



Newsletter (Ed. 9, April 2023) "Spring Into Action"

Greetings

Hello to the MMIHS families and community! I hope you are all doing well. It is hard to believe that it has already been four months since our last newsletter was sent out! I am hoping you are feeling more of the spring season than we are here in North Dakota. We just recently had a late start to school due to yet another snow storm. The nice thing about this time of year is that the snow never stays long and the world seems a little more colorful once again! In many ways, spring serves as a reminder of the new and fresh beginnings just waiting around the corner. With that idea in mind, I chose the theme for this newsletter to be "Spring into Action." As you will read through this information, there are so many new and exciting MMIHS-related topics on the horizon. We, as an MMIHS board, encourage you to think about taking action on all or some of these items listed throughout this newsletter. We are so excited about the positive steps we continue to take as a foundation and could not do our work without the help of our community. So please, take a little time to read about the MMIHS happenings from the last couple of months!



The MMIHS Foundation

The MMIHS Foundation board of directors met on Sunday, February 19th to review goals and continue discussing strategies in which to move forward. Below are the main topics reviewed and discussed in accordance with our goals.

MMIHS Foundation Goals:

- **Patient Registry** - We are in the process of partnering with Sanford Health to create a patient registry for MMIHS patients. A patient registry is a collection of information about individuals, usually focused around a specific diagnosis. Patient registries help establish a communication network and contribute information to research in the field. We are currently in the process of creating an MMIHS specific template for families who want to be a part of this registry. It is completely voluntary.
- **Rare Impact Grant Program** - This program provides grants for organizations of rare diseases to help with funding for in-person meet-ups. Meeting other MMIHS families in-person would be such a celebration! Our goal is to get an application submitted within the calendar year.
- **Oley Conference** - The Oley Foundation is a national, non-profit organization that provides information, peer support, networking opportunities and more for individuals who depend on home intravenous and/or tube-fed nutrition, their families, professionals, and others. This year, the MMIHS Foundation plans to host a booth at their annual Oley Conference. Please see below for more information related to this topic!

Add to our Team of MMIHS Board Members

We are still looking to add a couple of members to the behind-the-scenes team! If you have a passion for the incredible MMIHS community, skills to share, and the time and effort it takes to make a meaningful contribution, please consider joining us. The application will remain open until: Monday, May 1st.

Specific skill sets we are seeking, but are not required include: grant writing, social media expertise, and fundraising leadership.

See the attached documents for more information and complete your application using the following link:
<https://docs.google.com/.../1FAIpQLScOzRedYnW.../viewform....>

WWW.MMIHS.ORG MARCH 15, 2023

theMMIHSfoundation

The time has come to seek volunteers and nominations for people to help make up the official participants of the MMIHS Foundation!

There are essentially three different ways one can be involved in the continued development of the foundation. After reading the descriptions below, if you are interested please visit the provided link to answer a few short questions.

In addition, if you know of anyone who might possess a specific skill set that would be helpful to the foundation please nominate them as well. Once we have received all interested parties we will move forward to fill the positions. If you have any questions please feel free to contact us at admin@mmihs.org.

- ### 1 BOARD MEMBER

We are currently seeking to fill 2 seats on our board. See the next page for a more in-depth descriptions of duties.

Responsibility and Time Commitment: Participation in quarterly meetings, has voting privileges and will be assigned designated tasks and fiduciary responsibilities.

We would love to find someone who has experience in grant writing!

Application: Use the link to complete the short online interest survey.
- ### 2 FUNDRAISING CHAIR

Our annual fundraiser takes place in September and we encourage other fundraising opportunities throughout the year. If you are interested in taking the lead in our efforts please let us know!

Responsibility and Time Commitment: Lead fundraising efforts and regular virtual meetings as our fundraising date approaches and complete designated tasks.

Application: Use the link to complete the short online interest survey.
- ### 3 SOCIAL MEDIA MANAGER

We are seeking someone who is interested in helping manage our online presence.

Responsibility and Time Commitment: Keeping up with our Instagram and Facebook pages. Posting regularly and monitoring direct correspondence.

Application: Use the link to complete the short online interest survey.

Add to our Team of MMIHS Board Members

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ABOUT BOARD MEMBERS:

The board is responsible for the overall policy and direction of the foundation as well as managing and delegating responsibility of day-to-day operations. Members have voting privileges and also contribute in other roles. One area of need is someone with experience in grant writing!

At a minimum the board will meet quarterly. These meetings will take place via phone conference or virtually unless otherwise arranged.

