

MMIHS

Newsletter (Ed. 4, June 2021 - "Finding the Support")

Greetings

Hello! It's hard to believe that it has already been three months since the last newsletter was shared. I hope you are all doing well and having a nice start to your summer months! Last edition, the focus of the newsletter was the importance of taking time for yourself. Although the focus of this edition will be different, I do hope you are continuing to find little pockets of time to do whatever it is that makes you feel rejuvenated, relaxed, and happy. You deserve it!

This newsletter edition will center around the word "support." According to Google dictionary, "to support someone means that you help them." In my own MMIHS journey with my daughter, I have found that it truly takes a village of people to not only support my child, but also myself and my family. Although I certainly don't have all the answers, this newsletter will hopefully be filled with some supportive solutions to assist you in your village as well! Please take a little time to read about all things MMIHS and let me know if you have any questions or comments.

I also ask that you take a moment to view the next section and keep the Richts family in your thoughts. To the Richts family, we are certainly here as a support system for anything you need. Please reach out if you do!

SURROUND
YOURSELF WITH
SUPPORTIVE PEOPLE

In Memory of Mieke Richts



Mieke's fight ended on May 8, 2021. We look back on an eventful year with sadness but also with great joy. Mieke taught us so much. She was the happiest, most curious little girl we have ever met. She touched and impressed many people. In our hearts she keeps laughing forever.
~Anne Richts (Mieke's mom)

The MMIHS Foundation

The MMIHS Foundation board of directors met on Sunday, May 2nd to review goals and continue discussing strategies in which to move forward. Below are the two main topics reviewed and discussed in accordance with our goals.

MMIHS Foundation Goals:

- Fund MMIHS Specific Research
 - Mollie Caspers, our president of the MMIHS non-profit organization, was in touch with an individual last week who provided a wealth of information regarding official grantmaking procedures. The findings will assist in allowing us to seek applicants and distribute grants, in order to contribute to advances within the MMIHS community. This is a great step in the right direction as we continue to move forward!
- The Annual MMIHS Fundraiser
 - A great deal of our meeting was focused on the 2021 fundraising season which will begin very soon. As a reminder, our large MMIHS online fundraiser is always held in September so the planning and prepping for this will be taking place in the coming months. If you are interested in helping with the planning phase, we will be sending out facebook posts throughout the summer, looking for volunteers to assist with smaller pieces, in order to put our large fundraising puzzle together. We welcome all who are willing as we know there is a lot of talent out there! Please consider helping. More to come soon!



Tool Box

Below you will find five resources that may or may not assist you on your MMIHS journey. If you have any helpful "tools" you would like to share in the future, please let me know and I will be sure to include them!

1. **IKEA pop-up sun/wind shelter:** a nice way to get some shade/air in the hot summer months.
Found on Amazon.com (\$59.99)
Found on Ikea.com (\$24.99)



2. **Geek Aire Rechargeable Fan:** battery operated rechargeable and portable fan. A great tool to accompany you on hot days.
Found on Amazon.com (\$119.99)



3. **Glacier Tek Children's Cool Vest:** Helps to keep your child safe from heat stress. Maintains a comfortable 59 F for up to 2.5 hours in 100 F heat. Weighs less than 3 pounds with cooling packs. Cooling material is bio-based, biodegradable and nontoxic. Mesh bag makes it easy to transport, recharge and store the packs.
Found on Amazon.com (\$129)



4. **The MMIHS Map:** in an effort to provide support and resources for those affected by MMIHS, the foundation has created a map so that families who have experienced this rare syndrome can connect with each other.
Website: www.mmihs.org/real-families-real-stories/mmihs-map/

5. **Procedure Room:** One of our MMIHS parents recently shared her experience with a "procedure room." This room allows the medical procedures to be completed separate from the patient's room. This may be something to inquire about at your local hospital if you think it may help with the medical trauma of a procedure being completed in the room they are staying in.

MMIHS Spotlight Briar Rose Magel

Thank you to Morgan (Briar's mother) for providing the below information about their MMIHS journey with Briar thus far:

Briar was born on June 24th, 2021 and is currently 11 months old. She lives with Ryan (Father) Morgan (Mother), Addilyn Jay (2) in Hanley, Saskatchewan Canada

Briar is bubbly, loves to talk and enjoys making others laugh. She loves being outside, playing with her sister and animals!

