

The Sun is Always Rising

Newsletter of the



OCTOBER 2020

OCTOBER IS DOWN SYNDROME AWARENESS MONTH!



Alaska Families During COVID-19

THE LINDBLOMS

When I think about the past six months of "hunkering down" for COVID-19, the first thing that comes to mind is spending a lot of time together as a family. Too much time. With two teenagers and a ten year old. Just us. All the time.



On good days we walk around the neighborhood – wave at an elder neighbor, pet our favorite dog, hike up moose hill, and observe the activity around bird nests along Cheney Lake. I love those walks with Karina (16). I talk, she gives a chuckle or side-long glance at appropriate times in my dialog, and we hold hands—a habit that we didn't have before COVID ended many of our activities.

On bad days we grumble at each other, moan about the rain, spend too much time staring at screens and sit in our bedrooms.

On good days Karina's brothers, Jared (14), and Caleb (10), help her with her math homework, play a game with her, or set her up on zoom calls for school or speech therapy. Before COVID her two younger brothers had slowly drifted away from her, busy with their own activities and boy things. But when their social calendar suddenly emptied, they slowed down enough to sit in her room and chat with her, or take her for a bike ride.

On bad days Karina sits in her room alone for too long, listening to music on her radio.

On good days we play games together in the evening, which is how we discovered that Karina is quite good at dominoes, if they are color coded. She amazed us with her thoughtful placement of each domino.

On sunny good days we go for family bike rides, which have been made so much easier with the new Buddy Bike Karina received in the spring. She was awarded a grant through Stone Soup and we enjoy using this tandem bike. She loves to bike to local playgrounds and swing, or go on a favorite ride in Portage Valley along The Trail of Blue Ice.

Once a week in the summer our good days included putting on masks and bowling with friends, using Kids Bowl Free coupons. I hadn't bowled with my kids in years. I discovered that Karena knew quite well when it was her turn, thank you very much, and just dropping the ball works just fine.

There are lots of good days and quite a few bad days during this strange time of COVID, but it has taught us a lot more about each other, and for that I am grateful.



The Alaska Down syndrome Network Continues During COVID-19

For months now Alaska has moved through the maze of COVID-19. As families and caregivers, we adapt to changing information, conditions, and restrictions. We deal with new issues and attitudes. We make decisions on what is best for our family.

Local governments, schools, and organizations, also struggle to decipher the wealth of information as they plan a safe course to help families. So too, does our own Alaska Down syndrome Network. This past spring and summer, the board followed state social distancing guidelines, and decided to revamp events. The AK Walk for Down syndrome went virtual; the annual picnic cancelled.

The board considered ways to help our members while avoiding large gatherings. Potential on-line opportunities were discussed. Please stay tuned for more information on trainings and possibly an annual meeting.

Families should know that despite a low profile during the pandemic, we are still here for you. We recognize the diversity of our families, where they live, and the issues they face. We want to help. We need your input to do just that. Please let us know ways we can help you.

One way the board voted to help families was to increase the 2020 scholarship amount to \$500. Families please apply for and utilize these funds. (See information to right).

President Michelle Hoffacker resigned this summer and the board appointed Tristan Gorski as Interim President. Several board positions remain open. In order to conduct our business and provide the best for families, we need a full board. Please consider taking a turn to volunteer. Members from rural communities may be able to zoom in for meetings. If interested, contact Tristan.

The board considered current COVID conditions, along with State and CDC recommendations, and decided it best to cancel all group social activities until further notice. These events include; our Annual Meeting, the Christmas Party, bell-ringing with the Salvation Army, and any other social gatherings such as dances, swimming, rock climbing, or the toddler group.

The 2021 Summer BBQ and the AK Walk for Ds remain unscheduled at this time. We hope to resume all activities as soon as safety is assured.

SCHOLARSHIPS

The Board invites all members to apply for a 2020 scholarship for up to \$500. If you already applied for a 2020 scholarship, you may reapply to utilize the entire \$500 amount. **Applications are due no later than December 1st**; one is included for you in this issue. Items purchased should be used for the direct benefit of the person with Down syndrome,



Ideas for scholarship are many and varied. You could purchase a stroller or backpack. Exercise equipment like Courtney's water rower (above), a treadmill, bike, swim gear (snorkel, special goggle), skis, skates, or boots are all ok. You could apply for therapy items such as special chairs, balls, ergonomic utensils, and orthotics.



Lessons may be included like piano, art, karate, and dance. You may submit for media items or upgrades such as a new device or online learning tools. Specialized clothing needs are also acceptable.

The easiest method is to reimburse families for their purchases. Receipts must be submitted along with the application. If this is not possible a check may be written directly to the business/ vendor.

