn't advocate for myself. She searched the internet for information and found a hospital in the UK with experience in treating women with MRKH. She pleaded with me to go and meet the team there, and I reluctantly agreed. At my first appointment, they confirmed my diagnosis and explained what it meant: I was born without a womb and cervix, and there was nothing that they could do about that. And I was also born without a vagina, but if I wanted to have treatment, there were options available to me – I could have surgery or use dilators. Although I already understood my diagnosis, hearing it out loud again felt like being kicked in the stomach. But without giving it much thought, I decided to start treatment using dilators – at the time, it felt like there were just so many aspects of MRKH that I couldn't control, and this felt like a problem that had a solution. So I spent a few days in hospital and continued treatment at home three times a day, every day for three months. It was one of the most physically and emotionally demanding experiences that I've ever faced, but I just wanted to get it over with. And at the end of three months, they told me that I was done and that I would never have to use a dilator again. So I went home and tried to erase it from my memory.

But when I attended the conference here for the first and second time, I realised that I had been given the wrong follow-up advice. I heard the consultant say that when you're finished with treatment, you still need to continue to use a dilator about once a week. So two years after finishing treatment, I came here for a second opinion and it confirmed my fears – if I wanted to have treatment, I would have to do it all over again. I was devastated – I was so angry and frustrated and upset that I had gone through so much for nothing. MRKH had taken me to three different doctors, in three different hospitals, in three different countries. But they say that the third time's a charm, and in this case, it most certainly was. I often feel like whenever I have an 'MRKH-related' experience, I leave a piece of myself wherever it happened, and I carry a piece of that place

with me. Sometimes I wish I could rescue myself from those places that didn't treat me with the care that I deserved, but when I think of the piece of myself that is here, I feel safe and supported. Here, I was treated with kindness, compassion and respect. They saw me as a person first and a patient second and I knew that I had the power to make a decision that I was comfortable with. So although it still wasn't easy, when I decided to go through treatment for the second time, I could trust that I had been cared for properly.

After that, I started to get more involved in these conferences by co-facilitating support groups and talking to young women with MRKH on the online chats that are hosted here. The experience I have here on this day every year is always incredibly emotional and so cathartic. This day is special to all of us for different reasons. For me, coming here every year has enabled me to give MRKH some sort of purpose in my life – to share my experiences and viewpoints in the hope that they may resonate with some other people here. It has given me the opportunity to meet other inspiring women with MRKH, whom I respect and admire so much. It is also perhaps part of the reason I decided to pursue a career in health psychology, so it's safe to say it's had a big impact on my life. But as wonderful as it is to have this day, it's always hard to go back home and try to process the intense emotion that you feel here. And then you have the other 364 days of the year to live your life.

For me, MRKH didn't stop me doing anything I wanted to do during those other 364 days of the year. I went to college and got my degree, I worked at the same time, I played hockey, I had a great social life, and I had the most wonderful friends and family that anyone could ask for. So after finishing treatment and attending the conferences, as far as I was concerned, I was fine. I had overcome MRKH and I felt invincible. I was so strong that there was nothing that could get in my way. But sometimes when you go through a traumatic experience, it can feel like you're hurtling through it at such speed that you don't really get a lot of time to just pause, and breathe, and process what you've been through. And then when you finally do get a chance to breathe, it can all come crashing down on top of you.

Three years ago, I had just finished my undergraduate degree, had taken a year off studying, and worked part-time. So for the first time in a long time, I had a lot of head space think about all that had happened to me

since the day I was diagnosed with MRKH six years previously. I began to relive all of those experiences that caused me so much pain. Unwelcome flashbacks flickered through my mind day in and day out, and that suffocating, panicky feeling that I once knew so well reintroduced itself to me. At a time when I thought that I had “overcome” or “accepted” MRKH, it started to intrude into my life again and it caught me off guard. It scared me, because I once again had that fear that I was losing to it and that I wasn’t strong enough to cope. After six years, it felt like I was waking up from a trance and frantically trying to grasp on to some sort of explanation for why this happened to me, and trying to make sense of something that made no sense to me at all.

I had always prided myself on the strength I showed in dealing with MRKH, and I was sometimes reluctant to seek help when I may have needed it. But when I started to feel those feelings again, I decided to take on board a piece of advice my Dad had offered me when I was first diagnosed: “Please don’t let your inner strength become as much a burden as it is a help”. So I booked an appointment with a therapist. I decided that I owed it to myself to find a space to talk through my experience of living with MRKH and to give myself the time I needed to try to understand it and find a place for it in my life. And although it was deeply challenging at times, that decision turned out to be one of the most rewarding, and life-changing decisions I have ever made.

