The Foundation for
FNMS
Nager and Miller Syndromes

Winter 2022

All About Us

All About Us *is the newsletter of the Foundation for Nager and Miller Syndromes. We took our name from a story submitted by Monica Quinn in our Autumn 1991 issue. Monica captured our entire theme and purpose in three little words.*

"Us" is all persons who live with our syndromes, the members of our families, our friends, our neighborhoods, the medical community and everyone we can reach. We offer information and communication for everyone interested in Nager and Miller syndromes.

As you read our newsletter, as you think about getting involved, as you contribute your features, reports, photographs, or your own experiences and poetry, think to yourself —

"This is all about us."

FNMS is an international support group dedicated to helping those affected by Nager and Miller syndromes. We serve as a clearinghouse of information and link families seeking support, hope, and advice. FNMS empowers families and guides them through the process of surviving to thriving.

FNMS is a parent-run volunteer organization with a 501 (c) (3) not-for-profit status.

FNMS Family Conference Provo, Utah

When it was announced in Boston that the next FNMS conference would be held in Utah we were excited!

At the time that planning started in early 2019, we were still moving forward with a planned mid-face advancement surgery for Peyton in the spring. Therefore, I got started early reaching out to potential donors for items for the welcome bags. I focused on three main categories of businesses – those that could offer tickets or gift cards for local services, those that were businesses unique to Utah and those that had products children and adults with the syndromes utilized. And where I could, I tried to make the request personal – like including a photo of Peyton with her Shiley tracheostomy, her Mini feeding tube or her Cochlear BAHA.

In late February, we received the terrible news that Peyton's surgeon was taking an indefinite medical leave and any hope for a surgery date vanished. However, that meant she could fully enjoy the conference and her summer without the restrictions the surgery would have required.

As we headed into summer the excitement grew and our spare bedroom became conference headquarters storing all the items that would go into the welcome bags. It was fun researching local activities to include in the packets and picking out items to include to make the families more comfortable during their stay.

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The big day arrived and we were fortunate that it was only a 30 minute drive to the hotel when we knew many families had so much further to travel. Once we were settled at the hotel, it was fun watching all the families arrive – many familiar faces but a few new ones as well. Peyton was thrilled to see some of her friends from past conferences and they started chatting away as if it was only yesterday that they had seen each other last.

The ice cream social felt like a family reunion – kids running around, parents catching up and young adults reconnecting with each other. The room was buzzing with energy and although we knew we had several more days with each other it was hard to call it a night.

There were several great educational sessions on Friday that I had been looking forward to and I knew Peyton would be in great hands with the volunteers and all the activities they had planned.

On Saturday, we had a great time exploring the pioneer village but Peyton couldn't wait to go to the water park next door. She definitely shocked a few people barreling down the water slide into the pool with her trach! We could have stayed all day but we had the dinner dance to get ready for and it is always the highlight of the conference! It has always felt a little magical to me as I watch the kids and the adults relax and let loose on the dance floor.

Sunday morning dawned with a lot of last minute photos and hugs as families got ready to leave. It is always bittersweet knowing it may be years before we see each other again. Thankfully with social media there are opportunities to stay involved and support each other until the next conference rolls around.

Several weeks later, I sent thank you cards to each donor along with a personal message and a group photo from the conference. There is no way to really convey to these donors the importance of these conferences for the families who attend, but seeing the group photos and all the smiling faces as I addressed the cards reminded me that though we may be spread across the world we are a family.

We can't wait to see where the next conference will be and hope to see some of you in Utah again in the future if your travels bring you this way!

-Tracy Smith

Thank you to the Morton Grove Foundation for sponsoring our "Ice Cream Social"

Pictured:Erica, Bridget, Jackson, and Sherman representing the first come first served rule!

All About Us

www.fnms.org

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Director's Note:

Where do I even begin? You may be wondering where we have been and what we have been up to during the world-wide shut down due to Covid 19. Like most people, our entire life changed. Perhaps, unlike most people, rather than being in lock-down, I went to work. Our business is an essential business and due to the panic and confusion in the early days, we lost a few key employees, who for their own reasons, needed to stay home. So, I gave up real estate and went to work in Seattle full time. As with most major life changes, I had not realized how much free time my former career in Real Estate truly afforded me. Hindsight!

