

MMIHS

Newsletter (Ed. 2, December 2020)

Greetings

Hello! I hope this newsletter finds you doing well. I can't believe it has already been three months since our first edition came out and that it is December! 'Tis the season to be **THANKFUL** for all the blessings that encompass our lives! With all that is going on in our world right now, I continue to be so thankful for the tight knit MMIHS family we all have worked to create and sustain! With every member that is added, new question that is asked and support that is offered, I'm continually reminded that although this syndrome is rare, no one is ever alone. We are here for one another and that in itself is a blessing to be thankful for! In this newsletter, I did my best to highlight the MMIHS happenings within the last three months. As you read through it, if you have any questions, comments or concerns, please feel free to reach out to me. Also, please be sure to share it with others who may not be a part of the support group. This might be a helpful way to share some of the current news with them as well.

I hope you enjoy the information presented in this newsletter and look forward to working with you in the future!

~ Erin Peterson

thankful

The MMIHS Foundation

The MMIHS Foundation board of directors meets quarterly to review goals and continue discussing strategies in which to move forward with both the short and long term goals outlined on the MMIHS.org website. The board met on November 1st via Zoom and below are the two main topics reviewed and discussed in accordance with our goals.

Long Term MMIHS Foundation Goals:

- Organize an annual fundraiser
 - We put an incredible amount of time and effort into 2020's MMIHS Day and we were amazed by the outcome. We felt that this year's fundraiser was a great indicator of the growth we continue to make. It validates the work that we are doing and motivates us to keep moving in the right direction. (See following section for additional information on this specific fundraiser).
- Fund MMIHS specific research
 - With the funds we have raised we would like to not only support medical professionals in the work that they are doing but encourage it! Therefore, at this time we are hard at work drafting organizational bylaws that will allow us to seek applicants and distribute grants that will contribute to advances within the MMIHS community.

Fundraising Recap

Our third annual MMIHS day was held on Saturday, September 12th. The purpose of this day was to increase awareness and advocacy for MMIHS and raise money to support our foundation's goals. We want to thoroughly THANK all of you for your participation. Whether you submitted a video, donated your status or money, sported MMIHS apparel, or helped in another way, you contributed to making this year's MMIHS day a huge success! Last year on this day, we made a total of **\$12,603.50**. This year, we managed to raise a total of **\$14,302!** We also noticed a significant increase in traffic on the social media outlets meaning that people were checking in and following this day in order to learn more about MMIHS. We certainly chalked this day up as a win!

Also, a huge thank you to the fundraising committee who met weekly and put in countless additional hours to make this day possible. Thank you to Mollie Caspers, Amanda Koble, Kristin Gutknecht, Lisa Shoemaker and Kami Harvey.

This year's MMIHS Day theme was, "This is Me." On this day, we honored and celebrated the individuality of those with MMIHS because they are strong, brave and add so much greatness to this world!



Continued Involvement Opportunities

Although our third annual MMIHS day has come and gone, it's important we continue to increase awareness and advocacy for MMIHS all year long! Below are some ways you can continue to participate!

- Print and pass out the MMIHS brochures (found on the MMIHS.org website) to friends, family members, educational staff, or anyone that knows or works with someone who has MMIHS
- Educate someone about MMIHS
- Wear any MMIHS apparel you have
- Donate your birthday on social media
- Hold a private fundraiser
- Post anything you are comfortable with on social media regarding MMIHS
- Share our December MMIHS newsletter
- Check in with another MMIHS family or join us for our next Zoom call (see date and time in "Concluding Thoughts").

**"There is no
power for change
greater than a
community
discovering what
it cares about."**

MARGARET J. WHEATLEY

MMIHS Highlight

Sarah Marshall

Age:

From:

Grade in School:

Diagnosed with MMIHS:

Favorite subjects in school:

Hobbies:

Zane's Unique Quality:

Favorite Color:

Favorite Movie:

Favorite Book:

Favorite Music:

MMIHS Tool Box

Standards and Protocol: With the combination of cold and flu season and the pandemic risk, a helpful document to have in an emergency bag is a standards and protocol file previously typed up by a regular doctor to . That way, if you do have to visit the hospital, specifically the Emergency Room, the attending doctor is able to use this document for .. , hopefully decreasing the amount of time spent there and unnecessary little procedures as possible.

Information Includes but not limited to:

- Information about MMIHS
- Test to Run
- Protocol
- Expectations

MMIHS Doll:

- Description:
- [Story of the Warrior Doll](#)
- Contact Information
 - Janna Westerholm
 - Facebook Page: Henrik's Heroes - a non profit organization that helps children and families go through medical treatment.
 - Email: jannalynn05@gmail.com
 - Phone: 701-306-2803

"We arrived home yesterday evening and we were able to give Maliyah a gift that we were saving for this big day. Henrik's Heroes makes warrior dolls to help little ones learn about their medical condition and how to take care of themselves. She even has the same broviac central line that Maliyah had placed yesterday to help her feel like she's not alone in this. Maliyah loves her doll." ~ Linda Shin Caswell



Social Media Opportunity \$100 GIVEAWAY!!!

