

The Sun is Always Rising

Newsletter of the



May 2023

Pay It Forward By Marti Bolan

Twenty-five years ago, my son, Caleb, became part of our family. I vividly remember all the feelings that came with the diagnosis of Down Syndrome: I was shocked as I went through the painful and difficult process of burying dreams. At the time, I lived in a small town on a reservation in the Southwest. There were no support groups. Fortunately for me, I lived in the middle of the best accidental support group a mom could have: My neighbor across the street had a son with Down Syndrome, my neighbor beside me came from a family that had several disabilities.



Friends and family were supportive and caring as our little family learned to navigate the new normal we had become part of. Every day was a learning experience that broadened my horizons as I fell in love

my sweet Caleb. Alexander Graham Bell said “When one door closes, another opens but we so often look so long and so regretfully upon the closed door, that we do not see the ones which open for us.” I tried to make sure I looked for the new doors that opened in my life because of Caleb.

A couple of years into this journey, my son’s pediatrician asked if he could pass my name along to a mother that had recently given birth to her Down Syndrome son, who was feeling alone and needing support. I was honored to be asked and became a mentor to her sweet family. As we became friends, I was able to make a difference in her life and help ease her concerns while she, too, learned to embrace the miracles of Down Syndrome.

Over the years, I have had the occasional phone call from different friends: They inform me that they have had a family member born with Down Syndrome and would like advice. Again, I find it an honor and privilege to be able to share the things I have learned along the way. In doing so, I cannot help but reminisce about my experiences with the wonderful people who were there for me as a new mom, in the sometimes-overwhelming new world of disabilities I found myself in. I feel a deep sense of gratitude for all that they did to help me in my new and unexpected circumstances. I know I can never repay them, but I can pay it forward!

The few experiences I have had with this have taught me that everyone can help make a difference—the things we do don’t have to be big—little things are what makes the world a better place.

I recently learned that Stone Soup Group has a parent mentorship program called MAP (Mentor Advocate Partner) Program. They connect families in need of a mentor with families willing to be a mentor. Unfortunately, there are far more families needing mentors than they have mentors available. They actually have a waiting list. When I heard this, I wondered how many people, like myself, were entirely unaware of this need. Mentorship is something that everyone is capable of. I have both been mentor and mentee. Each role has improved my life, introducing me to different resources and ways of learning and allowing me to help others in my journey. Each role has been incredibly rewarding and fulfilling. Mentorship can be as simple or as involved as you are comfortable with.

For more information on this program, take a look at Stone Soup Group’s information page at: Stonesoupgroup.org under the Connect tab. You might find yourself opening a new door in the wonderful journey of Down Syndrome!

Downside Up

Downside Up is a short 15-minute video that reveals a world where everyone has Down Syndrome. One day, Eric is born, a boy who’s different. Enjoy this short sci-fi comedy movie on YouTube.



Letter from the President Tristan Gorski

Hello members of the Alaska Down Syndrome (AKDS) Network,

We are off to a great start in a potentially stellar year. In addition to the traditional social offerings specific to our organization (see our website or Facebook for details), there are a few notable events and opportunities that though not hosted by us, are worth mentioning.

The 2023 Special Olympics Law Enforcement Torch Run is happening May 20th in multiple locations across Alaska. Matt Fraize, a board member, has been working with Special Olympics for several years to make this event happen. This 5K run is incredibly fun and represents a strong affirmation of support and interconnectedness for the Alaskan athlete with special needs. The AKDS Network is planning to host a table at the Anchorage Torch Run location. We invite any member interested in volunteering to come sit with us (like a backstage pass) and help represent the Down Syndrome community.

The 2nd opportunity is a mentorship group hosted by Stone Soup Group, MAP Parental Mentorship Group. The goal of this group is to pair experienced parents with inexperienced parents regarding raising a child with special needs in Alaska. Mary Middleton,

Coming Up...

The Walk for Down Syndrome will be on July 8th at the far west end of the Delaney Park Strip from 12pm-3:00pm. Lunch will be provided, along with free activities & door prizes. Vendors booth open to rent: \$100 if selling goods or free to businesses/organizations giving out information. Sponsorships are available at different levels; if you know a business/organization that is interested, please pass along this information.



the Executive Director of SSG (who also sits on our board) has inquired about recruiting more families to help fill their pool of experienced mentors. Each of us are experts of our own experiences and this is an amazing opportunity to impart some of that invaluable experiential knowledge to new families wishing for guidance. I believe the human super-power is information sharing and this is especially true in our community: We are stronger together.

If either option is of interest, send an email to Alaskads@gmail.com and put in the subject heading "mentorship" or "Torch Run" and we will contact you. Also don't forget we could use your help in all areas of the AKDS Network; contact us for any questions, ideas or concerns. We look forward to seeing and/or hearing from you soon.

