

MMIHS

Newsletter (Ed. 5, October 2021 - "Celebration")

Greetings

I hope this newsletter finds you well and that you are settling into the new season. Here in North Dakota, with the fall season comes crisp air and beautiful fall colors. Since Everly was born, it has become my favorite season because the temperatures are more manageable, making it easier to enjoy the outdoors with her. Although by most, the term season is defined by weather patterns and daylight hours, I have come to understand that the idea of changing seasons can mean much more. According to the dictionary, two synonyms for season include stage and condition. As a medically fragile family, we all know too well that the stage or condition of our journeys can vary dramatically depending on the circumstance. These differing seasons can include a variety of experiences and emotions, some positive and uplifting while others are just plain hard and scary. The seasons can also change quickly, while other seasons seem to stay put for a while. Just like weather, our seasons are constantly evolving into new things. Whatever season you find yourself in at the moment, I hope it includes times of happiness, times of calm, and reasons for celebration. As I was drafting this newsletter, I came to realize that we as an MMIHS family have a lot to celebrate. We may be in different seasons from one another, but these reasons for celebration are one thing that bind us together. Please take a little time to read about all things MMIHS related and let me know if you have any questions or comments. Happy Reading!

It is with much compassion that we lovingly acknowledge the passing of sweet Malaya Gohn:

***Celebration of Life
Malaya Lyn Gohn
March 25, 2017 - Sept. 23, 2021***

Malaya lived and loved to the fullest. She loved kitties, pretty flowers, beautiful days for walks, car rides, the beach, baths with her brother (rare given her complexities), cartoons, Frozen, wagon rides, bedtime stories, her beloved bear-bear and most of all her big brother, her "bubba." Malaya's strength, light, love and sassy but silly personality stole the hearts of anyone who got to experience her. Her courage inspired so many. Malaya has a whole world of people who rallied behind her. She was always the star of the show. She impacted every life and every heart that she came in contact with.

Everyday we will honor Malaya by living life her way - with strength, courage, light, love and laughter. We encourage you all to do the same. Life can get dark and suffering is a guarantee, but if you focus on spreading your light, you can make a world of difference for yourself and the world around you. Just like Malaya!

~ Bryn and Amanda (Malaya's Parents)



The MMIHS Foundation

The MMIHS Foundation board of directors met on Sunday, August 15th to review goals and continue discussing next steps. A large portion of the discussion was based around the 2021 MMIHS fundraiser. In addition, discussions regarding moving forward with the grant writing process took place. Below are more details on this topic.

MMIHS Foundation Goals:

- Fund MMIHS Specific Research
 - Mollie Caspers, our president of the MMIHS non-profit organization has put in countless hours researching the grantmaking processes and procedures and brought that information back to the board to review. There are two types of grants we hope to put together in the future:
 - The first grant would seek out applicants in the medical field who are interested in researching MMIHS specifically. Mollie has been in touch with the National Organization of Rare Diseases (NORD), *an organization that we can partner with to assist the board in putting together an MMIHS specific grant, along with seeking out and selecting an applicant.*
 - Our second grant program would focus on MMIHS families in need. It would help provide assistance for necessary medical related equipment or services that are not covered by insurance.
 - Both applications take a great deal of time and effort to compose. We continue to make strides and are excited about these possibilities coming in the near future!

2021 MMIHS Fundraiser

This year we set out to shine a light on the amazing community that we are made up of and we sure felt the love in return! There is no possible way to express our gratitude to those who supported us as we celebrated the 2021 MMIHS Day! Thank you for helping to make this day possible, helping to spread awareness, and for helping us surpass our \$10,000 goal! This year, on this day, we raised a total of \$13,959, which will help us continue with our MMIHS Foundation mission and goals.

Also, congratulations to the first 20 people who liked, commented, and shared the fundraiser on social media. These participants received an MMIHS window sticker in the mail! An individual was also randomly selected out of those 20 to receive an MMIHS Yeti mug!

Although our fourth annual MMIHS day has come and gone, it's important we continue to increase awareness and advocacy for MMIHS all year long.

Below are some ways you can continue to participate!



- 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
- Join us for the next Zoom call (see date and time below)

What does MMIHS Day mean to you?