In an attempt to continue raising awareness for MMIHS, we would like to keep our social media pages active! This month we would like to post highlights from 2020. They can be specifically related to MMIHS but don't need to be. Although it's been a year like no other, I think it's the medically fragile families that may have a unique perspective no matter what and are able to still find the positives. What a lesson to be shared with others!

Please email your 2020 highlight picture and short description to our social media manager, Kristin Gutknecht (kristin.gutknecht@gmail.com) by Monday, December 14th. Your name will then be placed into a drawing for either a **\$100 Gus Gear gift card** (see gusgear.net for possible purchases) or a **\$100 Henrik's Hero Doll** (see description in MMIHS Toolbox section). The choice is yours! The drawing will take place on Wednesday, December 23rd and will be posted on our support group page so stay tuned!

Example:

"A 2020 highlight for our family has been taking time to enjoy the outdoors more than we probably ever have before!"



Family Outreach Coordinator

As a reminder, Sarah Turman has taken on the role of Family Outreach Coordinator in an effort to ensure that MMIHS families are provided the resources and support they need. Below is a statement regarding the work she has done thus far!

Paragraph from Sarah:

Family Outreach Coordinator is a new role within the MMIHS Foundation Board of Directors, and I'm currently representing this role. The board is still developing specifics as to how the Family Outreach Coordinator can best be a liaison between the board and our MMIHS patients and families. At this time, I have been assisting with inquiries from families that are sent to the MMIHS website and/or to the MMIHS Foundation. Family Outreach is also partnering with the administrators of the MMIHS Foundation Support Group to provide additional connections and support to new MMIHS families and/or individuals in the support group that may be in need of additional communication. Future goals include working on a "Frequently Asked Questions" or a type of "Welcome Packet" especially for families with a new MMIHS diagnosis. If you have any ideas or suggestions of how to provide MMIHS patients and families with what is most needed, or how the MMIHS Foundation Board can provide outreach services, please email me at sarahannturman@gmail.com.



Pandemic Statement

During this pandemic, I'm sure we all have had that uncomfortable conversation at least once with others about why we are not able to make it to certain gatherings or be involved like most. In an effort to make that conversation more comfortable and streamlined, our support group administrator Sue Koprucki has so graciously provided a possible message that can easily be copied and pasted. We hope you find this helpful. Use if you wish!

From Sue -

How do I simply explain to others the importance of keeping my family safe during this Pandemic? This is something I have shared with my family and friends:

"As you know, people with underlying conditions often have a harder time battling everyday viruses and the flu. We need to protect not only my child, but my family as a whole (imagine- if a parent gets sick, that parent has to distance from the child as well, which means they may not be able to care for their child at home).

A simple virus can result in a hospitalization because of complications such as dehydration, secondary infections and sepsis. We respectfully ask that you do the following:

1. If anyone in your home has been sick, or has been with someone who has been sick, please just call and let us know. We can get together at another time. Even if you feel 'fine' or your child just as the 'sniffles,' you may end up unintentionally sharing something that my child's body may not be able to fight off so easily.
2. If we cancel plans, it is not because we do not want to spend time with you! It is because we have a responsibility to keep our family as healthy as we can. Please do not be offended or think we are being 'overprotective.'
3. WE LOVE to Facetime, Video Call, and Zoom with our family and friends! Let's arrange something fun! Playing games via video, or watching streaming services together using the Rave app is something we LOVE to do!
4. Please don't forget about us! We are isolating so that we can avoid putting our child and our family at risk. We love hearing from you and my child LOVES getting mail, a phone call, etc. There are days when a text can mean the world to all of us!

Staying Connected

We certainly value our time spent together and would love to get another MMIHS Zoom date on the calendar for anyone who is willing and able. Our next Zoom call is scheduled for **Saturday, December 12th at 12:00 CST** and will be hosted by one of our very own MMIHS moms, 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!

Concluding Thoughts

Thank you for taking the time to read all of the wonderful things going on in order to move forward. We could not do this without you!

For those experiencing this MMIHS journey for the first time, currently hospitalized, recovering from a hospitalization, or experiencing complications/hardships, please know you are in our thoughts and we are here for you with anything you may need. You are never alone. Together we are better!

~ Much love to you all.

"Sometimes in life, all we need is a hug. No words, no advice, just a hug to make you feel better. Here is a big hug from me to you."

