

MMIHS

Newsletter (Ed. 1, September 2020)

Greetings

My name is Erin Peterson and I'm the mom to Everly who is four and was born with MMIHS. Shortly after Everly was born, a family friend found the MMIHS support group on Facebook and as I'm sure you can all agree, it has become a lifesaver. Over the four years I've been a part of it, not only have the number of members continued to increase, but so have the resources! Our first ever MMIHS website and non-profit organization has been created, GI conferences have been attended to represent MMIHS, zoom calls put into place for families, and two successful MMIHS fundraisers, only to name a few! With all these wonderful things going on, I thought it might be nice to provide a quarterly newsletter, highlighting some of the MMIHS happenings within those three months. I love and respect the closeness of our MMIHS family and hope this continues to help keep it that way. I also know that raising a child with MMIHS takes a village and with not all family members a part of the support group, this might be a helpful way to share some of the current news.

With this being our first ever newsletter, I compiled the things I thought might be beneficial to share. However, in the future I will be asking for any input! I hope you enjoy the information presented in this newsletter and look forward to working with you in the future!

Erin

Interesting Facts

The Support Group:

In 2014, Sue Koprucki created the one and only online support group for MMIHS patients and their family members.

The Website:

In September of 2016 the rights to www.mmihs.org were purchased. A group of MMIHS family members came together to create an online resource that would overtake the outdated articles that once topped the searches, replacing it with current information as well as hope and support for families impacted by MMIHS.

There were 21 members in the support group before the creation of the website. Currently there are 192 members.

The pins on the map of our website represent the location of our MMIHS families.

Pins include: Asia: 1, Europe: 13, Middle East: 1, North America: 39, South American: 1



The Non-Profit:

On August 15th, 2017 we became a certified non-profit.

The MMIHS Foundation is a volunteer non-profit organization dedicated to bettering the lives of those affected by MMIHS through the cultivation of a supportive and resourceful community which promotes advocacy, awareness, education, and research.

The MMIHS Foundation

Previous to the creation of this foundation, there was no organization specifically for MMIHS.

Overall Goals of the Foundation

- Increase awareness and advocacy for MMIHS in the medical community and the general population
- Provide a forum for providing support and resources within the MMIHS community
- Support and fund researchers as they work for better treatment and diagnostic procedures.

Short Term Goals

- Complete and continuously update the MMIHS website
- Distribute brochures to any family that wants them free of cost
- Distribute brochures to specified members within the medical community

Long Term Goals

- Organize an annual fundraiser
- Fund MMIHS specific research
- Attend relevant medical conferences and have an MMIHS exhibit to spread awareness
- Hold an MMIHS specific conference with families and professionals
- Create an animated video describing MMIHS
- Create MMIHS specific educational books and videos

General Comments: The MMIHS Foundation board of directors currently consists of nine members. Most members are parents to an MMIHS person, along with an aunt and grandpa! The board meets quarterly to review goals and continue discussing strategies in which to move forward with both the short and long term goals outlined above.

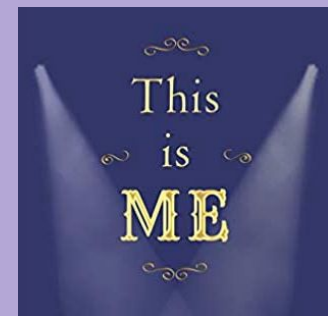
2020 MMIHS Day

Our third annual MMIHS day will be held on Saturday, September 12th! The purpose of this day is to first and foremost continue to increase awareness and advocacy for the syndrome. Secondly, we work to raise money in order to support our short and long term MMIHS foundation goals. Last year on this day, not only did many people learn about this syndrome for the first time, but we were also able to raise a total of \$12,603.50! With your help, we can continue to move forward and make this year's MMIHS day a success as well!

