



Newsletter (Ed. 7, July 2022)
"Seasons"

Greetings

Hello and happy summer! I hope you all are having a wonderful start to this new season! It seems each season brings a whole new array of topics to discuss. This newsletter will be focusing on all things related to the summer months. These months can often present challenges for MMIHS families as many things revolve around food, heat, and water. My hope is that this newsletter will provide some helpful hints and ideas of ways in which to enjoy this time, while staying safe and comfortable!

Each time I begin drafting a newsletter, I refer back to the older editions. It's always such a strong reminder of how far we continue to come as an MMIHS Foundation and family! We have a lot to be proud of!

Whether you are new to this journey, or have been here for a while, we are so glad you have joined this support system! The journey is not always an easy one, so the more we can rally together, the better!

Please take a little time to read about the MMIHS happenings from the last couple of months and let me know if you have any questions or comments.



The MMIHS Foundation

The MMIHS Foundation board of directors met on Sunday, May 15th to review goals and continue discussing strategies in which to move forward. Below are some topics that were discussed:

1. The MMIHS Grant Application: One of the main topics discussed was our first ever research grant application! Below is the information related to this grant. Although the deadline has approached, it would still be helpful to share this with your doctors, so they know for the future. This is a huge step forward in the MMIHS world!

Information: MMIHS Community, get loud! 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! For more information, please visit the MMIHS Foundation facebook page.

2. The MMIHS Fundraiser: Our annual MMIHS Fundraiser will again take place in September. This will be our third annual fundraiser and we hope it will be our biggest one yet! Please stay tuned for ways in which you can participate in order to make it as successful as possible!

MMIHS Spotlight

This newsletter edition, an MMIHS couple was chosen as our spotlight! The hope is that they can provide support and recommendations to other family members caring for someone living with MMIHS. Brandon and Sarah Turman currently reside in The Colony, Texas and are proud parents to Ava! Thank you to both of you, for taking the time to provide such insight into your lives!

What do you each do for a living?

Brandon is an Account Manager for Teksystems, selling IT services within Healthcare. Sarah is a Licensed Professional Counselor and works with teenagers in a juvenile correctional facility

How long you have been married

Married 17 years, been together/dating for 23 years

How long were you married before Ava was born?

Married for 8 years prior to Ava being born

How old is Ava and what grade?

Ava is 8 (almost 9) and will be starting the 4th grade this year

What do you enjoy doing as a family?

Watching University of Oklahoma football games, going to movies, attending church, taking Ava to fun places like the zoo, parks, museums, trampoline parks, spending time with our extended family.

What do you enjoy doing as individuals and as a couple?

*Brandon - playing soccer and volleyball. Coaching Ava's volleyball team, pool or lake time, snowboarding and spending time with friends and family.

*Sarah - having peaceful time to myself or watching a favorite tv or Netflix show, spending time with girlfriends just laughing and talking, shopping at Target (especially by myself)

*Couple- minimal opportunities for this, but try to go out to dinner or do a date night occasionally, when possible. It doesn't really matter the activity, just nice to have uninterrupted conversation

MMIHS Spotlight

How are you able to support each other on this journey?

*Sarah - To be transparent and honest, this is really difficult a lot of times because both of us are doing the best we can and trying to maintain Ava's care, both of us having full time jobs, and taking care of all of life's other responsibilities. Brandon definitely supports me with encouragement and offers to help when I am completely maxed out or overwhelmed. He also helps so much by just listening to me vent after a frustrating day and/or interaction with a medical clinic/supply company/insurance, etc.

*Brandon - Sarah supports me by being the overall organizer and calendar for the million different appointments, when to do medications and refill dates, etc. She also brings a calming sense to the chaotic world that is our "normal".

What (if any) natural roles do you each play in this journey?

Sarah is the "hub" and a natural scheduler and organizer of all appointments, supplies, meds, home health nursing, etc. We share roles of the medical care such as Brandon always preparing TPN each night, us equally sharing twice per day Lovenox injections (one does morning dose, one does evening dose), both of us complete dressing changes together. While in the hospital, Sarah is a natural detail oriented person and has all the information and dates and dosages. Brandon is the strong advocate, not afraid to ask the hard questions or call out a medical professional if things are not right, and he will protectively fight for Ava and her care no matter if people's feelings are hurt or not. We try to play "good cop, bad cop" while at the hospital, but sometimes we both want to be "bad cop."



MMIHS Spotlight

Any advice you have for other adults raising a child with MMIHS?

Connecting with other MMIHS families and caregivers was a game changer for us. This MMIHS world can be isolating, as the rest of the world has a very hard time fully understanding the day to day stress and complication that goes along with this diagnosis. Knowing there are others that truly understand and can provide support and ideas is completely priceless. I would also say give yourself grace to not be perfect. Being a "typical" parent is hard enough, but add this stress onto being a parent and it is enough to break most people. Remember YOU need support and help too. Also you are the only one who will be an advocate for your child. If you are not comfortable doing something you have the right to deny/decline services. Trust your gut, but seek to understand the situation from educated professionals (ie your care team/ doctors) then make an informed decision.