The Journey Begins: Briar was born 3 weeks early and immediately began spitting up. We were told it was just mucus and not to worry. She was released after 36 hours of being born and only 9 hours later we were in the ER. An x-ray revealed a blockage in her intestines and a week later, we also found she had E Coli meningitis (only the 7th case our doctors have found in English history). At first, it was thought that she had either Cystic Fibrosis, Hirschsprung's, or CIPO . While researching through the TPN facebook page, I was in contact with MMIHS parents who recommended genetic testing. My research paid off because I was correct, it was MMIHS. Four months of waiting and wondering if our child would even be able to come home.

At four months of age, Briar was officially diagnosed with MMIHS.

The Journey Continues: Once we had a diagnosis and understood how to handle and deal with as much as possible, we were told we were able to bring Briar home. We were so excited and were given a week to get our stuff in order. The day came and we were informed that unfortunately we would not be able to take her home due to lack of funding. Contact was made to our MLA and prime minister. I was on my phone and computer daily contacting anyone and everyone I could... waiting for emails, returning and taking calls, and leaving voicemails to anyone who would listen! I felt very defeated! Our story was featured on local news channels (Saskatoon, SK News, Regina, Toronto News) and it was after that, that we were funded to take Briar home. We spent 141 days in the hospital, were home over Christmas and then back into the hospital for a month. Briar has had a total of 5 surgeries in her tiny little life, and we are on the top of the waiting list for a multi visceral transplant. Briar has now been home for three months.

Life at Home: Briar is TPN dependent for 18 hours a day and has a g-tube and ostomy. We usually have to change her ostomy bag once every 24 hours . Her g-tube is just for medication administration. She is able to eat and loves it but her ostomy output gets too high so are only able to feed her tiny bits. I feel very guilty because she wants to eat so bad and gets very upset when we are eating and she can't have any. It's very, very hard to witness.

At first, it was very stressful and I was super paranoid, but now unfortunately it comes "natural" to do everything we have to do with an MMIHS baby. Life is as normal as it could be at the moment. The most stressful part is having that semi anxiety attack when my phone rings thinking it's THE call, where we will have to pick up and basically MOVE a province, not knowing where or what is going to happen when we do get the transplant call, especially with Covid.

Recent Struggle: Briar wanting to eat and drink.

Recent Victory: Briar is starting to crawl!

Advice to an MMIHS Family: Just stick with it! It will be hard at first but don't give up! Appreciate the small victories and don't beat yourself up if you go one step forward and two steps back. Also, speak up as you need to be the advocate!

Teachable Moment Since Briar: Don't take life for granted and spend as much time with them as you possibly can!



Therapy Support for those with MMIHS

Below are different types of therapy options and how they are used to support the development of individuals living with MMIHS:

1. **Play Therapy:** We are trained to understand what children are communicating through their play by looking at metaphors and symbolism of the toys they use and the interactions in their play.

"I had the privilege of working with a child with MMIHS. This therapy allowed the child to have their special play time to work through issues they could not talk about. Some of these issues included medical trauma, emotional isolation, low self worth and self confidence, peer struggles, feelings of inadequacy compared to others, and questioning "why me." - Registered Play Therapist

2. **Music Therapy:** We use music to help support people's non-musical goals. We can work in hospitals, schools, rehabilitation facilities, and much more. Some of the goals we might be supporting are managing pain and anxiety, reducing stress, enhancing wellness, expressing feelings, or improving communication.

"I have had the privilege to work with a little lady with MMIHS. She receives music therapy as procedural support during her port dressing changes and lab draws. These appointments occur at least weekly and have always caused her anxiety. With music therapy present, we were able to sing favorite songs with her, her parents, and the hospital staff doing the procedure." - Registered Music Therapist

[YouTube Video of Music Therapy](#) - also found on the MMIHS.org website

3. **Physical Therapy:** We use specially designed exercises and equipment to help patients regain or improve their physical abilities.

"I have been working with a little girl born with MMIHS for the past couple of months. We are currently working on increasing balance and strength while helping her become self aware of adaptations before she heads to school." - Trained Physical Therapist



Therapy Support for those with MMIHS

4. **Occupational Therapy:** We practice self-care and work/play activities to promote and maintain health, increase independent function, and enhance development.

