

The Sun is Always Rising

Newsletter of the



February 2023

Thank You, Miss America By Marti Bolan

Yves Saint Laurent, the world-famous fashion designer once said, “The most important thing in a dress is the woman who wears it.” It seems that this is also true of a crown. On December 16, 2021, at the 100th anniversary of the Miss America competition, Emma Broyles, the then current holder of the Miss Alaska 2021 title, was crowned Miss America 2022. As the sibling of a special needs brother, I can think of very few better equipped to wear this crown.

Being engaged in and advocating for the special needs community has been a part of the entire Broyles family culture since the very beginning. They have been actively engaged as long-time members of the Alaska Down Syndrome Network and Special Olympics, participating behind the scenes as board members and coaches, as well as attending and supporting the various events. For the past 20 years, no matter what the event, it was almost a guarantee that one would see and speak to the Broyles family! As a family they put their heart and soul into supporting the special needs community.

Both Emma and her brother, Ben, spent their childhood supporting their brother, Brendan, as they accompanied him to therapy visits, sporting events and school. In Special Olympics, they enjoyed hanging out with the athletes and had fun helping at practices. From the beginning, both siblings interacted with and enjoyed those with disabilities. Growing up, they had plenty of playdates with kids with different disabilities, playing with kids in waiting rooms while Brendan had therapy and students in their elementary school classes. The entire family practiced inclusion, empathy and acceptance as it was a normal part of their daily lives. The Broyles family did what any other family does with a loved one

with a disability: They included Brendan in everything. His siblings understood that he could participate in their activities and were quick to make accommodations when needed.

In high school, Emma served as the president of Service High’s Special Olympics Partners Club. She believes youth centered programs are an opportunity to foster inclusion at an early age, shaping the minds of the younger generation. These experiences will teach those involved, “open-mindedness, inclusion and empathy”. Her goal as Miss America was (and is) to help people from all walks of life be heard and respected through practicing inclusion, not just for those with intellectual disabilities.

While completing her tour of Miss America, regardless of the subject of the interview, Broyles always took time to talk about the significance of Special Olympics and other programs designed for inclusion. Compassion, open-mindedness and inclusion became the theme of every interview. Her passion was clearly evident in the message she spread across the nation, using the scope and influence of the Miss America platform. That passion clearly leads directly back to her family.

Because the Broyles family practiced inclusion and support for all family members, it gave the necessary credibility and authenticity to Emma’s message. Had her upbringing been any different, her message would not have been nearly as genuine and effective. After watching and reading countless interviews and appearances, the natural honesty of her appeal is apparent: As a parent of children with different disabilities, it touched my heart. It can be heartbreaking to see your children excluded, regardless of disabilities. The more people this message of inclusion reaches, the better my children’s lives become.

In October 2022, LEGO announced that beginning in January 2023 they would be adding characters to their LEGO friends set and TV show that include “varying skin tones, cultures, physical and non-physical disabilities and neurodiversity” with Down Syndrome featured prominently among them. Perhaps their decision was influenced partially in response to this message of inclusion.

Emma represented the best of Miss America. From me and all the parents I represent, I give our deepest thanks to Emma Broyles for being the ambassador of a message most dear to my heart. And with those thanks, I include the experiences that being part of the Broyles family gave her to serendipitously prepare her for this opportunity. It is true: The most important thing in a crown is the woman who wears it—along with the family behind that woman!

Letter from the President Tristan Gorski

Letter Intent: Hello, members and friends of The Alaska Down Syndrome Network; my name is Tristan Gorski. I have been presiding over the Board of Directors for our network over the last 3 years and have fielded many questions about what this board does and how we make decisions. As I've answered these inquiries, I started to realize that many of you might have similar questions, so the intent of this letter is to inform our members how AKDS functions and to ask for your help!

My Time As President

During my time as President, the network has gone through many challenges: the peak of the COVID pandemic, an IRS audit, a crashed website, hacked emails, and we've also seen big changes in our Board structure, as all senior members have officially retired. Though we are sad to see them leave, it is a healthy transition as we learn to find our footing. But we are not quite there. I must be completely honest with everyone reading this letter. Over the last 3 years our Network has almost dissolved on two different occasions. Further, many of our social offerings have declined. We've stopped sending the newsletter (until now), our website is outdated, and we have struggled with communication to members. These realities have us wondering what the future holds for this organization. There are many things I wish we could do better, but it's important to understand a little context.