“A day to raise our voices, advocating for MMIHS patients, while supporting and improving their daily quality of life.” ~ Nurse Solange (Ava Turman’s RN)

Celebrating a Community Member

We know the MMIHS community is made up of many important people so this year we are taking time to celebrate the entire community and get to know them a little better. In this newsletter edition, we wanted to highlight one of those community members who works day in and day out to help one person living with MMIHS live her very best life! Please take a moment to read about Nurse Solange!

Name: *Solange Oliveira (RN)*

Connection to MMIHS: *Ava Turman's Nurse*

Tell us a little bit about how MMIHS affects YOU:

Working daily for about 7 years with a patient with MMIHS, one way it has affected me is continuing to improve in the quality of my daily nursing skills and tasks, and how important that is.

What is something you have learned from your experience with MMIHS or the MMIHS community?

I have learned so much about MMIHS in these 7 years working with Ava Turman. The one most important thing to me is the need for MMIHS patient's parents/guardians to be committed in their child's daily lives.

Why do you think it is important to have a strong community?

Because more voices advocating for MMIHS patients means a better quality of life for them, more research, and better treatments.



Is there anything you think other people should know?

Educating the community about MMIHS is crucial. People need to learn what MMIHS is, and how important it is to support MMIHS families.

This year our slogan is, "Stronger together, moving forward with community and courage." Can you tell us what your experience has been in seeing the strength of the MMIHS community or the courage this community exudes?

I have seen and experienced how strong the MMIHS families can be and how this makes a huge difference in the patient's lives.

~ Thank you Nurse Solange for sharing your experiences and giving us a glimpse into your life. Your work matters so much and we thank you for all you are doing to help care and advocate for someone living with MMIHS!



Celebrating a Birthday

Unfortunately many of us, when given the MMIHS diagnosis, were handed an outdated article, which included a grim prognosis. For that reason and so many more, the celebration of each birthday year is a really big deal! It signifies another year of a very brave fight, surely filled with many ups and downs. Each year is a very deserving celebration!

Below you will find some possible substitutions to your traditional birthday cake:



Fruit Birthday Cake



Melissa and Doug Triple Layer Party Cake: Wooden Play Food Set (Amazon: \$15)



Cotton Candy Cake



Celebrate Good Times!



A large portion of our donations outside of our annual MMIHS day have come from people choosing to "Donate their Birthday" via facebook! If you are comfortable with this format, you may consider this as a way to increase awareness and advocacy while also raising funds to help us move forward as an organization!

A large thank you to those of you who have already donated your birthday!!

School Support

With the fall season, comes a new school year. For many, this can mean a mix of emotions. Certainly this is something to be celebrated but also can be very scary when it relates to the medical aspect of a person. Many have posted in the past with questions about the different kinds of support that exist for someone living with MMIHS. Susan Koprucki has graciously provided some wonderful information regarding the two main types of support that are in place in schools and her experience with both. Jessica Steffen has also provided information below!

1. **Individualized Education Plan (IEP)** - a plan or program developed to ensure that a child who has a disability identified under the law and is attending an elementary or secondary educational institution receives specialized instruction and related services.
2. **504 Plan** - a plan developed to ensure that a child who has a disability identified under the law and is attending an elementary or secondary educational institution receives accommodations that will ensure their academic success and access to the learning environment.

Thank you to Susan Koprucki for providing your insight below:

504 Plans vs IEP Plans

- Depending on the area in which you live and how your child is affected by MMIHS, you may find that one of these plans might be more advantageous over another. In our area, our daughter did not qualify for an IEP because she had no educational needs, so she had a 504 plan. Our friend living in Chicago who had a son with similar issues had an IEP because their district would not cover his needs with a 504 plan.
- An IEP is generally used for students who require 'educational services' to excel in school. The child needs to have one or more of the 13 disabilities listed in IDEA (the Individuals with Disabilities Education Act, which is a federal special education law for children with disabilities). The disability must also affect the child's ability to learn in a general education environment and they need special instruction in order to make progress in school.
- A 504 plan uses a much broader spectrum of 'disability' which includes any disabilities that limit one's ability in one or more basic life activities - things like learning, reading, communicating, thinking, or any other challenges. It is often considered with the term "Other Health Impaired," as the disability will interfere with the child's ability to learn in a general education classroom.