How do you handle the stress of this journey as individuals and as a couple?

*As a couple - we are always on the same page about Ava's care and advocating for her. It does not matter if we are irritated at one another or just had a disagreement, when it's time to talk to the doctors or whoever, all other life stressors are secondary to making sure Ava gets what she needs and that we do our very best for her.

*Sarah - the most helpful thing for me is talking to other "medical mamas" and/or people that can relate to this world (even if not an MMIHS specific family), relying on my faith, and having family support. To be honest, there are many days I do not feel like I'm handling the stress as well as I could. Always a "work in progress."

*Brandon - This was very difficult to grapple with the stress early on. The feeling of helplessness and loneliness was overwhelming at times. Finding someone to talk to who truly gets what you're going through is an amazing way to cope with the stress. Also for me it was/is imperative to continue to do things that dissolved stress prior to having a child with MMIHS, so for me being social, continual exercise, and having relaxing me time.



MMIHS Spotlight

What other support systems do you have to assist you?

Family lives approximately 4 hours away, have home health nursing in place, church, friends, linked with another MMIHS family in the area (shout out to the Steffens!!!), utilize assistance through Children's Organ Transplant Organization (COTA), able to receive additional benefits through the Medically Dependent Children's Program (MDCP) - but this varies state to state.

Anything else to include that would be helpful to families?

This is random but I find it most helpful to have a community page on social media to update everyone at the same time, especially when Ava is hospitalized or has something else significant happening. It has saved me from having to explain and re-explain 100 times to everyone and that way everyone gets the same information at the same time. Works well for us, but you have to do what is best for your family.



Summer Activities

MMIHS families were asked about their favorite activities during the summer months. Below are some of the responses!

Outdoor Movie Nights
Playgrounds
Biking
Theater Classes
Camping
Lemonade Stands
Golf
Tennis
Fishing
Going for Walks
Horse Riding
Playing in the Sandbox
Playing in the Sprinkler
Flying a Kite
Planting Flowers or a Fairy Garden
Jumping on the trampoline
Music Classes
Enjoying summer treats



Summer Treats

MMIHS families were asked about their favorite treats during the summer months. Below are some of the responses!

Homemade Popsicles:

You can make popsicles in the summer using these silicone popsicle molds found on Amazon for \$9.99. You can just use water or make it flavorful with juice or lemonade.



Banana Ice Cream:

Deyn likes bananas, but doesn't eat solid food, needs to stay away from extra sugars, and likes cold things in this heat right now. I've taken bananas and cut them into small chunks and frozen them. Then I just pull them out of the freezer and put them in a mini food processor with a squirt of lemon juice and a small amount of milk. Voila, fresh banana ice cream. I've also heard it would be tasty if we added a little bit of peanut butter.
~Breanna Larson



Freezies and Snow Cones:

These are a nice way to stay cool in the summer months. They are more digestible than most treats and come in all sorts of colors and flavors!

Summer Parfaits

So many fun options and varieties for a summer parfait (oreo, banana split, fruit, chocolate chip, etc.). Half the fun is the experience of making it, while licking the whip cream off the top!



Summer Resources

Below you will find four resources that may or may not assist you on your MMIHS journey, especially in the summer months!



1. **California Company Tent:** a nice way to get some shade/air in the hot summer months. This tent is so easy to set up and take down, and comes with a shade topper!
Found on: <https://thecaliforniabeachco.com> (\$139.99)

2. **Glacier Tek Children's Cool Vest:** Helps to keep your child safe from heat stress.
Found on Amazon.com (\$129)



3. **Geek Aire Rechargeable Fan:** battery operated rechargeable and portable fan. A great tool to accompany you on hot days. Found on Amazon.com (\$122.80)

4. **Hand Free Mini USB Personal Fan:** This fan has three levels of air and fits perfectly around your neck. It is also very easy to travel with.
Found on Amazon.com (\$14.99)



5. **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)



6. **Radio Flyer 3 in 1 Off Road Fold Wagon:** A nice way to provide a break on far walks or to carry all your medical supplies.
Found on Amazon.com (\$129.99)



The MMIHS Funds for Families Grant is accepting applications!!!

👉 Calling all MMIHS families! 👉 We are so excited to be able to offer our Funds for Families Grant to you for the very first time!

All of the items displayed under the Summer Resources column are perfect examples of items that these funds can be utilized for!

Visit MMIHS.org for more information and get your application in by **August 7th** to be reviewed at the next MMIHS Board meeting on August 14th.

We can't wait to see how we can help you thrive!

MMIHS FUNDS FOR
FAMILIES GRANT!

Accepting Applications!

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Water Care

The conversation around water safety has been a common topic amongst the MMIHS support group. Please know that below are simply suggestions. You may want to consider a consultation with your doctor to decide what they and you are comfortable doing prior to trying one of these options.

1. Shortie Hickman Line Dry Suit:

This fitted Shortie Drysuit was originally designed specifically for children with a PICC line (Hickman Line).