Origins, Who are We, Revenue

Simply speaking, the Alaska Down Syndrome Network started 30 years ago as a collection of families with the goal to "connect" "support" and "advocate" on behalf of people with Down Syndrome and their families. Donna Davidson and a group of other parents founded the original Board of Directors. They set the Network up as a non-profit 501c3 organization to be run by volunteers. Through the years we have collected several sources of revenue. Pull Tabs has provided the largest amount of yearly income. Other sources include membership fees (and if a member can't afford dues, they are waived), charitable donations, and profits from events like the Walk for DS. The money earned each year is enough to help pay for events, functions and scholarships. One thing I've learned, thanks to our prior board members, our revenue stream is relatively consistent year to year. Many other nonprofits struggle to achieve this same

result. This sets us apart in a really good way: we can afford to put on our same events each year and pay for annual scholarships for our members without the challenge of fundraising or grant writing. However, a sobering reality to note, if the network were to dissolve, we couldn't regain our revenue stream as it is now. Future efforts on behalf of the Network or Alaskan's with Down Syndrome could be hindered by this reality.

The Board of Directors

The Board of Directors make decisions about how the budget is set and money is spent. Each decision affecting the budget is made with a vote and each board member has 1 vote. Furthermore, the Board of Directors is governed by the Network's bylaws. These were written long before my time and they are the rules for how the Network runs. It is set in our bylaws that new board members be voted in by the members at large, and that was the electronic vote we had this last December. As you can imagine this is a huge responsibility, one that prior boards and the current board take very seriously. Some words of assurance; two years ago, our Network experienced a federal audit for the first time. The federal auditors were checking to make sure our organization was functioning in compliance with federal laws that govern 503c3 nonprofits. And fundamentally what the auditors were looking for is how the Board of Directors is managing the organization's money—if the money we earn each year is spent in the way specified by both our bylaws and our mission. For the record, we passed our audit with flying colors, and I believe they were looking back as far as 10 years.

Realities of a volunteer board

Despite having passed this audit, we as a Network and our Board of Directors function well in some areas and poorly in others. And this is ever changing, mostly because we are solely run by volunteers, which means we cannot expect volunteers to give more than they are willing and able. I can ask, but if no one answers the call there is not much that can be done. **We have a persistent problem: finding people willing to commit the time required to volunteer by either being on the board or helping in a committee.** Network offerings only happen when someone volunteers. The honest truth is we struggle finding people to come forward and help.

Where we need help

First, thank you to all past or present board members. Board members by far commit the most time to this

Network and end up shouldering a disproportionate amount of work. Second, **WE NEED VOLUNTEERS.** Our Board is made up of committees and each committee needs help. Our biggest events, The Walk for Down Syndrome and Christmas Party, need both same day volunteers (set up, take down, manning tables) and organizers (committee members to help coordinate and plan the event). **Our Social and Volunteer Committee** need individuals willing to head up new events for all ages. This Committee is an area where our potential is great, but offerings are limited, I can't stress this enough. These events don't need to be complicated: summer park playdates, parent support groups, toddler groups, adolescent games or dances, coffee hour, talent shows; the only limit is willing hands. We also need volunteer coordinators for our **Education Committee.** This does not require you to be a professional educator, but just a curious individual with time to coordinate and set up a venue of learning. We need help in the **Membership Committee.** We need to re-coordinate with regional area representatives so to give a better voice to rural Alaskans with Down Syndrome. We need community ambassadors to attend city and private events as advocates. We need help managing our website and social media accounts. This list is not exhaustive, and I hope it gives an idea of where you could help. Please respond to this and bring whatever you can offer to the table. If you have suggestions, please reach out to us. Below is an email or for those who work better old-school, please feel free to call the number and leave a message. We will call or email you back.

Letter End

I want to end this letter with assurances that currently this Network is not at risk of dissolving, but there is never a guarantee. This year's board of directors and committee chairs are rising to the challenges, but there are still holes that need to be filled. Also, this will be my last year as President. In addition to completing my 3-year term limit, my family is potentially moving out of state, but as of yet there is no one willing to step into the role of President. With that said, the year is young, and I have all confidence a solution will arise, but not without your help. On behalf of myself and the Board of Directors, we thank you for your continued support in this Network and we look forward to seeing and hearing from you throughout the year!

Tristan Gorski
President
Alaska Down Syndrome Network

Once a year our members with Down syndrome are eligible for a \$250 scholarship.

This scholarship can be used for activities, medical expenses, equipment, etc.

Examples of the many ways our members have taken advantage of this benefit include equine therapy, skis and other sporting equipment, gym memberships, nutritional supplements, communication devices, adaptive clothing, and fitness trackers.