When your child is going to enter Kindergarten, it is a wonderful time to start the conversation with your school district:

- Contact the school nurse or guidance counselor, and ask who is in charge of special education.
- Ask them to set up a meeting to discuss your child's unique situation. A first meeting can be done over the phone, a second can be done in person with your child.
- Attend all meetings **PREPARED**:
 - Write everything down on a piece of paper, including what a typical day is like for your child, naps or rest time, snack times, bathroom breaks, medical breaks, etc.
 - Ask questions such as what kinds of safeguards would the school feel is needed and how would they want to handle things. Ask if they have had any experience with this in the past?
 - **COME PREPARED WITH YOUR OWN SOLUTIONS** - "I know a child who had this accommodation, and they did this - it worked well, but they found they needed to tweak it in this way, etc.."
 - Do not expect perfection from the starting gate. You want to open doors by asking people to be part of your child's **TEAM**.

Please reach out to Susan Koprucki for any further questions. She would be happy to answer them for you!

School Support Examples

Susan Koprucki (An MMIHS mom) ~ In our case, our daughter did not qualify for an IEP plan because she had no academic challenges - her challenges all related to the fact that she missed school due to illness, didn't have the stamina to do the work, etc.... The accommodations were geared to help her 'even the playing field' so to speak.

Our requests for accommodations included:

- A second set of books for home (to help her not have to carry things back and forth to school and conserve energy)
- Bathroom breaks whenever she needed them, not just when the class had them (she worked this out with each teacher with a special signal when she had to go)
- A drink bottle with her at all times
- Permission to carry iv fluids (infusing or not) with her at all time
- Gym Accommodations (no contact sports, no swimming due to central line)
- Snacks with her at all times
- Extended test taking times (due to her diminished energy levels)
- Parents could shorten homework assignments if needed due to energy levels
- Tutoring at home available after 3 days missed of school vs the district standard of 5 days
- Rest times allowed in the nurse's office as needed



Mark and Sara are enjoying their school experiences!

Elizabeth has a 504 and an IEP:

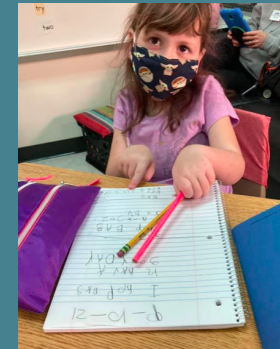
Elizabeth's 504 plan is pretty general and lists accommodations such as the private duty nurse and needing to leave class for medical interventions. It allows Elizabeth to leave class when necessary to empty her various bags or connect/disconnect her central line. It also states that the nurse can use her discretion for activities like recess, PE, or other special activities that may not be safe for Elizabeth to participate in without modification.

Elizabeth's IEP plan is more detailed. She has missed a lot of school for medical reasons and started falling behind. Her IEP allows for the following:

- no penalty for spelling errors except on final drafts
- oral administration of tests (entire)
- shortened spelling tests - up to 50%
- verbal modeling
- pull outs for additional reading support
- pull outs for social skill support
- intermittent homebound services

The homebound services have been great for Elizabeth. On days when Elizabeth isn't able to attend school (ie. no nurse, IBS flare, recovering from a procedure, appointments) the district sends an instructor to our house. The instructor spends an hour of one-on-one time with Elizabeth. She is not counted absent from school on those days. She is also more cooperative with the homebound teacher than she is with me.

~ Written by Jessica Elmore Steffen (An MMIHS mom)



Evaluations

Whether it be testing for insurance purposes, therapies, or school support, evaluations are a large part of receiving assistance or services. For someone living with MMIHS, these evaluations may reveal a "slightly below average" result, simply because a majority of the questions are heavily weighted on the cognitive aspect of this person, not the physical. In our experience, it has been important to demonstrate to the evaluator the larger picture, beyond cognitive abilities. We call this catering to the "whole child." We have created and attached this document to numerous evaluations in the hopes they will look beyond the scores. Feel free to use this information if it is helpful to you!

The Whole Child: There are many challenges that exist due to Everly's syndrome. These challenges have and will continue to impact her socially, emotionally, physically, and academically; all components directly affecting her overall development (see below).