The National Down syndrome Society (NDSS) posted the following Preferred Language Guide on their website www.ndss.org

DOWN VS. DOWN'S

- NDSS uses the preferred spelling, Down syndrome, rather than Down's syndrome.
- Down syndrome is named for the English physician John Langdon Down, who characterized the condition, but did not have it. An "apostrophe s" connotes ownership or possession.
- While Down syndrome is listed in many dictionaries with both popular spellings (with or without an apostrophe s), the preferred usage in the United States is Down syndrome. The AP Stylebook recommends using "Down syndrome," as well.

Sarah Marie Thomas
9/22/15 to 5/30/20



Sarah lived 4 1/2 beautiful years on this earth with us. She never formed a full sentence, only verbalized a few words, but she taught us so much in her little life. Sarah was a light and full of happiness

everywhere she went, we always called her the "family favorite" and no one ever questioned that title.

Sarah was diagnosed with AML leukemia a week after her 4th birthday, she fought so hard, receiving 6 round of chemo, but the cancer was too strong for her little body. She passed in her daddy's arms, with mom, brothers, Asher and Elijah, and her Safta (grandma) kissing and singing her nighttime songs to her.

Sarah's favorite things to do was watch football with daddy, dance with mom, push her big brothers around, watch signing time, eat chicken nuggets and popsicles. Her favorite therapy was swimming, least favorite was speech (halacha). She loved to swing and slide at the playground, and throw the ball for the dog.

We ask that you do a random act of kindness in honor of Sarah, passing along this card for her light to continue to shine.

Global Down Syndrome Foundation Provides Information on COVID-19 and Down syndrome



For insight into health issues for people with Down syndrome and COVID-19, the Global Down Syndrome Foundation published a complete list of helpful **Questions and Answers** for families and caregivers. For the full text, visit <https://www.globaldownsyndrome.org/covid-19/> and follow links to their FAQs.

We encourage families to read the full document and offer the following very brief guidelines summarized from the Global Foundation's Q & A resource. In addition, families may access current information from these sites that pertain to all people and COVID; Center for Disease Control (cdc.gov/), the National Institute of Health (nih.gov/) and our own Alaska State Department of Health (dhss.alaska.gov).

COVID affects people with pre-existing conditions more than others. Some people with Down syndrome have these conditions (such as sleep apnea, respiratory illness, kidney or heart disease, and diabetes). Individuals that live in group homes or long-term care facilities may also be in a higher risk category.

If you or a family member experiences mild symptoms, (coughing, headache), CALL your doctor. If you or a family member experiences severe symptoms (such as difficulty breathing), call a doctor, hospital or 911.

GLOBAL urges families to follow local guidelines as a **minimum** precaution to decide when people with Down syndrome should return to normal activities. Pre-existing conditions should figure into that decision, as well as the individual's ability to socially distance and wear a mask.

GLOBAL recommends that families practice 20-second hand-washing skills, maintain social distancing, and wear a mask in public. Global also offers suggestions on how to help individuals with mask aversions.

Random acts of kindness for

SARAH

9/22/15-5/30/20

SARAH MADE THE WORLD A BETTER PLACE. LET'S CONTINUE TO SHARE HER LIGHT THROUGH KINDNESS. COMPLETE A RANDOM ACT OF KINDNESS AND PASS THIS CARD ALONG TO YOUR RECIPIENT.

#SUPERSARAHFOREVER

ARE YOU ON THE BONE MARROW REGISTRY? VISIT BETHEMATCH.ORG TO REQUEST YOUR SWAB KIT.



FAMILIES REPORT ON LIFE DURING COVID-19

From the Editor

Much thanks to the families who took the time to write a piece, share information in a phone interview, or email a photo. We had more articles/photos than space. My apologies for the edits. As always, I am surprised by the attitudes and perspectives of our families. Families shared, that at least in part, they survive shelter-in-place because they live in Alaska. Access to the outdoors improved their mental health. Walking and hiking topped the list. To my delighted surprise every person relayed something positive that has occurred during COVID, many without prompting. I hope you enjoy their stories as much as I enjoyed talking with our members.

The Stahls hail from Talkeetna. Mark owns and operates Denali Log and Lumber. Sandy homeschools son Nathan, now 12. Four older sons and daughter, Amanda, a senior at UAF, round out the family. Sandy felt guilty to admit how little they have been affected by COVID. Perhaps location, circumstances, and attitude contribute to that. You be the judge.

Sandy reported that the building business slumps in March and April, so that was expected. She claimed they are more affected by the spruce bark beetle than any business restrictions due to the pandemic.

Nathan, already homeschooled, saw little change in that regard. Occupational therapy sessions, two times a week in Wasilla, that included swimming and horseback riding, were discontinued. Nathan and Sandy moved to teletherapy once a week via laptop. Sandy called it "challenging." Easy to see the comparison of swimming/horseback vs. fine motor on a computer. Around the end of



May, restrictions eased and Nathan returned to his Wasilla bi-weekly visits.

Amanda, a Resident Advisor at UAF came home for spring break and returned to school as scheduled. Shortly thereafter, UAF closed and Amanda returned home until start of the fall semester. Sandy said a benefit of COVID was the extra spring month with her daughter. Amanda, back in Fairbanks now, attends mostly on-line courses.