To apply for your 2023 scholarship, fill out the form found on the website, include a copy of your receipts for reimbursement and return it to alaskads@gmail.com or mail it to the address on the form.

Nice To Meet You...

Say hello to my daughter, Mia Grace. Born in 2020, Mia's gift was to bring this world joy. Pure. Joy. She won't stop smiling ... and I'm okay with that! She's recently found herself. Her hands, her sign-language, her voice, her brain, her understanding, her wiggling of toes, and her concept of left and right. It's soooooo amazing to see life unfold. I can't believe it she's



almost a 'threenager'! She's rarely defiant, but always picks the perfect times to tune me out so she can tend to what is most important ... which is whatever she is playing with or working on or curious about. This girl is curious!! Mia loves to figure things out. Puzzles. Toys. Phones. Food packaging... Ah, yes, speaking of food. Mia is a foodie. Eats EVERYTHING (that's edible). Asparagus, eggplant, brussels sprouts, smelly cheeses, and way, way more. She even went back for more hot sauce the other day!

Mia Grace, here are some things I love about you: I love how you stare at me. You sit my lap and calmly stare at my face, observing features and sharing connection. I love how you communicate with me. Sometimes with your eyes, sometimes with your signing, and sometimes with a yawn filled with your tired success. I love how you never stop moving. Ha-ha ... because that reminds me of me! I love how you participate in everything that we do. I love how you mimic and challenge yourself in the details of life. What I love most is how you choose to be you--how you love your family and your friends and your community around you. How you love your teachers and class-mates. How you love your dentist and therapists and doctors. I love how you teach the world around you by bringing them joy. Thank you. You give me joy and that fills my whole bubble. -Dad

Meet Bobby Hill. Bobby has trained and competed with Special Olympics for the past 34 years in athletics, basketball, bowling, floor hockey, golf, and powerlifting. He will represent Special Olympics USA in powerlifting. Bobby represented Alaska in the Special Olympics World Games Dublin 2003 and in the Special Olympics World Games Shanghai 2007. Bobby will be going to Germany this summer for Special Olympics.

Bobby regularly attends University of Alaska Anchorage hockey games and is a super fan of the Alaska Aces, a former professional ice hockey team. He is famous for his signature "Horseman" routine, which he performed at every home game for 16 years in 2015 he was chosen to the Alaska Aces Hall of Fame for the number 1 fan. In addition to all of this, Bobby somehow managed to find the time to complete his Eagle Scout. Thanks, Bobby, for being such an inspiration to all of us!

Bobby Hill with Team USA



If you would like your DS Family member to be featured in our Nice To Meet You... section, please email a few pictures and either a write up of them or enough information that we can write about them. We'd love to get know all of you!

Meet Reilly F! Reilly is a boy that has a ready smile for everyone. One of his favorite pastimes is helping his parents in the kitchen. Currently he is a fifth grader where he's very helpful and empathetic to the other students. He is doing inclusive PE and has joined the after-school ski club. Reilly is very athletic and participates in soccer, gymnastics, swimming, basketball and skiing in Special Olympics. When not busy with Special O, he is in boys' gymnastics at Arctic gymnastics.

Some of his great loves are music, sports-as you might have already guessed- and his dog, Rider. He's a regular at University Lake Dog Park, where he greets everyone and wants to know the names of each dog he passes. Another of his passions is caves. He loved visiting Laurel Caverns. During that experience, he went 17 stories underground and saw a waterfall. The next time you see Reilly at a AKDSN event, say "Hi" and enjoy one of his smiles.



Reilly and his best friend, Rider!

Reilly F. loves swimming



The **National Down Syndrome Society (NDSS)** designed the **321go!** program to promote healthy lifestyle choices in physical activity, balanced nutrition, and emotional wellness among individuals with Down syndrome and their families. The foundation of the **321go!** program is a set of 3 goals and 21 challenges that encourage a daily focus on overall wellbeing. Resources for the program provide education, support goal setting, and foster independent skills. NDSS recommends a minimum of 8 weeks for your **321go!** journey. Check it out at: <https://www.ndss.org/321go/>

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Stone Soup Group ★

Supporting families who care for children with special needs

STONE SOUP GROUP 2023 PARENT CONFERENCE MARCH 23-24, 2023

Stone Soup Group (SSG) is a statewide non-profit organization created in 1992. Parents and caregivers of children with special needs came together to found an organization that offered collaborative and family-driven assistance to other families because they realized that often the most helpful support they received came from another parent, not a doctor or a specialist who was caring for their child.

