



Newsletter (Ed. 3, March 2021)

## Greetings

Hello! I feel like the cliché statement for the first newsletter of a brand new year would be something along the lines of, "I hope you are off to a great start in 2021." However, who are we kidding? Our MMIHS life is too full of ups, downs, twists, and turns to clump it all into one blanket statement like that. With that said, I will keep it at, *"I hope within this New Year, you have found times of complete happiness, moments of calm, and bravery/resilience to weather all the rest."* That seems to be more fitting for who we are and what we are about.

This past year has certainly been full of unknowns, which in a medically fragile world naturally brings on even more stress and a lot more work. I hope that as you read through this quarter's newsletter, you will feel connected. Whether it's through something that is written, a familiar picture included, or just knowing others in your boat are reading this, too. May this serve as a reminder that you are never alone in this journey. We are all here for each other, through the moments of happiness/calm, and also through the trials/tribulations where bravery and resilience are not options. Together we are always 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, February 21st to review goals and continue discussing strategies in which to move forward. Below are the two main topics reviewed and discussed in accordance with our goals.

### MMIHS Foundation Goals:

- Fundraiser
  - Our MMIHS Apparel sold through the Custom Ink. website in November raised a total of \$627.34. This sum will be added to the foundation's total to help further our short and long term goals as a non-profit organization.
    - Due to the pandemic, we realize that unfortunately some of the apparel was not received before the holidays like expected. We apologize for this inconvenience and discussed the possibility of starting this fundraiser earlier next year.
- Fund MMIHS specific research
  - With the funds we have raised, we would like to not only support medical professionals in the work that they are doing but encourage it! We continue to work on drafting organizational bylaws that will allow us to seek applicants and distribute grants that will contribute to advances within the MMIHS community.

## Remembering and Honoring Peyton Dempsy

Peyton Dempsy was born on February 22nd, 2012 and was diagnosed with MMIHS shortly after birth. Amidst the challenges Peyton was continuously faced with, she was a warrior who fought so bravely each and every day. At the age of seven, Peyton earned her angel wings and is deeply missed by so many who loved her. In order to honor Peyton for who she was and the impact she still has on this world, Peyton's mom, Danielle, so bravely shares Peyton's story below. Thank you, Danielle for sharing your story with us (see below).

**Peyton's MMIHS Journey:** Peyton was first diagnosed within the first week of being born. It was crazy not knowing if she would even make it past two weeks. Peyton had it all... a vesicostomy, g-tube, central line for infusion, required catheterizations, and received a multi organ transplant.

Peyton handled her diagnosis like a boss. Much like the other children, she didn't know any different. Mom on the other hand, was a mess. Not all of the time, but when time allowed.

Peyton loved Minions, her tablet, and Peppa Pig. She also had a new found love of swimming and taking regular baths.

Peyton was funny, outspoken, knew what she wanted, sassy, and an old soul. She loved making people laugh and was so humble.

Peyton had a great smile and quick sarcastic wit!



**Advice:** Take time for yourself when you can. You can easily become a lost soul and get caught up in all the medical things. Breathe. The small things matter. Take in all of them you can, and cherish them!

**Honoring Peyton:** Remember to laugh everyday. You are much stronger than you think. Peyton showed us that!

My main goal in life was keeping my daughter alive. Nothing else mattered. No matter what she entailed medically, this little girl taught me so much about life. There are many ups and downs. More downs than I would like to count to be honest. Looking back, just having her make it through one more surgery each time was more time with her and I wouldn't trade it for anything.

There is not a day that goes by that I'm not reminded of Peyton. I still watch some of her favorite shows and laugh like we would together. I know she is watching and laughing from above. I like to use a lot of her sayings to help me through the day. Her favorite saying was, "I hate it!"

I could spend all day telling you about Peyton. She was my hero and she touched everyone's life. She is the brightest star in the sky and I know she has them cracking up in heaven everyday. In fact, I'm sure she's probably told someone to "pull her finger" on a regular basis!