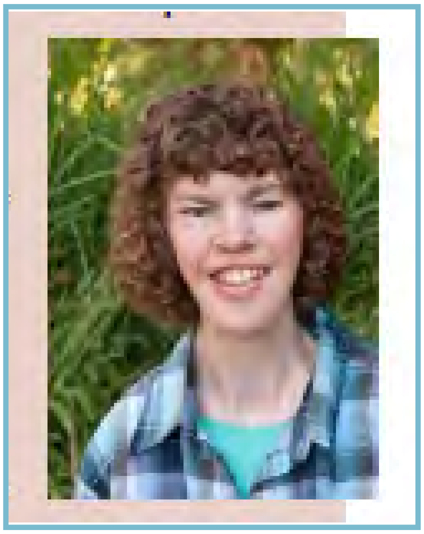
– Right? As if that wasn't enough of a change, we decided that the middle of a world-wide shut down was the perfect time to sell our home and make a long distance move from Seattle to Orange County, California. Who moves in the middle of a pandemic? We do apparently…Our facility in Orange County required more hands-on management than our Seattle location and so we moved. In addition to a new career, work schedule and address, the new world order required the shelving or elimination of many great plans that were in the works for FNMS. First and foremost, the cancellation of the 2021 FNMS Family Conference, was a very difficult call to make however, the health and safety of our members is of the utmost importance to us. Plans were then in the works for a 2022 Conference, however the lack of solid, reliable information on whether the virus and it's unruly offspring will be under control by that time, has led us to pause those plans at the present time. We hope with all of our hearts that we will see an eventual, permanent ebb to this virus and that we will be able to safely gather as an FNMS family once again. Who is up for meeting in 2023?

In the meantime, we are revamping the FNMS website, updating our databases, and hoping beyond hope that you will all still be watching and waiting for more from us. Which brings me to the sad news that follows.

- Every loss is a tragedy, we here at FNMS are not immune, nor are we unacquainted with loss of our FNMS members. Over the past year we lost two of our dear FNMS Family members. Heather Madsen lost her battle to cancer. Heather, her brother Logan and their mom, Debbie have been members and a vital part of FNMS since the beginning. With her passing we are reminded that it is not always the illness or procedure that you most fear that prevails in the end. Heather's triumph was that she was a beautiful soul who touched all those who took the time to know her. Her spirit lives on in her poetry and writings and in her mother and Brother. We will miss you, Heather.

- Tragically, we also lost sweet little Gabriel Revis. Gabe was an earthbound angel for 6 brief years. Yet in those years his smile and amazing spirit touched hundreds, perhaps thousands of lives. Gabe's mom, April, is a huge inspiration to us and so many others for her constant and unerring love and advocacy for her baby boy. There are no words that can help her through her grief, only love.

- This issue is dedicated in loving memory of Heather Madsen and Gabriel Revis



FNMS
Conference
2019
Provo,Utah

THE FNMS CONFERNCE
BY CARLA PERRY

The FNMS conference at Provo Utah was an extra special one for us. Not only was the town of Provo beautiful, and the venue so welcoming, but Utah and Salt Lake City, brought back memories for us.

34 years ago, we made a side trip to Salt Lake City, to visit a family whose children had Miller's Syndrome. Erica was 2 years old, and we had no idea of her future or capabilities. We met Debbie, Heather and Logan, and our hearts were lifted up with joy and we could see a wonderful future ahead for our Erica.

That little visit was the small seed that eventually became the FNMS worldwide family. Margaret Ieronimo contacted Debbie when Bridget was born, and Debbie in turn put Margaret in contact with our family, and we went and met the Ieronimo Family, when Sherman was 18 months old, Erica was 5 and Bridget was a bit over a year old. Margaret, like us a few years before, was touched by seeing the future in older children, and their capabilities, not their limitations. Margaret subsequently met a family whose daughter had Nager Syndrome, and Margaret's drive and passion brought together FNMS and our first conference in 1996.

Since then, our FNMS family has grown, and we have seen our young people become capable adults, and new young families find FNMS, and the help, hope and encouragement that FNMS brings.

I would like to thank DeDe for keeping Margaret's passion and vision alive, and for supporting us all through our journeys. Also, a big thank you to DeDe and the organizing committee for finding such a wonderful venue, and all the hard work that goes on behind the scenes to pull together a supportive and informative conference.