Almost all of our staff and board of directors are parents or siblings of children with intellectual/developmental disabilities. Because of this personal experience, we are familiar with available community resources and supports and are able to help guide other families as they navigate life with a child who experiences disability.

Each year, SSG hosts a Parent Conference where we bring families and the professionals who support them together to learn about tools and resources that promote healthy development and strengthen support networks. The 2023 Parent Conference will be held March 23rd & 24th at the BP Energy Center in Anchorage. The theme, "What's In Your Control" came about after reflecting on the last three years of life in a pandemic. Our lives have often felt very out of control during this time and it's our desire to help families see what is in their control and how they can focus their energy and efforts on those things.

The conference will feature guest facilitator, Pete Wright, who is a special education attorney empowering families to be advocates for their children in the classroom. Special education services can be very complex and can feel very overwhelming. Mr. Wright's presentation helps families to know what to expect when their children start school and how to have a strong relationships with their children's schools.

We are very excited for this year's conference to be an in-person event. It'll be our first since 2019! We will have 2 days of educational presentations and will have representatives from other service providing organizations join us to share about ways they support families. We are offering travel scholarships for families who live outside of Anchorage. Registration and scholarship information can all be found on our website www.stonesoupgroup.org or you can call our main number at 907.561.3701. We hope to see you there!

For information about all of SSG's upcoming events, please visit the Community Calendar on our website and don't forget to follow us on facebook!

Mary J Middleton
Executive Director
Stone Soup Group

BP ENERGY CENTER ANCHORAGE By Mary Middleton

New Board Member

Meet our Membership Chairman. Sara Montgomery has been in Alaska since 2013 working as a physical therapist at All For Kids Pediatric Therapy Clinic in Anchorage. She loves working with children through play-focused sessions and providing outdoor sessions, hippotherapy, and group therapy. She has volunteered for many Down Syndrome events over the years, including the annual walk and the Christmas party. She also participates in MDA events, Autism Awareness Month, Special Olympics Healthy Athlete Screening, acts as the current State Liaison for the American Physical Therapy Association (APTA) Pediatrics, and is a member of the Diversity, Equity, and Inclusion APTA Pediatrics committee. She is passionate about helping kids grow and participate in all that Alaska has to offer! On a personal note, Sara loves to ski, snowboard, backpack, and fish. She has participated in multiple half Ironmans and many local triathlons. Sara is excited about this opportunity to serve the community of Anchorage!

AKDSN Calendar 2023

Feb 1: Registration opens to all DSDN Rockin' Moms™ on February 1! (Destination: San Antonio, Texas)

Registration opens to all DSDN Rockin' Dads™ on February 1! (Destination: St Louis, Missouri)

Feb 18: Bowling @ Dimond Bowl

Feb 28: Transition Series – Transition Age Youth and Benefits: WIPA & Disability Benefits 101

Mar 18: Rock Gym

Mar 21: World Down Syndrome Day

Mar 28: Transition Series – Self Employment, DVR and Tribal VR

May 13: Swimming @ West High

April 25: Transition Series – Assistive Technology

May 20: Special O Annual Torch Run

Jun: Annual Family BBQ*

Sep 9: Swimming @ Chugiak High

Oct 21: Rock Gym

Nov 4: Bowling @ ER Bowl

Nov: Annual Member Meeting*

Dec: Annual Christmas Party*

*Check our website or Facebook for more details

Runs for a Purpose

World Down Syndrome Day Run/Walk (runsforapurpose.com)
Registration deadline to receive a shirt is February 25th.

Pals Socks

Let's be Pals – Pals Socks (palssocks.com)
Order socks earlier for delivery before WDSD!

Members At Large

Also need members to fill **Committees** (but are not voting board members). Ideally thought of as steppingstone onto the board.

- Social Volunteer
- Newsletter
- Walk for DS (Formerly known as Buddy Walk)
- Christmas Party
- Education
- Website
- Social Media

If you are interested in writing an article or submitting pictures of your child for the Newsletter, we'd love to hear from you. Send your submissions and ideas to: martibolan@hotmail.com

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Emma Broyles, Miss America with her brothers.



Emma Broyles with her brothers as kids.



Emma Broyles, Miss America with her family.



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Assets Printing designed and printed this issue!

Are you a school district employee assisting families of children with disabilities?

This issue comes to you as a courtesy from the Alaska Down syndrome Network. Please read and pass on to a family or fellow educator.

Join us for a \$25 membership at akdownsyndrome.org hover over “Connect,” then click, “Membership.”