1. Social

- a. Everly's life depends on existing in an environment that limits her exposure to much that could be detrimental to her health. This includes minimizing the risk of extreme temperatures (preventing her tubes from freezing in cold temperatures and her central line dressing to lose adherence from her skin in hot temperatures). Everly is therefore not able to take part in activities that occur in these types of environments.
- b. Everly is also not able to take part in various age appropriate activities (eating, drinking, swimming, certain physical activities, bathroom breaks, etc.).
- c. A simple cold or virus could result in ER visits and possible hospital stays. Therefore, we generally avoid places, especially in the winter months, where she would be more prone to getting sick (play areas, gym bin, etc.). These are places where other children are often present and interacting with each other.
- d. Everly's tubes attached to her central line, along with her ostomy and g-tube limits her ability to fully interact with others her age. In addition, for the majority of the day an adult is required to follow close behind with Everly's TPN backpack. This affects her ability to be self-sufficient and interact solely with others her age.

1. Emotional

- a. Everly has spent 150 plus days in the hospital, has had multiple surgeries, and has been involved in many medical procedures. The resulting stress and anxiety has created emotional barriers often preventing her from trusting or communicating openly with people. She is very cautious and a bit reserved.
- b. As mentioned above, Everly is unable to take part in many activities (eating, drinking, snack, bathroom breaks, certain physical activities, swimming).
- c. Everly is starting to become aware of her differences. She currently meets with a play therapist weekly to help her cope with these differences.

2. Physical

- a. Everly is hooked up to a TPN (nutrition) pump that runs for 16 hours a day. Because of this, she is limited in her mobility much more than a typical child her age. She is also much more cautious because many activities tend to put stress on her g-tube and ostomy.
- b. Due to Everly's syndrome, her ability to self help is much less than an average six year old. She often is required to rely on an adult to help with these things.

3. Academic

- a. When Everly is not feeling well due to various reasons related to her syndrome, she needs to stay home. A simple cold could result in ER visits and possible hospital stays. Everly regularly attends various medical appointments (in and out of state). Due to these reasons, she would be required to miss the academic experience much more than a typical child.



MMIHS School Journeys

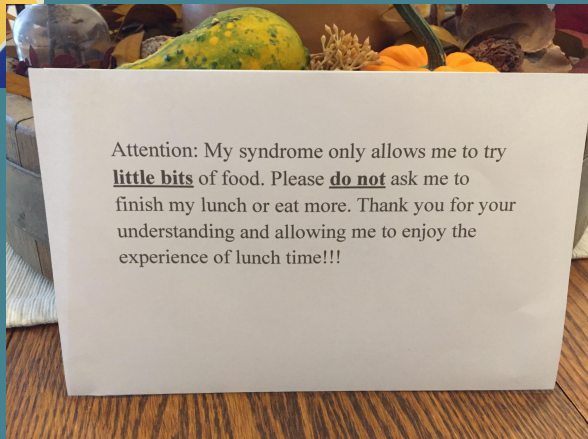
There are many things that make one person living with MMIHS, unique from the other. One of those unique qualities is a person's level of comfort regarding what they would like to share with others about their syndrome. Following a discussion with us (Everly's parents) and her play therapist, Everly decided she only wanted to share with her kindergarten class what was visible. In her case, this is her "backpack" and her inability to eat much of any food. Below is a picture of Everly and me teaching her class

about these visible aspects of MMIHS. I have also included a youtube link with a detailed explanation of the demonstration if you would find this helpful.

Demonstration Link:

<https://youtu.be/xj0qMYkKcPU>

"Wow Everly, you really are a superhero"
~ Kindergartner after hearing Everly's presentation



Lunch: Everly was also nervous about any lunch personnel asking her to eat more or finish her lunch. I personally spoke to each one of them, explaining her situation. She also wanted the attached note set at her lunch spot each day. This important information prevents any unnecessary questioning. I understand that this may be a point of sensitivity for older MMIHS students, but at this time, it gives Everly a level of comfort in Kindergarten. We also filled out a "Medical Statement to Request School Meal Modification" form in order to create awareness when she is trying food, but not consuming any. This was provided to us by her school.