If you've never been to a conference, start saving now, and come to our next one, you will NOT be disappointed. You and/or your child/young person will learn so much, and it is empowering for our young people to be together, to meet people "just like them". They talk about the challenges they face, and how to overcome them. Things that we or professionals can never understand or figure out, because we don't walk their journey, we just walk alongside them and support them to the best of our ability.

Carla Perry New Zealand

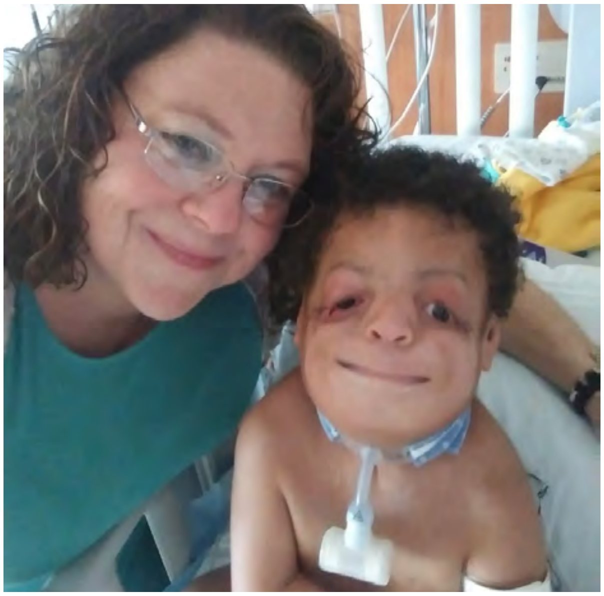
Donations received in Memory of Martha Valentine (Lauren Guminey's Beloved Grandmother)

Laura Theiss
Jeff & Lisha Guminey
Marjorie & Robert Scorvronski
Park National Bank

IN LOVING MEMORY OF GABRIEL REVIS

FNMS Angel,
May he rest in peace!

Donations received in memory of Gabriel
The Perry Family
The Van Quill Family
Lara & Dave Beranek



Like the one you were named for,
You are God's Hero
You walked so briefly among we mortals
Your soul called home in service of heaven
Your spirit shone bright to all that you met
We will love you & miss you & never forget

Donations in Memory of Wanda Ryba:
Roxanne McCarville
Suzanne Bartlett
Lisa & Brian Ryba

It Is Not Too Early to Start Planning for Care Transition!

We were extremely fortunate to have Dr. Justin Alvey , MD FAAP speak at our conference regarding the importance and process of transitioning from Pediatric to Adult Healthcare. Although, we all have differing circumstances and may be at different stages of parenting, this topic is critical for all of us at some point and that point is sooner than most of us think!

There are a host of considerations and steps involved in the transition from pediatric health care to Adult health care, when a person turns 18. The complexity of this transition is significantly increased when the individual transitioning has chronic medical conditions. Therefore, the planning is not only more involved but also more critical. Rules, regulations and HIPPA laws limit parental involvement after a child turns 18 years old. Other legal issues come into play when developmental delays or significant impediments to self-care are involved. Pediatric and adult medical care are vastly different.

Pediatric Care

- Headed by a primary pediatrician or group of Doctors
- Services may be through specialty clinics where Specialists confer together on all treatment and treatment schedules
- Patient focus is on treatments, procedures & care of the whole individual & their needs
- Parents or caretakers play large part in care plans, treatment discussions, advocacy
- Continuity of care and medical team members is important

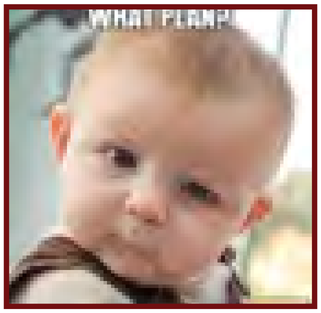
Adult Practice

- May or may not involve 1 primary physician
- Focus is on maintenance & wellbeing through aging process
- Decision making is between the patient & Doctor only
- Less time is spent in appointments
- No Specialty clinics where all specialists confer on treatments
- Patient self-advocacy vitally important
- Often referrals required for specialty care/clinics/physicians

Transition Process

- Discovery/Education – providers develop & communicate transition policy age 12-14 years
- Tracking health info. – patient learning conditions & care elements age 14-18
- Preparing to transfer – patient engage in own advocacy, care info. ages 14-18
- Planning – provider discuss adult options for care, insurance options, etc. age 16-18
- Transfer of Care – Medical summary to new, identified adult provider, Medicare/Medicaid/SSI notification from patient age 18-21
- Completion – patient transition to adult physician or team

DO YOU HAVE A PLAN?