ABOUT FUNDRAISING CHAIR:

- Prepare adequately and lead fundraising committee meetings.
- Contribute to and review the fundraising plan with The MMIHS Foundation's President and Board to define short-term and long-term funding needs and ensure progress towards our goals.
- Set priorities for fundraising efforts; evaluate plans and strategies; and present outcomes to Board of Directors, as appropriate.
- Identify and solicit funds from external sources of support including, but not limited to: foundations, corporations, community organizations, and individuals.
- Support the organization through the planning and implementation of fundraising events and campaigns.
- Engage in advocacy and networking.

SOCIAL MEDIA MANAGER:

- Administrate the creation and publishing of relevant, original, high-quality content for the foundation's Instagram account and Facebook pages.
- Create a regular publishing schedule and promote content through social advertising.
- Implement a content editorial calendar to manage content and plan specific, timely marketing campaigns.
- Collaborate with other teams such as the board of directors and foundation committees.
- Solicit feedback and suggestions from the MMIHS community regarding applicable content.
- Get the community involved and create relationships with other organizations.
- Generate, edit, publish and share engaging content on a regular and ongoing basis (e.g. original text, photos, videos and news).
- Communicate with followers, respond to queries in a timely manner.
- Provide input and content for the website.

The Oley Foundation

This year the Oley Foundation is holding their annual conference in St. Louis, MO. from June 27-30. A couple of MMIHS families have already committed to attending and we'd love to know if you'd like to be there, too!

The MMIHS Foundation would like to host a booth and depending on how many more families choose to attend, we'd also like to organize a casual meet up specifically for MMIHS families. This event has the potential to be one of the biggest MMIHS family gatherings to date, so we hope you'll consider attending.

Please complete this short survey to help us start making some plans!
<https://docs.google.com/.../1FAIpQLSdIoHjIx3z.../viewform...>



Funds for Families Grant

We know that living with a rare disease can lead to added unexpected and astronomical costs for a family and that managing these financial burdens can make an already difficult situation even more challenging. As part of our mission to cultivate a supportive and resourceful community, we have created the MMIHS Funds for Families grant giving program. Please visit MMIHS.org for more information and to get your application!

We are now accepting applications to be reviewed at the May board meeting

MMIHS FUNDS FOR FAMILIES GRANT!

Accepting Applications!



Some of our MMIHS families have used the Shortie Hickman Line Dry Suit as a way for their child to experience water! As summer approaches, this is something to consider applying for through our grant program!

Shortie Hickman Line Dry Suit:

This fitted Shortie Drysuit was originally designed specifically for children with a PICC line (Hickman Line) so they could safely swim!. Found on <https://hammond-drysuits.co.uk> (\$295)

MMIHS Map

*We've added another pin to our MMIHS map.
This time in Tampa, Florida!*



According to Orphanet, the prevalence of MMIHS is unknown but has been reported in 230 patients. Therefore, in an effort to provide support and resources for those affected by it, we have created a map so that families who have experienced this rare syndrome can connect with each other. It is also a visual reminder that although MMIHS is a rare disease, you are certainly not alone!

We'd love to hear from you! If you would like to get in touch with one of the families in a given location, please contact us. If you, yourself would like to place a pin or know someone who would, please complete a short 4 question survey using the link below. We'd be happy to add you to our map!

<https://www.mmihs.org/real-families-real-stories/mmihs-map/>

MMIHS Tool Box

Below you will find three 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. **The Butterfly Pig Boutique** - specializes in dolls and accessories that instill the values of self-love, respect for diversity, and inclusion of all. We have our own line of doll sized medical devices!

www.thebutterflypig.com



2. **Dried Food:**

<https://www.wickedgoodfoodsne.com>

A small business that freeze dries foods such as fruits, vegetables, candy, and custom mixes. "We have found this form of food to be much easier for our daughter to consume!"



3. **REI Co-op Tarn 12 Pack-Kids:** This backpack has worked very well for multiple MMIHS families as kids start wearing their own TPN. Found on Rei.com (\$39.95)



Spring into Action

The start of a fresh season brings the possibilities of new activities to enjoy! However, for someone living with MMIHS, these activities may or may not look different. Below are some MMIHS families sharing what they take part in during the spring season!



Audrey loves to swing when she is cycled off of her TPN. We usually wait for the afternoon shade so she doesn't get too hot. If her feed is still running, we just tuck the bag behind her.



Grace loves to garden!

Spring into Action



Ava is doing various activities like, volleyball, violin, park/scooter, indoor skydiving, and art.



Charleston loves to go to the park with her buddy, Rex!



Alfred is currently 4.5 years old and we live in Sweden. We are a family of 5 and Alfred is the middle child. During Easter, we went skiing, something we love to do together as a family!