Ways you can help on Saturday, September 12th:

- On MMIHS Day, we encourage you to change your profile picture and share the video to help amplify our mission! We will be providing both closer to the actual day.
- Spread additional awareness by:
 - 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
 - Simply educate someone about MMIHS
 - Wear any MMIHS apparel you have
 - Any other creative ways you can spread awareness are encouraged

This year's MMIHS Day theme will be, "This is Me." The theme was chosen to honor and celebrate the individuality of people who have MMIHS.



MMIHS Highlight

Zane Shoemaker

Age: 7 years old

From: Texas

Grade in School: 2nd

Diagnosed with MMIHS: within first six weeks of life while in NICU

Favorite subjects in school: Lunch & PE

Hobbies: Hiking, bike riding, hunting, going to the beach

Zane's Unique Quality: His knowledge beyond his years.

Favorite Color: Red

Favorite Movie: Jumanji

Favorite Book: American Dog: Brave by Jennifer Shotz

Favorite Music: Zane likes a variety of music including country and rock & roll.

Zane loves sharing his knowledge about MMIHS including his ostomy to help others!



MMIHS Tool Box

- **MMIHS Website:** mmihs.org
 - This site is dedicated to increasing awareness of MMIHS and providing support and resources for those affected by it.
- **MMIHS Brochures:** mmihs.org - resources - printable brochures
 - **General Brochure** - contains a description of MMIHS and a glimpse of what it can "look" like. It also includes an explanation of typical symptom management strategies and a list of things you should know straight from MMIHS families themselves.
 - **Professional Brochure** - contains more detailed information regarding diagnosis and symptom management. This may be a great resource for people within the medical profession that work with MMIHS patients or should be aware of the syndrome.
- **Gus Gear Website:** gusgear.net
 - Provides safety and enhances quality of life for those with medical challenges, enabling them to live their life to the fullest.
 - This website offers central line vests, along with ostomy and line covers.
- **Children's Educational Books:**
 - **There's More Than One Way to Eat: A My Tubey Book** by Rhiannon Merritt-Rubadue
 - **My Tubey Goes to School: A My Tubey Book** by Rhiannon Merritt-Rubadue
 - **My Tubey: A Day in the Life of a Tube Fed Girl** by Rhiannon Merritt-Rubadue
 - **My Tubey: A Day in the Life of a Tube Fed Boy** by Rhiannon Merritt-Rubadue
 - **My Belly Has Two Buttons: A Tubie Story** by Meikele Lee
- **TPN Facebook Site:** Living Life on Total Parenteral Nutrition
 - This is another support group for parents and/or individuals experiencing life on TPN with medical complexities.

New Roles

Kristin Gutknecht: Social Media Manager

Kristin Gutknecht is from Greeley, Colorado and is mom to Norah who is 2 and was born with MMIHS. She so graciously took on this role of Social Media Manager in an effort to continue to spread awareness about MMIHS. If you have any pictures, videos, or information you would be willing to have posted on our MMIHS social media sites, please don't hesitate to send them to her through email!

Email:

kristin.gutknecht@gmail.com



New Roles

Sarah Turman: Family Outreach Coordinator

Sarah Turman is from Dallas, Texas and is mom to Ava who is 7 and was born with MMIHS. She so graciously took on this role of Family Outreach Coordinator in an effort to ensure that MMIHS families are provided the resources and support they need. If you have any questions, are looking for resources, or would like families to reach out to, please don't hesitate to contact Sarah!

Email: Sarahannturman@gmail.com

Upcoming Events

- **Saturday, September 12th:** 2020 MMIHS Day
 - Please take some time to spread awareness on this day!
- **Tuesday, December 1st:** Second Newsletter Edition
 - I will send a reminder closer to the date, but please at any time contact me if there is information you would like to include or like to see included in our next newsletter.

Thank you for taking the time to read all of the wonderful things going on in order to move forward with the goals listed above. Together we certainly are better!

I leave you with a quote I often refer back to in my own life. Although this MMIHS journey can seem overwhelming at times, forward is forward, no matter the speed and that is something to be proud of! Keep moving forward!