Transition: Legal Considerations

- Parent is no longer legal guardian.
- Patient must sign all paperwork
- Patient is responsible for all payments/copays
- Provider can only communicate with patient unless a release is signed
- Patient must make all appointments and phone calls
- These things all go in place regardless of developmental level unless guardianship has been granted to another individual

Guardianship

- Wards and guardians. Court appointed. Not always the parent.
- Reversible and modifiable.
- Requires evidence that the ward can not care for or make decisions for themselves
- Guardian makes decisions

Supported Decision Making (SDM)

- Patients and supporters. Determined by patient, not Court appointed.
- Modifiable
- Patient makes final decision
- Health Care Proxy
- Power of Attorney
- Patient responsibility for bad decisions

Carla Perry, long time member and highly experienced parent had this comment regarding Dr. Alvey's presentation and the subject of transition:
"When our children transitioned from pediatric care to adult care, it was really hard for them. They had a trusted pediatrician who kept his finger on the pulse of all their surgeries, their specialist appointments, their blood tests and other tests. They had a relationship with him, as they saw him 3 or 4 times a year over several years. Once they were in adult medicine, they had a General Practitioner who managed their overall health, for regular prescriptions and blood tests, but they had no specific doctor for their specialised issues. If they went to hospital, they saw whoever was on call. We didn't prepare our children for transition, and it took its toll on them and us. I would highly recommend taking on board the advice that Dr Alvey shared, to get our kids as prepared as possible for the adult world of medicine, so that they feel empowered to manage their health well."
– Carly Perry

Justin Alvey, MD FAAP
Associate Professor, Department of Pediatrics
Medical Director, Pediatric Outpatient Clinics
Comprehensive Care Program for Children with Medical Complexity
University of Utah School of Medicine, Salt Lake City UT

IN LOVING MEMORY OF HEATHER MADSEN

I love you sweet Heather Madsen! What fun we had spending some very precious moments together in your hometown last time I was in America, I especially love that we got to recreate a childhood photo, and on the same blanket even!! I got to meet your sweet cat Thomas and see where you live, I got to watch you do tricks with Thomas and we got to have a movie night and ate chick fil a, life has never been easy for you, but you faced each new challenge with grace, you fought to live, but now you will no longer need to fight for every breath to breath, I will miss You Heather, such a great example to all of us with Miller syndrome and other struggles.

Love Erica

Donations made in loving memory of Heather Madsen

Carla & Maurice Perry
Melanie Madsen
Mark C. Miller
Peggy Clark
David Viskochil
Kathy & Jack Newton
Rubin Saint James
Ryan & DeDe Van Quill

Harriet & Ray Gestseland of Columbine Press
The Beranek Family

Photo Courtesy Reubin St James

Carla & Maurice Perry donated in Memory of Margret Perry & in memory of Byron Andrews – A little fighter to the end!

We celebrated Max's 21st birthday in our first lockdown. His 22nd birthday was in our third lockdown! We had a pub crawl around our house and garden with different themes in each room!
We are all ok and luckily have stayed Covid free so far.

Dave and Lisa Challenger and Max Baldam. Take care and love to you all xx

Member Updates

Hi, my name is Peyton Smith. I have a surgery coming up and it's pretty huge! Basically it's where they take my non-existent chin and move it forward to sort of fit my face. I am currently in middle school – 7th grade. I will be missing a lot of work! We are starting in the middle or end of March.

To be completely honest, I don't really want to do it, but it has already been delayed 2 years already. Now I am twelve and more mature. I know it has to be done.

I have amazing friends who have been so supportive and caring when they heard this news. But overall I'm nervous about the pain and IV's and I'll miss school and my friends.

Donations In honor of Marty Robbins' Birthday were received from:

Theresa Bennett
Janie Dawson
Jen & Chris Welsh
Bob & Connie Furger
Dave & Lara Beranek
Jason & Deb Camper
Greg & Christine Gage
Rebee & Dave Phillips
Andy & Anita Krautkramer

We are deeply humbled and truly grateful for the Legacy Donation made by Shai & CJ Fathers & 7 Wandering BackPacks

www.7wanderingbackpacks.com

Getting to Know You

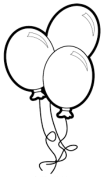
A warm hello to everyone who is reading this!
My name is Vivian Vollmer and I come from Germany.
I was born in December of 1998 and will be 21 years old at the end of this year.
I was diagnosed with Miller's syndrome and tell you something about me today, how I feel about it, and everything else.