Tristan Gorski
President
Alaska Down Syndrome Network



Lovevery Toy Subscription Review

By Wendy Gorski

We found Lovevery during lockdown in 2020. Coda had stopped seeing his occupational therapist and I was searching for ways to help him progress even though I didn't know a thing about being an OT. Lovevery is a subscription company that sends stage appropriate boxes of toys designed to support brain development. Lovevery boxes are not low cost, as the toys are quality items. Because it was so expensive, I used Coda's AKDS scholarship to help pay for his kits. The boxes are age specific, such as 18-24mo, and though Coda was already three, as I looked through the descriptions, I thought many of the 12-month toys could still be helpful.

I reached out to Lovevery's customer support and they connected me to Coda's very own disability specialist. Maral asks questions about what Coda

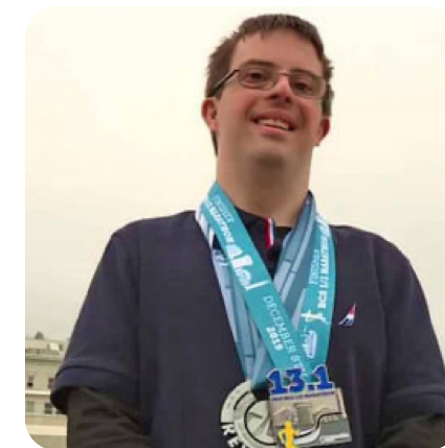
is currently doing and goals we have, then sends us his custom play guide that tells me how to work with the toys we've ordered (both past and present). She can send us boxes earlier or hold them if we need more or less time with the toys. Although lockdown is over and Coda sees an OT again, we still love every time we get that extra boost of support on our doorstep.

www.lovevery.com



Daniel Chaplino running marathons to raise awareness and support for Down Syndrome By Marti Bolan

In 2012, Daniel Chaplino, of Birmingham, Alabama, was in a health class at Samford University. The final exam was to complete a 5K. It was a major struggle for him. When he started preparing for it, he could barely run 25 feet. With training, he managed to



finish, taking over an hour to complete. He never thought he could run at all, as he spent his entire childhood overcoming health obstacles associated with Down Syndrome.

Since that time, Daniel has set the goal for himself

to run a half marathon in all 50 states. His first run was in Talladega, Alabama. This summer he will be coming to Anchorage to run the Mayor's Midnight Half Marathon, making Alaska his forty-fourth half marathon. In December 2022, with the help of his coach, Kevin Burke, Chaplino completed his first full marathon at the Rocket City Marathon. It was a very emotional experience as he completed something he never thought he could do. In November, he is

signed up for the New York City Marathon. Chaplino's interests are not limited to running: He is also a talented Ballroom Dancer, participating in Dancing with the Stars finale.

On June 17th, at the 2023 Anchorage Mayor's Marathon and Half Marathon, one of our members, Jackie McMahan, a NDSS Athlete Ambassador, will be running with him. If you are interested in joining, contact Daniel on his Facebook page. He'd love all the support he can get.



Summer Travel Plans?

Ted Stevens Anchorage International Airport (ANC) has a sensory-friendly family room in the South Terminal.

For more information, visit: ancairport.com/pr/anc-adds-new-upgrades-to-enhance-customer-experience/

Alaska Airlines offers accessible travel options.

For more information, visit: www.alaskaair.com/content/travel-info/accessible-services/specialservices-rights

Nice To Meet You...

Meet Alex Davidson! Alex loves his life (when we don't include all the medical issues he has had to deal with). He lives in a family assisted-living home with two other guys in our Network, who are his best friends. He has mild autism as well, which manifests particularly in severe language difficulties. He has a terrific sense of humor and is great to be around. When he is very comfortable with people, he becomes chatty. He loves sports and is quite active in Special Olympics, having participated in most of the Alaska sports over the years. This winter he is back to x-country skiing, loving to whoosh down the hills. He also enjoys the HOPE Community Resources art classes, doing a variety of painting. Alex works at the Hearts and Hands of Care agency, two mornings a week. Alex comes home many weekends and all holidays. We feel exceptionally blessed with him in our life! *By Donna Davidson*



Alex Davidson, age 38. He received good looking new glasses and was asked to stand like a model. He rocked it!



Esa McMahan is just turning 5 years old, she is the youngest of 4 children in her family. She loves giving hugs and smiles. Esa brightens everyones day, with just one of her smiles. She loves music and dancing and enjoys playing games like Tangrams, Hoot Owl Hoot, and Sorry. Esa loves to be outside, tumbling around with our dog, Oshie, and riding her sister's horse, Turner. She says she wants to be a barrel racer when she grows up! She also likes playing knee hockey, catch, and going on adventures with her family. She loves all animals and is very excited for the ducklings we are going to hatch. Esa's family spends their time in Palmer or Gakona. She very much enjoys and learns a lot through the therapy she attends at Backcountry Therapeutics and with her speech therapist, Molly, in Anchorage. Esa is an absolute blessing to her family and all those she meets.

By Ever McMahan, her sister



Hi, I'm Olivia G. from Bethel. I'm 11 years old and can't wait to be 25. I live with my parents, grandmother, and my brothers. I have a sister and nephew in Fairbanks. My favorite things to do are horseback riding, going to church, flying on Alaska Airlines, and spending time with my best friend, my grandma. I love going to school and my favorite class is ASL. I am happy and get excited about everything, especially when we have a party because that's "The best day Ever"!