In the beginning it was difficult to allow another person to delve so deeply into an experience that felt so private and personal to me. It was hard for me to allow myself to feel vulnerable and to talk about the parts of MRKH that made me feel so unsettled and upset. But as the weeks went on, I found myself talking more openly and honestly about how I felt about MRKH than ever before. And in doing so, I gradually teased apart the knots that MRKH had tied so tightly in my head. I have learned so much about myself since then and I have gained an insight into myself that I know will be invaluable to me for the rest of my life. I have learned that sometimes, it is okay not to be okay. I have learned that it is imperative to honour the sadness, the grief and the loss that I have felt since being diagnosed with MRKH. But perhaps most importantly, in giving myself permission to honour my experience, and in giving myself the time and space I needed to find meaning in that experience, I have given myself

the freedom to honour my life; to give all of myself that I have to give, and to embrace all of the opportunities that life has to offer.

I know myself well enough to know that there will be times when MRKH is tough, and upsetting, and pushes me to my limits. But I also know myself well enough to know that during those times, I will have a greater capacity to cope because of all I have achieved in the past 9 ½ years. I trust in myself enough to know that if there comes a time when I want to have a child, or indeed do anything that I feel I can't do because of MRKH, I will make those things my priority, and do everything in my power to make sure that they happen. So in moving through your life with MRKH, please give yourself permission to honour your sadness, your grief and your loss. But also give yourself the freedom to honour your life; give all of yourself that you have to give, and embrace all of the beauty that life has to offer. And remember that although the meanings that we all find in MRKH may differ, each and every person's experience is just as important, just as true and just as valid.

- Susan

The First MRKH Conference:

The first MRKH conference I went to was my first opportunity to learn about a piece of me that I had to acknowledge. When I started listening, I was overwhelmed by the experiences of other women that understood. I suddenly recognized that I wasn't alone. I became determined to learn as much as I can about who I am. I didn't choose MRKH, but it always was a part of me. I was still myself. I gained a new understanding of my body. Even though I got that new insight, I was still recovering. Everyone needs time to heal when they are hurt. I know that it is tremendously important to practice self-care and mental wellness. It took a while to find something that worked for me. But, I have found ways to check in and reassure myself that I'm alright. If I do happen to need help, I let someone know. Reaching out and talking to trustworthy people is incredibly important. Honestly, I wish I figured that out sooner. The hardest thing I struggled with was the fear of speaking out. I feared everyone knowing something so private about me; I did not want to feel vulnerable.

I get extremely anxious about circumstances beyond my control. That anxiety started the day I was diagnosed and it still follows me today. My senior year of high school I sought out a therapist, someone I can talk to about anything. She suggested mindfulness, a process of paying attention to experiences that were happening in the present moment. I took what I learned in therapy and found that meditation helped me become more aware of my breathing, my thoughts, feelings, and body.

My therapist also told me once to be selfish. Obviously, don't disregard thoughtfulness and respect for others, but be concerned with your own personal indulgence. Find at least one thing a day solely because it makes you happy. Use that selfishness to get out of your comfort zone, become the boss of your own life. I wanted to experience life as much as I can. I pushed myself because I didn't want to be vulnerable anymore. I went rock climbing, despite being terrified of heights. I'm no expert and I still get that gut wrenching feeling as I climb higher, but I learned how to trust my body. I went Ecuador for community service and to complete a three-day trek through the mountains. That's when I found my passion for hiking. Since then I have returned to Ecuador, and I plan to keep returning to South

America to find more trails to conquer. I'll continue to find more countries to explore, trails to triumph, and borders to cross. It's been a long process but I've learned to fall in love with things I feared. I continue to motivate myself to experience everything I can.

I want you to know that every choice you make happens on your own terms. Talk when you want to talk. Take care of your body, take care of your mind. Get out of your comfort zone, and become the boss of your own life. I have become proud of who I am and I'll be proud of the woman I'll become. If I can learn how to love something like my fear of heights, I can learn how to love my MRKH.

- *Claire*

Resources at *youngwomenshealth.org*

Annual Conference for Teens with MRKH and their Families:

The Center for Young Women's Health (CYWH) hosts an amazing annual conference for teens diagnosed with MRKH and their families which is open to the public.

For more information and the schedule of events, visit:
youngwomenshealth.org

Monthly Moderated Online Chats:

The CYWH hosts three free monthly MRKH chats that are moderated by a nurse educator and media coordinator; two for teens (one in the afternoon and another in the evening), and a monthly evening chat for parents.

For more information, visit:
youngwomenshealth.org /online-health-chats.

This virtual support group is an opportunity for teens to talk with others with whom they can relate.

BeautifulYouMRKH.org

Mrkh.org