Even before I was born, my parents learned that I would most likely have a severe physical disability. After the initial shock, my parents decided to get me and here I am.
According to the doctors, I probably shouldn't live to see the first year of life, but I fought my way through from the beginning and have now lived 19 years longer than predicted. I always say that the doctors don't know everything either, after all, we're all just human beings ... My parents started as early as possible with all the subsidies in order to enable me to live as "normal" a life as possible later on, visits to the doctor were the order of the day for many years. When I got a little older, I hated that, I can still remember that today.

I then came to a normal kindergarten and settled in well there and also felt comfortable. If you wanted to know why I don't have a 5th finger, I told you that it has always been like this. After that, everything was clarified and the game continued. Children are much less complicated in this respect than teenagers or adults, as I later discovered. But more on that later...
When I started school, I came to an integrative school near us. There, students with and without disabilities learn together. Again, I had no serious problems, apart from a few quarrels, which certainly everyone had had at some point... I never wanted an extra treatment, but to be treated like everyone else. On the whole, it went quite well, except for a few things where I needed support. For example, I wear hearing aids and used to need an FM system (a kind of small portable microphone) so that I could better understand my classmates or mainly the teacher. Meanwhile, I don't use this anymore because the technology has evolved enormously and I can see everything well with my current hearing aids (most of the time, but that's sometimes a matter of "not wanting to hear").
After primary school, I went to an integrative comprehensive school, where I graduated 9 years later. I always liked going to school, because I usually had a lot of fun learning and wanted to learn new things. Admittedly, I could have done without my homework, but it was part of it...
I also got along well at this school, the atmosphere among each other was friendly and appreciative. I only became very aware of this later. M a friend and I wanted to continue learning French after the 11th grade, instead of starting a new language (e.g. Spanish). But because our school no longer offered French lessons, we had to go to another school for 3 hours a week. This school was a completely "normal" school, where no or very few students with a disability were taught. Especially the first few days you were sometimes stared at by the other students, which was not so nice. Ahead up and keep running. I had to learn that very early, not get hurt and make myself small just because you're different. So what? Being normal is boring, I always say. Either you can handle it, or you don't, nobody is forced to be happy with me, or whatever...
After graduating from high school, I started an apprenticeship at a health insurance company about one and a half years ago. Getting an apprenticeship was another hurdle I had to overcome. Many companies have cancelled from the outset, why I still do not know... Maybe it was because of the severely disabled pass that they did not want to hire me. But I don't really worry about that. Just because you have such an ID card, you didn't fall on your head or stupid on principle. Yes, that sounds harsh, but it has to be said.

I still find it unbelievable how fast time flies, it seems to me as if only a few months have passed since I held my diploma in my hand...

Henri & Mary Arts – Columbine Press
donated honor of Paul Cunningham's
Birthday!



In honor of Erica Perry's
Athletic Triump
donations were made by:

Bob Wendt Beth Atkins
Christina Johnson Patricia Moore

Even now in my training, I have to go back to vocation-al school. I recently had a problem with my classmates, which I wanted to briefly address here.
Even as a child I had a hard time meeting new people, but with adults it was no problem at all. At that time I was relatively shy and in combination with my disability this was not a good start... The older I got, the better it got, now I rarely have a problem talking to people my age.

In any case, at vocational school I had the feeling that I was somehow excluded. I wasn't aware of that for some time, because the whole thing happened rather passively. Nobody said we didn't want you to come to us, but when I asked something, there was often no answer, or my back was inconspicuously turned when we stood together in a large circle during the break.

It was only after a few weeks that I realized this and wondered why. Whether I may have done something wrong, or whether it is simply due to my disability... the whole thing made me very sad, especially this ignorance of why, was hard for me to bear. I was afraid of talking to the group at first, as I didn't want it to get any worse.

Together with a teacher, I talked about it with the people concerned and we found a solution together. Now the problem is gone, but maybe I've just thought too much about everything.

Why am I telling you all this? I want to tell you that it's important to talk about problems, even if you feel really bad about them at first. Maybe everything is not so bad in the beginning, but if you endure it in silence, the consequences are much worse afterwards. I recently read a saying that says: "A man cries not because he is weak, but because he has been strong for too long". I think that isvery appropriate in this context.

