

the MMIHS foundation

The Future Looks Bright

Greetings

Hello and happy summer from the MMIHS Foundation! We hope this newsletter finds you and your family doing well. We are so excited to present this edition to you, as there are some very exciting things happening! We chose to title this edition, "The Future Looks Bright" not only because it aligns with our upcoming fundraising theme (see information below), but because we truly feel it highlights the additional information we have included in here! When we first started meeting as a board six years ago, we only dreamt that these things would be on the horizon for us as an MMIHS team. Not only do we have our first research grant awarded, we have our very first MMIHS meetup date on the calendar. We have taken part in medical conferences, increased our social media presence, and created our first Funds for Families grant, to name a few. We are so very proud of how far we have come, and feel energized to continue moving forward. The overall theme around all we do is to increase awareness of MMIHS and provide support and resources for those affected by it. We thank you for your continued support in helping us meet these goals. We hope you enjoy reading this edition around all things that help our future to look bright!



Erin Peterson, MMIHS Foundation Vice President

Board of Directors

In this Edition

- Greetings
- Board of Directors
- MMIHS Day
- NORD Grant
- Family Survey
- 2024 MMIHS Family Get Together
- Funds for Families Grant
- Reminders
- Concluding Thoughts

The MMIHS Foundation board of directors meets quarterly to review goals and continue discussing strategies. These goals and strategies align with both the short and long term goals outlined on the MMIHS.org website. The board met on Sunday, May 5th via Zoom. Below are the main topics reviewed and discussed in accordance with our goals.

MMIHS Fundraiser - our 2024 MMIHS Fundraiser is set for Saturday, June 15th! Please see below for more details.

NORD Grant - the MMIHS Foundation awarded its first ever research grant through the NORD Foundation! Please see below for more details.

Family Survey - We will soon be asking for your help to complete a survey around your experience with MMIHS. All results will be compiled by researchers in the field to hopefully assist in providing positive implications for MMIHS patients and their families. Please see below for more details.

Board of Directors cont.

Family Get Together - our first family get together is scheduled for July 26th-28th in Keystone, Colorado! Please see below for more details.

Future Medical Conferences - a discussion took place about future medical conferences to attend in order to continue advocating and spreading awareness to this population of people. The NASPGHAN conference was discussed as a possible next step. This conference will take place in November in Florida.

Our next MMIHS board meeting is scheduled for Sunday, August 11, 2024.

MMIHS Day

The future is bright and we can't wait for our annual MMIHS Day on Saturday, June 15th! Please mark your calendars now! Our online celebration will highlight all the wonderful things in store for MMIHS families and the foundation. This fundraiser will be posted through our foundation facebook and instagram page. In order to reach as many supporters as possible, we would appreciate your help in spreading the news with your group of people, prior and on this day.

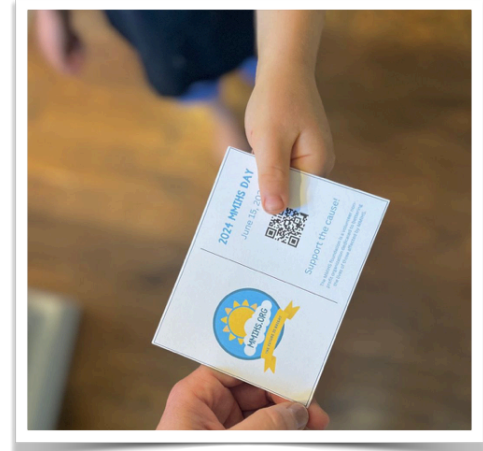
We have also created cards that you can print and pass out . The QR code will take supporters right to our website where they can donate to a great cause, arguably the best cause!

<https://www.mmihs.org/.../2024/06/MMIHS-Day-Postcard-3.pdf>



Each year, money raised helps us continue with our MMIHS Foundation mission and goals, like the NORD and Funds for Families Grant, the MMIHS Family Meet Up, and future medical conferences. With your help, we can continue to make great gains!

If you are new to our MMIHS family, please feel free to view our past MMIHS fundraising videos. These videos can be found on our MMIHS.org website under "The MMIHS Foundation" tab.



NORD Grant

The National Organization for Rare Disorders & The MMIHS Foundation, Inc. are pleased to award Dr. Robert O. Heuckeroth of Children's Hospital of Philadelphia a grant of \$30,000 to study Megacystis Microcolon Intestinal Hypoperistalsis Syndrome (MMIHS).

“Dr. Heuckeroth’s project is titled, “Phenotypic Class Switching in MMIHS and Visceral Myopathy.”

MMIHS is characterized by profound visceral (bowel, bladder, and uterine) smooth muscle weakness. While it seems likely that disease-causing gene mutations directly reduce the “strength” of smooth muscle cells, it is also possible that these mutations change smooth muscle in other ways.

For example, while we usually think of smooth muscle as cells that contract and relax, in many disease contexts, smooth muscle can become less contractile and assume a completely different set of cell functions. This process is called “phenotypic class switching.”

Dr. Heuckeroth’s team’s goal is to determine if bowel smooth muscle undergo phenotypic class switching in people who have MMIHS or visceral myopathy, since this could have implications for alternative approaches to therapy.”

Learn more about this grant at the NORD website: <https://bit.ly/4dRPxRA>



MMIHS Family Survey

Who: Dr. Robert Heuckeroth and Dr. Sharon Wolfson are both pediatric gastroenterologists at Children’s Hospital of Philadelphia. Not only have they received the NORD research grant, but they are currently studying MMIHS and have cared for patients with this syndrome.