Website: www.hammond-drysuits.co.uk

2. Cath Dry:

a dressing designed by a physician for patients with central venous catheters. The dressing allows for safe showering while minimizing the risk of infection by keeping the catheter in a sterile environment and free of contaminants



Website: www.cathdry.com

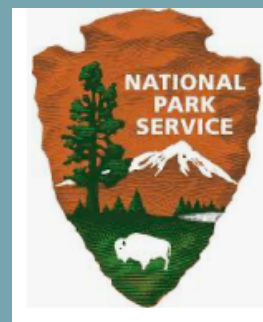
3. Pads, Tagaderm and Medical Tape:

another option is to place a pad(s) (such as a maxi pad) over the line and then place a large tagaderm(s) on top. In order to secure it even more, place a layer of medical tape around the edges of the tagaderm. Adhesive Releaser spray helps to get it off with minimal discomfort.



Helpful Hints

We are currently on a ten day RV road trip. Getting a handicap parking sign has been a game changer for us for traveling. It is so helpful to have our car full of medical supplies close by and to do medical care in our car. It helps with her not having to walk as far in the heat. I didn't think of it at first since she doesn't have a mobility issue so thought maybe some others haven't as well.



Additionally our kids can get a free disability access pass to US National Parks and monuments as well as using their Medical Assistant waiver Access card for the "Museums for All" program for many museums around the country. Traveling with our kiddos is quite the feat so every little bit helps make it just a little easier.

~ Laura Bisping

Everly loves to go for walks at night.

She is getting bigger and has outgrown strollers. This Burley is the perfect fit for her age and size! We hook her up to TPN, put it in the back, and off we go! She has also started becoming more comfortable with walking the Burley herself, TPN in tow!

A nice way to get outside and get some exercise later in the day when it's not so hot!



Where are my Words?

Although someone living with MMIHS is able to still take part in many activities, there are certainly times when limitations do exist. This can be disappointing and frustrating for all involved and sometimes hard to explain. For that reason, we have included a couple canned phrases that MMIHS families have used in the past. We certainly recognize that everyone has their own style and ways of handling scenarios such as this, but wanted to share in case it is helpful to you and your support system.

Declining an invitation from someone due to a limitation:

If it is someone we know well and/or will have a lot of future contact with, we explain that Ava is not able to do certain activities (submerging in pools, lakes, extended time in heat, etc) but are clear about giving examples of various activities she CAN do and suggest alternatives. If it is someone we do not know very well and/or someone that does not yet know about Ava's diagnosis, I typically say something like, "She has some significant/complicated medical issues and she is not able to do activities such as XYZ. I'll explain more to you another time."

Explaining to a sibling why you are not able to take part in an activity:

When David was younger, we would say something along the lines of: "Elizabeth just feels really crummy and sick. When you feel crummy and sick you don't want to do stuff and it's the same for Elizabeth."

Or, "I'm sorry we can't do X because Elizabeth is in the hospital. It really sucks." Sometimes there just isn't anything else to say.

For other people it's just something like:

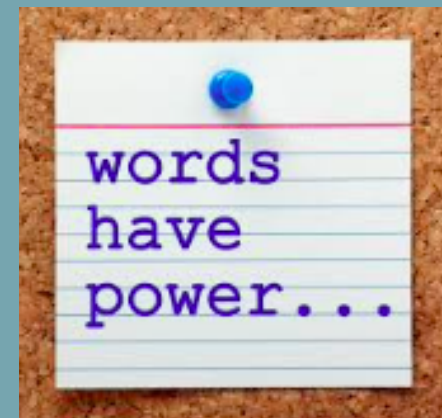
Where are my Words?

Talking to an individual with MMIHS about not being able to participate:

"I can see where this can be very frustrating and disappointing. Sometimes life is not fair and that is not fun. Your feelings are valid and it is ok to feel them. I would like to help you come up with some other ideas of things we can do for fun that will be safe for your body."

Talking to an individual with MMIHS wanting to wear a summer outfit that may expose things he or she may not be comfortable with:

"Your body is beautiful and I want you to feel free to wear what you want. However, I also know that you don't like questions and people may ask about your bag as it gets full. It is your choice. I would be happy to help you choose something else if you decide you would like to change."



"We can't because it's not a safe activity for Elizabeth."

Amazon GIVEAWAY!!

The MMIHS Foundation met a couple weeks ago and discussed the importance of having contact information compiled, serving as a method to get updated MMIHS information to you without having to constantly check Facebook (newsletters, fundraising information, etc..)! We don't want anyone who would like to stay connected to this type of information to miss out! For example, our next MMIHS newsletter will be not only posted to our support group, but will be emailed to people who have provided their 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, please pass this link on to them as well.

Contact Information Link:

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

On **Monday, July 11th**, one member who has provided their information will be randomly chosen and will receive a \$25 Amazon gift card! If you have already completed the form prior to this giveaway, you will also be included!



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 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 Coordinator, Kristin Gutknecht at anytime, kristin.gutknecht@gmail.com

Concluding Thoughts

Thank you for taking the time to read all things related to MMIHS. I also want to wish a happy belated Mother's and Father's Day to those out there continually showing up, supporting, and never giving up. It's certainly not an easy job, but you all do it so well. Be proud of yourselves!

Much love to you all,
Erin Peterson