Playing trucks in the dirt!



Elli enjoys attending dance classes!



Here is Shelsea Merliah doing some of the things she enjoys this spring: sharing with her dog, Honu, playing with her cousin, Kayrie, going to the park to swing, and outdoor walks.

Rare Disease Day

Rare Disease Day takes place on the last day of February each year. The main objective is to raise awareness amongst the general public and decision-makers about rare diseases and their impact on patients' lives (rarediseaseday.org).

February 28th was the fifteenth international Rare Disease Day and was celebrated by many families from around the world!

Thanks to Everly's school (see below) and others who are a part of "Team Everly", she enjoyed sharing about what makes her unique and helped to raise awareness on this day!

National Care about Rare Day!

Tuesday, February 28 is the annual "Care about Rare" day. This is a day to celebrate all the unique qualities that we all have. Everly's family likes to acknowledge this day each year because there are many wonderful qualities that make her unique and special. Everly wanted to recognize this day with her class, because these are people who are not only accepting of these qualities, but help to celebrate them with her. Just like unicorns are unique, so are we!

In recognition of all that makes us unique, please send your child to school in rainbow colors! If your child has some unicorn style outfits/headbands they may wear that too!



unicorns
Rare, beautiful, magical.
The most lovable thing
about unicorns
is that they sparkle
from within.



Rare Disease Day

Although Rare Disease Day is only one day out of each year, we encourage you to continue to spread awareness for MMIHS in any way possible. The more people that are aware, the more we move forward on this journey! 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 Coordinators (see below for contact information).

Below are some ways you can continue to spread awareness for MMIHS all year long:

- Print and pass out the MMIHS Brochure (found on the MMIHS.org website)
- Educate someone about MMIHS
- Wear any MMIHS apparel
- Donate your birthday on social media
- Hold a private fundraiser
- Post anything you are comfortable with on social media regarding MMIHS
- Share our MMIHS newsletter with someone
- Check in with an MMIHS Family
- Any others!

Staying Connected

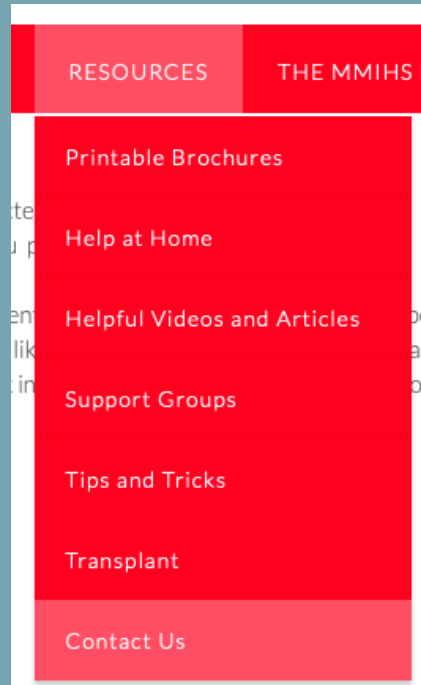
Online Contact Information: Please take a minute to fill out the survey below! If you have members of your MMIHS community who would also like to be updated on all things MMIHS, please pass this link on to them as well.

https://docs.google.com/forms/d/1PcjU2Siq3hOAtbBbNZkD3dZzTS6G5f9SHi1aXk9-E2E/edit?usp=drive_web

Additional MMIHS Support:

It can be difficult to predict what our MMIHS community may need at any given moment but we are here to support you! Maybe you are going through a particularly challenging time and could benefit from something like a phone call from another MMIHS family, a card, a meal, or some other gesture that would go a long way. If so, please get in touch through our website and we will get back to you as soon as possible.

<http://www.mmihs.org/contact-us/>



Staying Connected

Family Outreach Coordinator: Just a reminder that Sarah Turman has graciously filled this role for us! She is a wonderful attribute in assisting with inquiries from families and providing connections and support. Sara is more than willing to answer your questions or seek additional guidance if need be. Please don't hesitate to contact her, sarahannturman@gmail.com.

Social Media Coordinators: If you have any MMIHS-related pictures or information you would like to share on our social media platforms, please feel free to message our Social Media Coordinators, at anytime:

Kristin Gutknecht: kristin.gutknecht@gmail.com

Erin Peterson: erin.s.sullivan@gmail.com

Concluding Thoughts

Thank you for taking the time to read all things related to MMIHS. Please feel free to share this information with others who may be interested and be sure to reach out if there is anything we can do for you!

Much love to you all,
Erin Peterson
erin.s.sullivan@gmail.com