What: Together with our MMIHS foundation, these two medical professionals developed a survey to learn more about this disease and the lived experiences of affected children and families. They expect to publish the survey results to share with the medical and scientific communities, as well as with affected families.

When: The survey is in its final stages of development and will be shared with our community soon.

Where: a link will be shared through our foundation’s social media outlets, as well as through our email provider list.

Why: Results from this survey can help these professionals and other investigators focus research on issues that are most important to the MMIHS community. The answers might also lead to new therapies for patients.

WE NEED YOU: We are asking that one member from each direct MMIHS family complete this survey when it’s available. The more results these professionals are able to compile, the more accurate picture they will be able to compile around this syndrome.

Incentives: Besides directly benefiting our MMIHS community, an additional incentive for completing this survey will be some very fun MMIHS swag that will be sent to you! Thank you in advance for taking the time to complete this survey when it is available. More information to come soon!

2024 MMIHS Family Get Together



Anytime MMIHS families are able to meet, it is surely time well spent. It has been a goal of the foundation for a while now to put together an MMIHS meetup for any and all families who are interested and able! This year, we are making that happen in Keystone, Colorado on July 26th-July 28th. As of now, we have about 6 families that plan to attend and we would love for more to join us! We are in the process of putting together a specific itinerary for the days we'll be together. In the meantime, if you are interested, please see the attached information to get started on your trip details.

Travel Tips

If you are able to join the MMIHS Family Meet Up, chances are it will involve some type of travel.

Whether it be by plane or vehicle, travel can be a very daunting and challenging task for MMIHS families.

There are many things to take into consideration and tasks to complete in order to make it possible.

Our last newsletter edition (January 2024) included some helpful hints to hopefully make travel a bit more manageable for you and your family.

This newsletter can be found on our MMIHS.org website under the "Resources" tab.

Lodging

We have a group discount set up with Summit Cove Vacation Rentals. They have a variety of properties available with a range of sizes, amenities and price points.

You can browse available properties here:
<https://www.summitcove.com>

Use the discount code R.MMIHS when booking for a 10% discount.

You may book online or call to reserve. Mention MMIHS Family Reunion when you call to receive the group discount.

Summit Cove contacts:

CK Kavanaugh: 970-500-5023 (our group liaison)

Vacation Planner: 970-368-7023

Things to Consider

While not set in stone just yet, we are looking to plan group activities primarily in the "River Run Village" area. You can filter available properties to be close to the village. Many available properties are in or within walking distance to the village.

There are also close properties in West and East Keystone with short drives to the village. River Run Village has a large lot with free parking.

Many of these properties are also available on VRBO, but will cost less when booking directly through Summit Cove with the discount.

With additional questions, feel free to contact Jessi Richards @ jessi.richards@icloud.com or 314-800-8041.

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.

Visit [MMIHS.org](https://www.mmihs.org) for more information and to get your application, or visit the link below.

<https://www.mmihs.org/fundsforfamilies/>

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)

Reminders

MMIHS Map

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. 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.

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

Reminders Cont.

Contact Information Link

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. MMIHS newsletters are sent out directly to emails provided using this link.

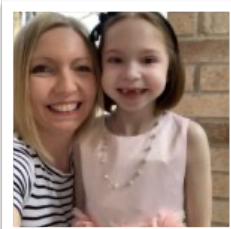
https://docs.google.com/forms/d/e/1FAIpQLSdQPhKnQSG6l_kiGrMzFYnhhoYdtsUUseaBOcd9HHji_JBxuA/viewform?usp=sf_link

Additional MMIHS Support

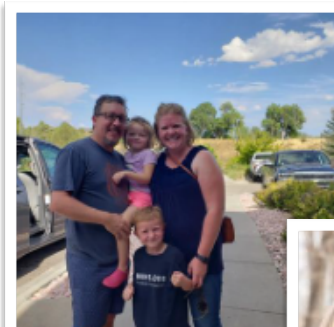
It can be difficult to predict what our community may need at any given moment, but we are here to support you! Maybe you are going through a particularly challenging time and could benefit from something like a phone call from another MMIHS family, a card, a meal, or some other gesture that would go 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/>

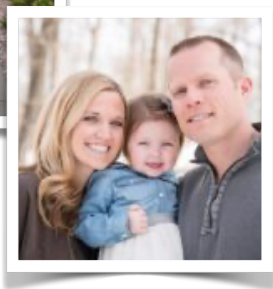
Contacts



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 Coordinator: 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, Kristin Gutknecht (kristin.gutknecht@gmail.com) or Erin Peterson (erin.s.sullivan@gmail.com).



Concluding Thoughts

The MMIHS Foundation plans to post additional information as it comes related to many of the sections explained above. We will do this through our foundation's social media outlets. We would appreciate it if you would be on

the lookout for these posts and respond any way you are able and willing. Together, we can make a positive difference for the MMIHS community!



If there is ever anything you would like included in our MMIHS newsletter, please don't hesitate to reach out. Also, a reminder that all past newsletters can be found on our site: MMIHS.org website under the "Resources" tab. Each newsletter has a title below related to the major themes of that edition. For example, you may choose to go back and review the newsletter related to school and IEP's when you begin that season of this journey.

Thank you for taking the time to read all the current information related to MMIHS. We continue to move forward as a foundation and could not do this without you! The future is surely looking bright due to all the commitment and hard work of our supporters. Thank you for being one of them!

Much Love,

The MMIHS Foundation