"I am working with someone born with MMIHS and we are currently focusing on successfully brushing her teeth and washing her face as she has some oral aversions and sensitivity around her face. We are also practicing working with different smells and textures." - Trained Occupational Therapist

5. **Speech Therapy:** involves treatment for speaking, language, and swallowing.

"Through speech therapy, my daughter practiced swallowing small amounts of liquid, as we were aware this type of interaction directly affected her speech." - MMIHS Mom

6. **Pet Therapy:** a guided interaction between a person and a trained animal. The purpose of pet therapy is to help someone recover from or cope with a health problem or mental disorder

"My trainer really worked with me and my abilities and I got to the point I was able to jump short fences!" - Em Koprucki



Support for Parents/Caregivers/Family Members

As stated in the introduction of this newsletter, not only is it important to seek support for the individual with MMIHS, but also those who help care for them. Support comes in all different forms and what is the right fit for one, may not be for another. Below are some support outlets that one may consider:

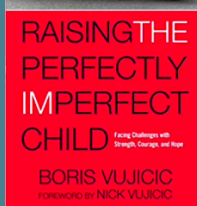
Therapy or Counseling - the process of meeting with a therapist to resolve problematic behaviors, beliefs, feelings, relationship issues, and/or somatic responses (sensations in the body).

"Raising a child with MMIHS puts you on a completely different life path than ever anticipated. Every day I, my child, and my family live with the weight of the emotional toll that complex medical needs place on our family. For myself, seeking out counseling has been the best place to find tools to face my reality of life. I need spaces where I can talk openly about the dark realities, the fears, and find support. With the tools and skills I've learned in counseling, I'm able to show up as my best self." ~An MMIHS Parent

"One piece of advice I would have is to make sure you find the right therapist for you! The first one may not be the one you end up with long term and that is ok. It's important not to give up the hunt. It took me two and I am so grateful for the time I get to spend with my therapist each week!" - An MMIHS Parent

Other Forms of Support:

1. **MMIHS Zoom Sessions** - a place where MMIHS families are welcome to join and support each other on their MMIHS journeys (see below for next scheduled date).
2. **Podcast: Mama Bear** - a place for women raising children with special needs get together and chat about life. Mary Susan McConnell and her guests discuss the beautiful highs and the extreme lows that can come with parenting on such unique journeys.
3. **Apple TV+ Documentary: The Me You Can't See** - a docu series co-created by Oprah Winfrey and Prince Harry, that explores mental health and emotional well-being with stories from people around the world. With storytelling at its core, this timely series gives voice to stories that aim to seek truth, understanding and compassion. It's about people, our experiences, and why we feel the way that we do.
4. **Book: Raising the Perfectly Imperfect Child** - the inspiring, powerfully transparent story of how two unprepared and overwhelmed parents—Boris and Dushka Vujicic—overcame their grief, fears, and badly shaken faith to raise such an accomplished, faith-filled, and perfectly imperfect son.



Support for Siblings

1. **Time:** Find time for independent time with each child..... siblings sometimes feel that they always have to 'share mom and dad'.
 2. **Conversation:** Be aware of people who ask about "the sick child" before they ask about you, or the siblings! Prioritize siblings, as the 'sick kid' will not be forgotten, but sometimes the siblings do.
 3. **Therapy:** If your child is exhibiting signs of extra neediness, overwhelming emotional outbursts, sulking, or just not 'being themselves', consider getting them involved in play therapy or talk therapy if they are older. Work to get them someone they can trust to express their feelings with.... someone that isn't the parent and can help them process this life without our preconceived notions.
- **Consider it for yourself as a parent, too, because you cannot be the rock of support for your whole family if YOU don't get support.**
4. **Plan:** Find time to NOT be medical. Find activities the WHOLE family can enjoy together, without a medical intrusion. An iv pump or ostomy change is fine, but plan your day so that you avoid the busiest medical times.

5. Let EACH CHILD pick a special day that they are in charge of - let them be the planner, and see what wonderful things they come up with. If they need mommy or daddy time, they will plan that, if they want to just be a family having fun, they will do that.

6. Do you talk to your children about their feelings? When the 'sick child' is in crisis of some sort, do you remember to ask the other children how THEY are feeling? Do you take the time to try (if possible) still have special time with the other kids when child 1 is in the hospital? Sometimes it is as simple inviting them to have dinner with you in the hospital cafeteria or car while the other parent visits with the child who is admitted.