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!

Did you know...

Did you know at Stone Soup Group, we record many of our live trainings and share them on our YouTube channel? Our YouTube channel can be accessed on



our website. The recorded trainings are captioned. Many are also translated into Spanish and some have been translated into Yup'ik. This is a great resource for families and the recorded trainings are viewable at any time.

Transition Series

The Alaska Down Syndrome Network and Stone Soup Group co-host the Transition Series each school year to help parents prepare for the transition to adulthood. We encourage families who have children of all ages to join us, because it is never ever too early to start planning!

New Board Member

Mary has been the executive director of Stone Soup Group since 2013 and moved to Alaska from Texas in 2001. Growing up an Army brat, she moved



frequently and still enjoys exploring new places. She is a graduate of Texas A&M University and has worked in nonprofit management for over 30 years. She has two children, including an adult son who experiences autism. Time away from work includes a spoiled dog, hikes and far-away travels.

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Summer Camps for kids with Developmental Disabilities:

Hillside Baptist Church is offering a special needs VBS June 23th through the 25th. It will be held in the evenings. There is no fee. A parent/guardian/caretaker must attend with the child. The online registration is available at hillsidebaptist.church and you can click on Twists and Turns.

If you're looking for a sleep-away camp for your child, you might want to check out **Solid Rock Bible Camp**. They have a FREE 4-day, 3-night camp for kids and adults with disabilities. Warning! It fills up quickly! <https://www.solidrockbiblecamp.com/lakeside>

Camp Shriver online registration is open now! For more info and registration, visit the Special Olympics Alaska page. This 2-week sports day camp is an inclusive camp. Athletes and partners participate in over 14 sports together while building friendships and memories that will last for many years to come. <https://specialolympicsalaska.org/programs/camp-shriver/>

FOCUS Summer Camp (Eagle River) - offers a summer day camp for campers 6 and older who receive Waiver and grant services.

Arc's Summer Work Program <https://www.alaskasnewsresource.com/2022/06/17/arc-anchorage-youth-summer-work-program-provides-job-skills-students-with-disabilities/>

Come enjoy our 10-week summer camp at the Lesko Discovery Center, part of **Hope Community Resources**. This year, camp will be hosted throughout the Anchorage area, heading out to the community to explore, to be outside, and to learn and try new things. This camp focuses on social, motor and listening skills, and on creating a fun and educational experience. Everyone ages 8-21 are welcome to attend! For those with and without Medicaid waivers. Scholarships available. hopealaska.org

The Calypso Farm and Ecology Center is a nonprofit farm that encourages food production and environmental awareness through educational programs in natural and farming ecosystems in Alaska. While they don't have a dedicated camp for kids with disabilities they do take kids on a case-by-case basis. Summer camps immerse children in life on the farm through play, creativity, and exploration. Campers explore the farm and Boreal forest, help with farm and garden chores, express their creativity with art projects, meet the farm animals, cook fresh vegetables, and snack their way through the fields! Calypsofarm.org

Sleepy Hollow Golf Alaska in Wasilla runs camps from May through August, focusing on a variety of topics such as golf, farming & agriculture and TREK. Some scholarships are available. They also have job opportunities for kids with disabilities. Sleepyhollowgolfak.com

Midnight Sun Golf Course in Fairbanks has a camp from July 31-Aug 4. Join us for fun games, golf, crafts, gardening, baking and more! Some scholarships are available. They also have job opportunities for kids with disabilities. Midnightsungolfak.com

National Camps:

PALS mission is to create inclusive camp experiences for people with and without Down syndrome. For 7 days and 6 nights, PALS participants engage in unique on-campus activities, explore the local sights, and experience life on a college campus – all the while building transformative, lifelong friendships and learning the true meaning of inclusion. PALS also offers a modified 5-day and 4-night program for participants during the off-season and for adults 25+ during the summer. PALS Programs.org

Our long-term vision for **Rising Light Ridge-Tim Tebow Foundation** includes serving individuals of all ability levels. Due to the current nature of our property, there will be certain limitations during our 2023 season. If you have any questions, please contact us at info@risinglightridge.org to discuss your campers' specific needs. risinglightridge.org

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.

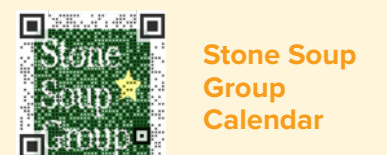
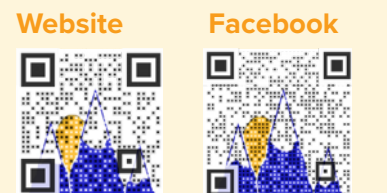
Examples of the many ways our members have taken advantage of this benefit include equine therapy, skis and other sporting equipment, gym memberships, nutritional supplements, communication devices, adaptive clothing, and fitness trackers.

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.



Interested in writing an article or submitting pictures? Send them to martibolan@hotmail.com

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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."