Do you know the movie "The Greatest Showman" with Hugh Jackmann? If not, you should definitely take a look at it. It's about fighting for acceptance, even if you're different. I think this film shows very well what I or we are. That we don't have to hide from the world just because we might not become the next topmodels. True beauty comes from within anyway, the character counts for me a lot more than the appearance of a person. What's in it if you look great, but you're a total rivet humanly? Exactly, nothing! Both are great, of course, but you can't have everything

What else is there to tell about me? I actually read every free minute (mainly crime novels and thrillers) and like to meet up with friends or listen to music. I used to ride horses regularly, but at some point I didn't have time for that because of the Abi, which is now limited to the summer vacation, galloping through the desert.

I've been skiing since I was about 6 years old, so I look forward to it every year. I was once water skiing with my class, which was a lot of fun (I didn't do it very well, but that's not what it was about). Otherwise, I'm pretty direct, so say what I think, but I'm sure you've just noticed...

Then I would like to thank you once again for giving me the opportunityto write this article and hope that I was able to give you some food for thought.
And remember: you are great as you are, stay that way!

Best regards,
Vivian

(This article was translated from its original language to English using Microsoft Translation, please forgive any errors within the translated version.)

Mr. Christopher Clark donated in honor of Lizzie Cerone & Naren Clark

We are humbled by the generosity of our donors!

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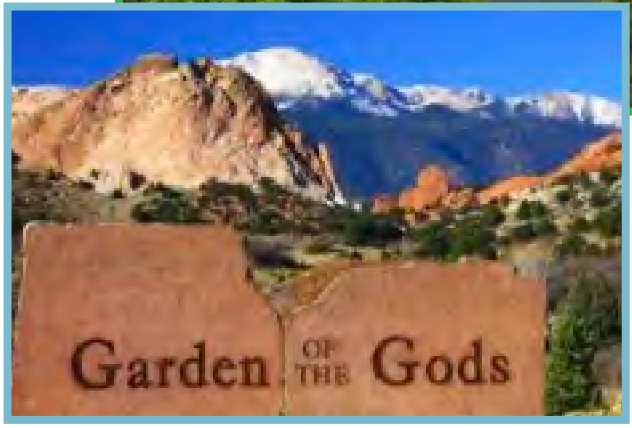
ANNOUNCING THE 2023 FNMS FAMILY CONFERENCE IN COLORADO SPRINGS, COLORADO



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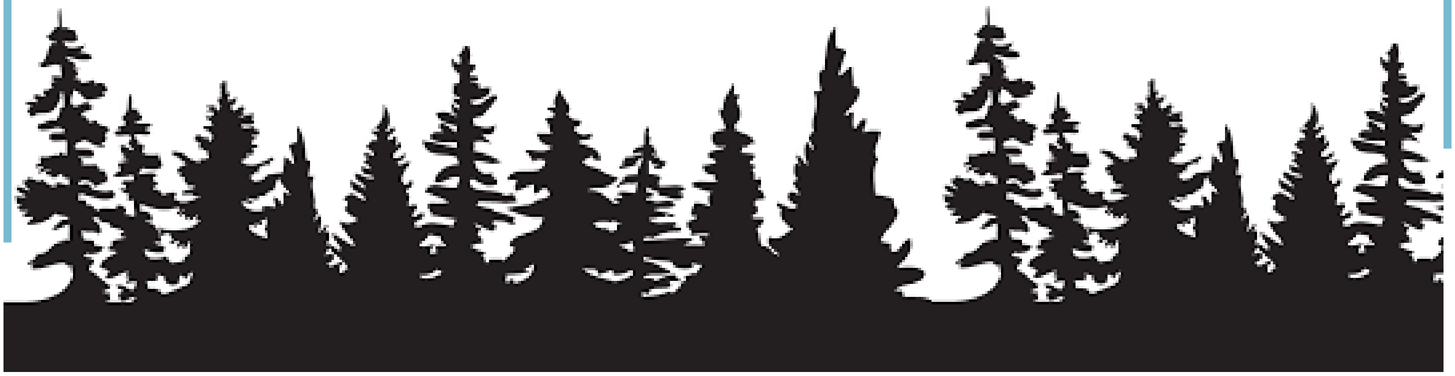
Tentative Dates: June 22-25, 2023 Details to be Announced



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Shai & CJ Fathers
for their generous donation
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