



Newsletter (Ed. 8, December 2022)

### Greetings

Hello! I hope December finds you all doing well. It has been four months since our last newsletter was released and we have some new and exciting things to share with you! We are now in our fifth year as a foundation, and we continue to make wonderful strides towards both our short and long term goals. We are so grateful for all the support to help us move along with what we are doing. It certainly takes a village, so thank you for any assistance you have been able to provide!

Please take some time to read all the current information related to MMIHS. Also, be sure to share this newsletter with any of your support systems so they can stay informed as well.

As always, reach out if there is ever anything we as a foundation can do to help you and your family along on this journey. We are always here to assist you!

I hope you enjoy reading the December edition of our MMIHS newsletter.



~ Erin Peterson  
MMIHS Foundation  
Vice President

### The MMIHS Foundation

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 November 13th via Zoom. Below are the main topics reviewed and discussed in accordance with our goals.

- Organize an annual fundraiser
  - We were amazed at the outcome of the 2022 MMIHS Day! We felt this year's fundraiser was a great indicator of the growth we continue to make. It validates the work 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
  - In partnership with NORD, the MMIHS Foundation has funded a \$30,000 research grant that we hope will help change the future of this rare disease! NORD is currently seeking applications that fit what we are looking for. We plan to be in touch with NORD soon about the progress.
- Open Board Positions
  - We will soon be looking for two members to fill general open board positions. Participants would be expected to attend online quarterly meetings and assist with our annual fundraiser. More information to come soon.

## Fundraising Recap

Our fifth annual MMIHS day was held on Sunday, September 18th. The purpose of this day was to increase awareness and advocacy for MMIHS and raise money to support our foundation's goals.

This year, our fundraising video was created with the intention of honoring the trials and celebrating the triumphs someone living with MMIHS experiences. We want to thoroughly THANK all of you for your participation! Whether you submitted a video/picture, 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!

This year, we managed to raise a total of **\$14,391!** This money will be put towards things such as attendance at medical conferences, funding for MMIHS families in need through our grant program, operational costs, and other future endeavors. We certainly chalked this day up as a win!



2022 MMIHS Day  
Trials & Triumphs  
Celebrating 5 Years of The MMIHS Foundation



First time outside at night with TPN.

## NASPGHAN Conference

In October, four MMIHS board members attended the NASPGHAN (North American Society for Pediatric Gastroenterology, Hepatology & Nutrition) conference in Orlando, Florida. Here, we represented MMIHS by hosting a booth and educating attendees about this syndrome. We were all very encouraged as we spent the days spreading awareness, building medical relationships, and advertising our first ever medical research grant! We were also able to discuss with medical professionals about possible next steps as an organization.

"The NASPGHAN conference was an incredible opportunity to advocate for our rare disease amongst a population of medical professionals across the country who work directly with our patients. We also had many conversations that allowed us to learn more from those professionals about what we can do to support them in their efforts going forward. We were able to share information about the MMIHS community and advertise the NORD research grant to those who are actually doing research in the field. On top of all that, it was an invaluable experience for the MMIHS Foundation attendees to have the chance to meet face to face and collaborate over the work we have accomplished and all we have yet to do."

~ Mollie Caspers  
(MMIHS Foundation  
President)



OCTOBER 12-15, 2022 • ROSEN SHINGLE CREEK • ORLANDO, FL



## Transplant Update

### Grace

**October 3, 2022**

125 days in Omaha

70 days inpatient

43 days post transplant

★ ★ ♥ ♥ DISCHARGED ♥ ♥ ★ ★

One step closer to WyHoming!



*"Fifteen years and this is the end of TPN. This is Grace's nurse who has cared for her for a long time, disconnecting her for the final time. All of Grace's nutrition is now being pumped through her new intestines. This is so exciting!"*

*Thank you donor family for this amazing gift.*

*~ April Albright (Grace's mom)*

**November 18, 2022**

♥ ♥ ♥ HOME  
SWEET HOME ♥ ♥



## Transplant Update

### Anniston

Anniston received the call on July 16th that they had an offer for intestines. We prayed and decided this just felt right. July 17th we got on a plane to NYC where Dr Iyer and Dr Moon would perform a 14 hour surgery on Anniston. Every second of the 14 hours felt like an hour. Anniston did well but he did go into acute rejection on about day 15. He was given some meds that help fight the rejection and was on the road to recovery. After 106 days in NYC we left and came home. Anniston is on g tube feeds and still has some accessories, but all in all we are happy we made the decision and thankful for our organ donor.