7. Sometimes hospitals will have programs for siblings - talk to the social worker on the floor or your clinics and ask them for advice on helping the siblings.

***** Thank you Susan Koprucki for your wonderful insight on this topic!**



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Supporting an MMIHS Family During the Summer Months

It seems in the summer months, many activities revolve around food and/or water, two things that most likely look different for someone living with MMIHS. If you are wondering how you can support this person and their family this summer, below are a couple things to consider. Of course, everyone is different, so the best thing to do would always be to ask.

Possible things to consider:

1. Plan activities/get together that don't always involve water.
2. Consider a buffet style "come as you please" meal option where people are encouraged to make a plate when they wish. That way, not everyone is sitting down at the table simply eating. In other words, the focus is not all on the food.
3. Consider providing options that are more easily digestible such as popsicles, icees, jello, fun drinks, etc...
4. Many people with MMIHS tend to get hot easier than others due to the extra layers they wear to protect their hardware. Consider planning a get together where shade is an option. The time of day and location is also something to consider.
5. In all seasons, if an MMIHS family needs to cancel, keep inviting. An MMIHS life can be very unpredictable so plans often need to change. Don't forget about including them if they can't make it happen the first, second, or third time!
6. Take some time to ask what they are most comfortable with and what works best for them. Sometimes, just the effort made asking how to accommodate someone with differing needs can go a long way!

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JUST BECAUSE SOMEONE
CARRIES IT WELL DOES
NOT MEAN IT ISN'T HEAVY.

Water Care

The conversation around water safety has been a common topic amongst the MMIHS support group. Please know that below are simply suggestions. You may want to consider a consultation with your doctor to decide what they and you are comfortable doing prior to trying one of these options.

1. Shortie Hickman Line Dry Suit:

This fitted Shortie Drysuit was originally designed specifically for children with a PICC line (Hickman Line).

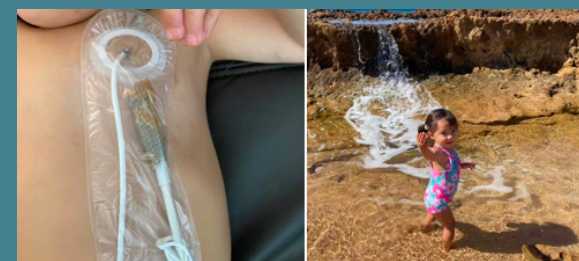
Website: www.hammond-drysuits.co.uk



2. Cath Dry:

a dressing designed by a physician for patients with central venous catheters. The dressing allows for safe showering while minimizing the risk of infection by keeping the catheter in a sterile environment and free of contaminants

Website: www.cathdry.com



3. Pads, Tagaderm and Medical Tape:

another option is to place a pad(s) (such as a maxi pad) over the line and then place a large tagaderm(s) on top. In order to secure it even more, place a layer of medical tape around the edges of the tagaderm.



Summer Fun Giveaway

In an attempt to collect ideas of summer activities for MMIHS families to take part in, we will be holding a "Summer Fun Giveaway" challenge. On Monday, June 7th, a message thread will be posted in the MMIHS support group asking families to post a picture of one of their favorite summer activities. On Sunday, June 13th, a winner will randomly be chosen. The winner will receive a \$75 Amazon gift card to be used towards summer fun!



Staying Connected

Family Outreach Coordinator: Sarah Turman is a wonderful attribute in assisting with inquiries from families and providing connections and support. Please don't hesitate to contact her, sarahannturman@gmail.com.

If you have any MMIHS related pictures or information you would like shared on our social media platforms, please feel free to message our Social Media Coordinator, Kristin Gutknecht at any time (kristin.gutknecht@gmail.com).

Zoom Date: Our next Zoom call is scheduled for **Saturday, June 26th (1:00-2:00 CST)** and will again be hosted by Brianna Larson. We will send out a reminder and link closer to the day but please mark this date. We hope you can join us for some or all of it as this is a great way to support one another!

Concluding Thoughts

Thank you for taking the time to read all things related to MMIHS. I hope this newsletter is a reminder of the many outlets that exist in order to support you on your MMIHS journey. You are not alone!

I also want to wish a happy belated Mother's Day and early Father's Day to those out there continually showing up, supporting, and never giving up. It's certainly not an easy job, but you all do it so well!

Much love to you all,
Erin Peterson

