



Newsletter (Ed. 10, January 2024)

Greetings

Hello and Happy New Year! I hope this newsletter finds you and your family doing well. Since our last newsletter was released, we have had quite a few new families, along with medical professionals join our email list. I want to take a minute to say welcome to you and thank you for being a part of our important community of supporters! We are now in our sixth year as a foundation and continue to make great strides towards increased awareness, and support and resources provided to those affected by MMIHS.

Each new year provides an opportunity for reflection ... reflecting on the past in order to move forward into the future. There are so many important milestones our foundation has reached and we continue to feel hopeful about our efforts and goals moving forward! With that said, please take some time to read all the current information related to MMIHS and our foundation.

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 January 2024 edition of our MMIHS newsletter.

~ Erin Peterson
MMIHS Foundation Vice President

A Moment to Remember

As many of us know and have experienced, living the MMIHS journey can be very complicated and unexpected at times. There are numerous unknowns, many of which are just plain hard and not fair. Part of this edition to the MMIHS newsletter is taking time to remember and honor the children who so bravely battled this disease and are no longer with us.

Thank you to Ashely and Chase for providing the information below on Tatum, so we can all help in honoring her. To all the other families who have lost a loved one to this disease, please know that you will always be a part of our MMIHS family and we are here to support you, in whatever ways we can.

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/>



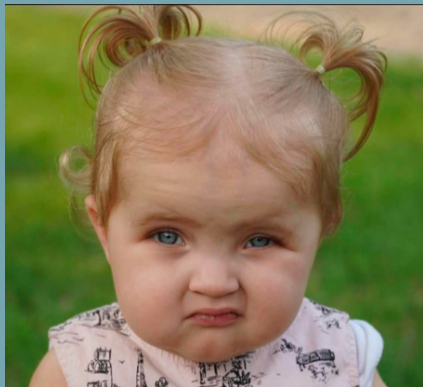
Remembering Tatum

On November 5th Tatum was born to Chase and Ashley in Rapid City, South Dakota. Five days later she was flown to Denver Colorado where she would stay for 3 months at the Anschutz Children's Hospital of Colorado. While inpatient, she was genetically confirmed to have the ACG2 gene, MMIHS. In just 3 short months Tatum was able to come home with us and finally get to meet her older sister Aubree.

As you all know, life with MMIHS is different. Lots of priming lines, dressing changes, straight cathing every few hours and taking constant inventory. But life with Tatum is best described as the "happily ever after" that you read about in your favorite books. She was so smart and absolutely beautiful. Her favorite shows were Mrs. Rachel and Sesame Street. Elmo, of course being her favorite toy, came with to all appointments and even was her "patient" at times. She was fluent with her language and knew over 50 words by 18 months of age. She was very independent and nothing could stand in her way when it came to learning what this world had to offer.

In June of 2023 she was diagnosed with stage 3 liver disease. This took a toll on her, but never took her spark. She still managed to show unconditional love to her family and it was happily accepted and returned. On August 26th of 2023 Tatum lost her battle to liver failure in Omaha, Nebraska at the Transplant center. She will forever be our biggest blessing and our sweetest baby girl. We love you forever Tatum tots.

~ Ashley and Chase
(Tatum's Parents)



Remembering Tatum



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 19th via Zoom. Below are the main topics reviewed and discussed in accordance with our goals.

- Annual Fundraiser
 - As a board, we decided to change our annual September MMIHS fundraiser to a later date this year. After multiple discussions, we decided that September is a challenging month to ask families to volunteer their time in helping to make this fundraiser as successful as possible. For many, this month is the start of a new school year, new activities, etc.. This is our largest source of income each year, so we want to make sure and make the best decisions related to it. We will continue to discuss a future date and be in touch with you as soon as possible!
- Board Expansion
 - We will be looking for an additional board member to serve on our committee in the coming year. 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. Specific skill sets we are seeking, but are not required include: grant writing, social media expertise, and fundraising leadership. More information to come at a later date.

The MMIHS Foundation

- 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.
- Sanford 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. Now that Sanford has completed their software, we can continue our process of creating an MMIHS specific template for families who want to be a part of this registry.
- Preferred Provider List
 - One of our goals this year will be to update the website to include additional providers that MMIHS families are currently seeing. This would be a way to spread awareness, for providers to collaborate, and for new families to find providers.

Our next MMIHS board meeting is scheduled for Sunday, February 4, 2024.

Funds For Families Grant

As part of our mission to cultivate a supportive and resourceful community, we have created the MMIHS Funds for Families grant giving program.

Congratulations to the Williamson family for receiving a Funds for Families grant! Cherica submitted a request to purchase her son, Jules a Shortie Hickman Line Dry Suit as a way for him to safely experience water. These drysuits are expensive and insurance does not cover them. This dry suit is 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!

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/>



"Jules loves the water! He does aqua PT and OT every week. We are so grateful for this gift to protect his line while he enjoys the water. One of the few activities he loves and can do. Thank you to the MMIHS Foundation!"

*~ Cherica Williamson
(Jules Mom)*

The Oley Foundation

The Oley Foundation was created to enrich the lives of those living with home IV nutrition or tube feeding through advocacy, education, community, and innovation. Each year, this foundation holds an annual conference. In addition to presentations by experts in the field of home IV nutrition and tube feeding, there are opportunities to meet other attendees and socialize. This year a fashion show, karaoke night, silent auctions, and themed galas provided these social opportunities. The exhibit hall is also a great place to learn about novel products, meet friends, and find the support you need.

The 40th annual Oley Conference was held in St. Louis, MO from June 27-30. A couple MMIHS families attended and not only enjoyed the conference, but also their time together!