*Peyton touched everyone she met, and hadn't met for that matter. Her comedic attitude and her tenacity inspired, and keeps inspiring from above.*

~ Danielle Dempsy





*It was an honor to meet Peyton and her mom, Danielle! I was in complete awe of them. Together, they had just been through so much, but continued to fight with a smile on their faces. As you can see from the picture, Everly sure enjoyed her time with Peyton as well, something I will cherish forever!  
~ Erin Peterson (Everly's Mom)*



*She was the weirdest, funniest, and silliest girl I ever met. She was the bestest friend anyone could ask for. I miss her so much. I will never forget that goofball!  
~ Grace Albright (Peyton's MMIHS Friend)*



*Elizabeth was so excited to meet another girl close to her age with MMIHS. Peyton gave her a Hello Kitty doll and every time we see one now, Elizabeth talks about meeting her!  
~ Jessica Steffen (Elizabeth's Mom)*



*I remember clearly how strong Peyton and her family were. She will always be talked about in our house and never forgotten. She's dearly missed and will always be a hero!  
~ Jonel Littleton-Barton (Autumn's Mom)*

## "Take Time..." \$50 GIVEAWAY!!!

As Danielle Dempsy reminded us, in order to be our best, it is so important to take time for ourselves. Of course, easier said than done. As we all know too well, when you are living in a medically fragile world, taking time for ourselves can quickly get put aside because there simply is not enough time in each day.

In an attempt to set aside some much needed 'me time,' I'm challenging you to do one thing for yourself at some point this week! I will be posting this challenge in the MMIHS Support group on Monday, March 8th. All you have to do is respond to the thread in the comments, sharing with us what you did to take some time for yourself. If you would like to include a picture of you completing this activity, even better but not required. On Saturday, March 13th, I will randomly select one participating member who will win \$50 to be used towards another 'you time' activity (massage, book, meditation app online, magazine subscription, a new pair of workout shoes, etc...). The choice is yours! The winner will be posted on our support group page so stay tuned!

This small activity may not only challenge you to take some time for yourself, but will hopefully reveal additional ideas from other members as well. You never know, someone may post a 'me time' activity that you have never thought of before. Below are some 'me time' activities you may or may not be interested in. Remember the point is to use this time as a moment to find your calm in an oh-so-busy world. Do not use it to check something off your to-do list:)

### "Me Time" Activities:

1. Go for a walk or take part in another exercise
2. Meditate
3. Work on a FUN house project
4. Read a book or a magazine
5. Drink a cup of coffee or tea
6. Watch a favorite show
7. Buy a plant or flowers
8. Call a friend or family member
9. Sit Outside
10. Take a nap
11. Listen to a PodCast
12. Journal
13. Just Breathe



*"Self-care is giving the world the best of you,  
instead of what's left of you." ~ Katie Reed*

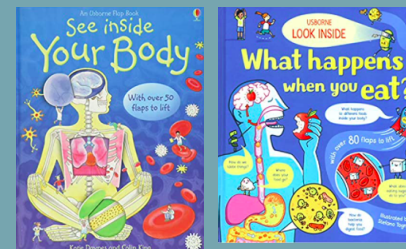
## MMIHS Tool Box

Below you will find four resources that may or may not assist you on your MMIHS journey. If you have any helpful "tools" you would like to share in the future, please let me know and I will be sure to include them!



1. **ParAid Flexible Fabric Fingertip Bandages:** the perfect bandage for all those painful cuts at the tips of your fingers because your hands are too dry from constantly washing them.  
**Found on Amazon.com (\$12.99 for 100)**

2. **Gus Gear Vest:** Gus Gear has come out with a new central line vest that has worked well for us.  
**Found on Gusgear.net (\$149-\$159)**



3. **Usborne Body Books:** these books serve as a great tool to help educate about the body. Not specific to MMIHS but can be used to describe it. Very child friendly!  
**Found on Amazon.com (\$17.99)**

4. **REI Co-op Tarn 12 Pack - Kids:** this backpack has worked very well for multiple MMIHS families as he or she starts wearing their own TPN.  
**Found on Rei.com (\$39.95)**



## 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 ([rarediseaseday.org](http://rarediseaseday.org)).

February, 28th was the fourteenth international *Rare Disease Day* and was celebrated by many MMIHS families from around the world! Thank you to Mark Cox (see below) and all the others who participated and helped to raise awareness on this day!



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 Coordinator, Kristin Gutknecht at any time ([kristin.gutknecht@gmail.com](mailto:kristin.gutknecht@gmail.com)).

## 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](mailto:sarahannturman@gmail.com).

**Zoom Date:** We certainly value our time spent together and would love to get another MMIHS Zoom date on the calendar for anyone who is willing and able. Our next Zoom call is scheduled for **Saturday, March 27th (5:00-6:00 CST)** and will be hosted by one of our very own MMIHS moms, 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!

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## Concluding Thoughts

Thank you for taking the time to read all things related to MMIHS. As stated above, I hope that reading this newsletter has in some way made you feel connected to others who are "walking in your shoes." In a world that can feel so different, know we are all in this together!

Remember to try and take a little time for yourself each day, even if it is just a couple minutes. You deserve it!

Much love to you all,  
Erin Peterson