**November 16, 2022**

At this time next month, Anniston will be central line free! There are no words to describe the feelings in my mommy heart. One month and he can sweat, take a bath, and take swimming lessons. We are going to NYC in December and they are pulling the central line. It's going to happen in the office.

Thank you will never be enough to anyone and everyone that has lovingly adopted Anniston as one of your own and prayed without ceasing for his recovery. He's doing great so far.

~ Team Anniston

Tricia LeBoeuf - Cancienne  
(Anniston's Mom)



## Holidays/Celebrations

Whatever holidays or celebrations you and your family participate in, often times, pieces to that experience look much different for someone living with MMIHS. Please enjoy the pictures and ideas of ways these experiences take place for families!



Even though Elizabeth won't eat any Christmas cookies, she still loves baking and decorating them.  
~ Jessica Elmore Steffen

I'm planning on doing an advent calendar in December. In the pockets I'm going to put little slips of paper with activities and acts of kindness to do. LEGO has an advent calendar with different themes. They put a little mini Lego together everyday. I'm going to do this instead of an edible treat.

~ Linda Shin Caswell



## Holidays/Celebrations



We're big into crafts this year!  
~ Cassy Hill

We embrace the winter months by enjoying sledding!  
~ Erin Peterson



Future Paleontologist with his T-Rax big brother  
~ Ekaterine Kankia-Carter

## 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/>

### 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.

[https://docs.google.com/forms/d/e/1FAIpQLSdQPhKnQSG6l\\_kiGrMzFYnhhoYdtsUUseaBOcd9HHji\\_JBxuA/viewform?usp=sf\\_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/>

## 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](http://MMIHS.org) for more information and to get your application.



Congratulations to Brianna Larson for receiving our first ever Funds for Families grant! Brianna submitted a request to purchase her son, Deyn a Gus Gear vest to protect his central line. These vests are expensive and most insurances do not cover it. This was a wonderful example of the types of things that can be purchased through this grant program. Please consider applying if you are in need of something medical that your insurance will not cover!

## MMIHS Toolbox

Below you will find four resources that may or may not assist you on your MMIHS journey.

### Winter Shawl:

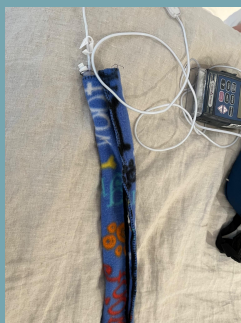
For those that live in colder temperatures during winter months, this shawl works great to help protect the TPN line from the cold temperatures/wind. We use it to wrap around our daughter when she has her winter jacket on and TPN backpack so she can safely walk into school while she is infusing. It is very easy to use and cute!

[Amazon Link](#)



### Fleece Line Wrap:

For those that live in very extreme cold temperatures, a fleece line wrap is a great way to protect the TPN line when out in the cold. We had these made by a family member who likes to sew!



### Inflatable Hair Washing Basin:

Bathing can be more complicated when working with a central line. This basin works great for washing hair, without getting anything else wet. We simply lay it on a towel in our living room and our daughter enjoys getting her hair washed, more often than she is able to bathe.



[Amazon Link](#)

## 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](mailto: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](mailto:kristin.gutknecht@gmail.com)) or Erin Peterson ([erin.s.sullivan@gmail.com](mailto:erin.s.sullivan@gmail.com))

## Concluding Thoughts

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

I conclude this newsletter with the hope for some quiet moments for you all this month. On top of a typical busy medical world, December can often feel extra. Whether it be a simple cup of coffee by a lit tree, time spent with family, or something else you enjoy doing, you deserve this time. Here's to hoping you are able to find it!

~ Much love to you all.