"We had the opportunity to attend the Oley conference in June with the Gutknecht family. The Oley Foundation is a non-profit home nutrition therapy community and advocacy group. We were able to attend educational and support sessions to better advocate for our kiddos with a bonus of spending time with other families who rely on TPN. This time was invaluable to our family and watching our kids become fast friends was an absolute gift!"

~ Jessi Richards (MMIHS Mom)

Next year, the conference will be held from June 29 - July 2 in Tempe, Arizona. <https://oley.org/page/Oley2024>

MMIHS Meet Up

Anytime MMIHS families are able to meet, it is surely time well spent. Whether it is discussions around similar medical journeys, casual conversation, or just to be in one another's company, finding others that are somewhat walking in your shoes can be very therapeutic for all involved. One topic of conversation amongst the board in our past few meetings has been a possible MMIHS meet up in the future. This would be one location where all families who are able, are welcome to join and spend time together. In addition, we are searching out possible organizations that provide money for these types of gatherings, like the *Global Genes* organization. We continue to brainstorm ideas in order to make this happen and will be in touch with more information as it comes.



"Meeting Oliver and his mom was such a blessing. Eloisa felt so excited to show her "accessories" to Oliver and to see he has many of the same ones. Her older siblings were also so excited to meet someone with the same thing as their sister. Thanks to the MMIHS support group, we know we aren't alone on this journey. Meeting other families just makes our lives feel so much more relatable."

~ Sofia Garibaldi (Eloisa's Mom)

Make a Wish

The Make-A-Wish Foundation is a nonprofit organization that helps fulfill the wishes of children with a critical illness between the ages of 2 ½ and 18 years old. Children are referred to by a variety of people, such as medical teams and family members.

Besides simply honoring a magical wish come true, there are many added benefits of a "Wish:"

- Research shows a wish can give kids the strength to fight against a critical illness. Wishes can create better health outcomes for kids facing critical illnesses.
- A wish renews hope, uplifts spirits, and encourages the belief in the impossible.
- A wish forever transforms the lives of children, their families, and entire communities.
- A wish unites neighbors, friends, and entire communities in life-changing experiences.

A couple MMIHS families have been referred and wishes have been granted.

For more information, visit www.makeawish.com

"Everly's wish was to visit the princesses at Disney World! Our entire experience from start to finish was beyond magical! The Make a Wish organization works hard to make sure these experiences are catered to the wishmaker and as stress free as possible for the families, so all can focus on this once in a lifetime experience."

~ Erin Peterson
(Everly's Mom)



Traveling Tips

A majority of the sections above 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. Below are some helpful hints to hopefully make travel a bit more manageable for you and your family.

By Car:

- Find a way to organize supplies, one that works best for your family. Some families organize by individual medical cares (catheters, central line, etc...) and others by individual days.
- Consider getting a medical bag on wheels, making it easy to transport from one place to another.
- Consider bringing a collapsible wagon or stroller for transporting all the medical supplies through the airport.
- A pop up tent is a nice option, making it possible to complete medical cares on the road without having to take everything out of the car for additional room.
- Always bring along an emergency bag with all items packed in case you forget anything when packing.



* Completing medical cares in the parking lot of a grocery store.
(See below for tent ordering information)

Traveling Tips

By Plane:

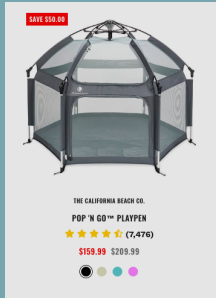
- Have a document signed by a primary care provider explaining the individual, syndrome, and expectations for care.
- Find a way to organize supplies, one that works best for your family. Some families organize by individual medical cares (catheters, central line, etc...) and others by individual days.
- Label all suitcases/bags with your contact information, along with medical tags to keep track of all the things (ex. Medical Bag 1 of 10, Medical Bag 2 of 10).
- Pack supplies in clear ziplock bags and label them. Airport security will want to look at the items and this way they will not have to open the bags.
- Call TSA Cares in advance to receive assistance at the airport.
 - TSA Cares - a helpline that provides travelers with disabilities, medical conditions and other special circumstances additional assistance during the security screening process. Call 72 hours prior at (855) 787-2227
- Require airport security to put on clean gloves when looking through your items.
- Consider keeping all medical items with you as a carry on, instead of checking these bags. This way, you have eyes on these important items at all times and if flights are delayed, you have the items you need.
- Ask for any open seats at the gate to allow for additional space for your situation.
- Board the plane first to allow for enough overhead space for your items. Medical items DO NOT count towards your carry ons.
- Pack collapsible coolers in a carry-on, in case the plane's upper carry-on storage is too small to fit the hard shell coolers (they can then be transferred into them for the flight).
- Consider bringing a collapsible wagon or stroller for transporting all the medical supplies through the airport.

Traveling Items:

1. **Everything Mary Rolling Craft Bag**
(Amazon): \$69.99



2. **Pop N Go Tent**
(California Company): \$159.99



3. **Collapsible Folding Outdoor Wagon**
(Amazon): \$86.53



4. **Bagsmart Toiletry Travel Bag**
(Amazon): \$27.99



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 (see rarediseaseday.org for more information).

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 you can think of!



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. 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

Be on the Lookout:

The MMIHS Foundation plans to post additional information as it comes related to the many sections explained above (board expansion, annual fundraiser information, a possible MMIHS meet up, Sanford registry meet up, a preferred provider list, etc...). We will do this through our social media outlets and email provider list. 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!

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

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!

I conclude this newsletter with hope for you all. With everything MMIHS families have going on in their busy world, many don't even live day by day, but moment by moment because that is much more manageable. Here's to hoping you have many happy moments in the New Year. You deserve it!

Much Love,
The MMIHS Foundation