Grace Albright

Age: 14

Grade: 8

Clear Creek Middle School, Buffalo, WY

Grace's Advice for Surviving Middle School with MMIHS

- Pack medical supplies in cute zipper pencil bags.
- Sign up for clubs.
- Be involved in school activities.
- Talk to the school nurse about taking a break if you need it (naptime).
- Don't worry about missing school if you are sick.
- Get a 504 plan.
- Keep your extra medical supplies with the nurse or in a special place in your locker.
- Make sure your teachers know a little bit about what you need, especially extra time in the restroom or needing to get up and leave in a hurry if you need to do something medical.
- Have a good friend that you can talk with about your medical stuff.
- Ask if you can keep your cell phone with you if you need to call your mom from the bathroom. Basically, have a plan for an emergency.

Mom's advice on middle school.....

Middle school is awkward. Life is all about the experience. Try not to let your fears limit your son or daughter's experience. Compromise is good. Trust that your middle schooler is capable of what they say they are. Set goals. Support your middle schooler. Have open and honest conversations with the school about what your son or daughter needs, create a relationship.

~ Grace & April Albright



College Life with MMIHS

My Name is Sarah, I attended Loyalist College here in Ontario three times. I took two different programs, a two-year Business Administration program and a Post-Graduate Public Relations program. Since graduating I have been doing many different things but I am currently starting work at a daycare.

While attending college, there was a lot of learning taking place... how to live alone, get along with roommates, and also get used to college life while making sure I kept up with my medical stuff. When it comes to dealing with medical things, it's important to be an advocate, especially when needing to deal with appointments, talk to teachers one on one, etc... Another thing I learned is if the college has a nurse on staff, make friends with the nurse! They will be a huge support system when it comes to all things medical. They will be willing to help if special tests like blood work need to be done.

Below are the top 5 things I learned in college:

- **Advocate to your teacher** – let them know if you're going to be absent due to medical appointments. If school work is due that day, see if you can hand it in early or have extended time.
- **Take it Day by Day** - Some days are going to be very overwhelming, but just take it a day at a time.
- **Schedules** - Make sure you get a good schedule/routine under control because then it will be easy to remember and become your normal.
- **If you have roommates** - Sit and have a conversation with them. Be slightly open about your medical things, especially if an emergency happens because they can help in some way.
- **Get to know the school nurse** - When it comes to medical things, they are the first person you to go to depending on the situation. They are willing to help in any medical scenario. They are super helpful to have in your corner when you are sick because they can do testing as soon as possible. They also can send medical notes to teachers if you are unwell.



Fall Giveaway

Whatever holidays you choose to celebrate, it's a wonderful reason to make memories with those you are closest with. More times than not however, food plays an integral part of the holiday season. This is something that often looks different for someone living with MMIHS. In an attempt to collect additional ways to celebrate a holiday, we will be holding a "Fall Giveaway" challenge. On **Monday, November 1st**, a message thread will be posted in the MMIHS support group asking families to post a picture of a person living with MMIHS celebrating a holiday, along with a unique idea of how that holiday is celebrated. For example, those that celebrate Halloween, we would love to see a costume picture, along with a celebration idea beyond the typical treats. If you do not celebrate Halloween, please post about an occasion/special time your family does enjoy celebrating!

On **Sunday, November 7th**, a winner will randomly be selected and will receive two child size MMIHS masks, along with two MMIHS window stickers. In addition, the first ten posts will also receive an MMIHS window sticker in the mail! We look forward to seeing your pictures and learning new ways of celebrating!



"Elli's school does a Halloween parade with costumes. There is no throwing candy, just parents in the streets and music!" Jessi Richards (Elli's Mom)

Staying Connected

Family Outreach Coordinator: Sarah Turman is a wonderful attribute in assisting with inquiries from families and providing connections and support. Please don't hesitate to contact her, sarahannturman@gmail.com.

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 Coordinator, Kristin Gutknecht at any time (kristin.gutknecht@gmail.com).

Zoom Date: Our next Zoom call is scheduled for **Sunday, November 21st (11:00-1:00 CST)** and will again be hosted by Brianna Larson. We will send out a reminder and link closer to the day but please mark this date. We hope you can join us for some or all of it as this is a great way to support one another!

Concluding Thoughts

Thank you for taking the time to read all things related to MMIHS. As I mentioned above, we as an MMIHS family have a lot to celebrate! I hope this newsletter is a reminder of that, no matter what season you find yourself in at the moment.

Much love to you all,
Erin Peterson