Sandy shared that one adult son, age 26, who lives in Fairbanks, contracted COVID along with several friends. They were tested and quarantined as required. She said her son had a headache and was tired, but recovered.

Like many families, the Stahls did not fly south to visit family as usual this year. Nathan enjoyed being outside whenever he could, to play on his trampoline and hammock, and to take walks. Sandy stopped taking Nathan with her on shopping trips or to run errands. Masks are not required in Talkeetna

Sandy believes it's most important to keep a positive attitude.

The Bakers, Ashley, Becky and Larry, live in a quiet neighborhood on the edge of Palmer. Larry works on The Slope, Becky recently retired from Valley Volunteer Extraordinaire and Ashley, age 26, everyone on their toes. Daughter Kasie is finishing up a doctorate in biochemistry in Oregon.

In March, the Bakers returned from a trip to Florida just prior to the required quarantine for travelers. Larry stayed home in March, worked all of April and is back on two weeks on, two weeks off.

Ashley normally receives supported living, day hab, and respite services several times/week. All those ceased with the shut down. I Love Bowling stopped. Bingo stopped. Trips to the gym stopped. Valley Super Stars stopped. Ashley and Becky concentrated on home projects.

Eventually, services morphed into some home visits. Ashley took up sewing, bought a sewing machine, attended her first quilt retreat (as





a quilter) and is working on a quilt! See her colorful apron!

Ashley also began cooking more. Becky reported worry that Ashley might cut herself, but said that

Ash is a safe cook. She loves to make tacos and spaghetti. Ashley won't chop onions.

Meanwhile at Oregon State, Kasie stayed safe and taught classes by zoom.

By mid-June, more activities returned with limitations. Superstars initiated smaller class sizes and outlined dancer space. Ashley returned to the gym only once a week with a personal trainer. No bowling programs have begun, but the local lanes are empty, so Ashley practices once a week.

Becky concedes their biggest loss during COVID is the ability to travel. An array of family travel plans cancelled due to both COVID and fires in the lower 48!

Most days Becky claims Ashley, "...is a trooper. But it's hard for her not to give and get hugs." Ashley is aware of the pandemic, washes her hands, uses hand sanitizers, and wears a mask when required.

When asked what helped her and her family during COVID, Becky replied "We stopped watching the news."

Hunker down for the **Peterson Family** began in March when pre-school shut down for both Kyle (3) and his big sister Sydney (4 ½). Merlin, a Civil Engineer with the US Army Corps of Engineers, began working from home. The family set a routine that incorporated Merlin's schedule, a homeschool agenda for two preschoolers, and Kyle's multiple therapy sessions. Isolation was not new to this family, as both Kyle's birth and heart surgery at 6 months of age required long periods of family quarantine.



Shutdown required Kyle's Speech, Physical, and Occupational therapy sessions to go online. Despite excellent therapists and pre-planning, the sessions did not translate well through laptop. Melanie received good information and access to staff, but Kyle's age and development prohibited a good learning experience for him.



Sydney was a great example to help Kyle with homeschool studies. Painting and reading were some of their favorite school activities to do together."

An outdoor-loving family, the Petersens looked to Alaska for fun. They hiked in Eagle River to access the water and glimpse wildlife. Kyle likes to throw rocks, and get wet and dirty.

The family took Kyle on his first canoe adventure to Fire Lake. They drove to Eklutna Lake with grandparents in tow and hit the trails with their ATV and UTV. After the first restrictions lifted, they visited the Alaska Wildlife Conservation Center for a wonderful up-close and personal with the animals.

Kyle and Sydney returned to pre-school in June. The social interaction motivates Kyle to walk and communicate. Excited to resume in-person therapies, Kyle likes to see the faces of his therapists. It's a challenge for him to learn how to speak and understand non-verbal communications with masks.

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MEET TIM GORSKI, NEWLY ELECTED INTERIM PRESIDENT



My name is Tristan Gorski and I have served on the board for about two years. I have the privilege of stepping up into the role of president. My goal is to see the Network through these interesting and difficult times.

I am a life long Alaskan, spending only about 8 years in the lower 48 while attending college, first in Missoula Montana where I met my wife Wendy, later in Portland Oregon while attending nursing school. Portland is also where we started our family. After nursing school I tricked Wendy to return to Alaska with the

promise that we would only stay 3 years. A decade later, we are still here. We have four children.

Wendy stays home with the kids, is an outdoor enthusiast and enjoys photography and writing. Atticus, our oldest at eleven, likes skiing, Dungeons and Dragons and pranks (which are not always funny). Tesla is nine, a detail-oriented artist, and a skilled skier who loves it when her sister borrows her clothes. At seven, Wren frequently calls her siblings 'mutton heads', collects Calico Critter toys, and secretly loves being forced to ski.

Coda, now almost four, enjoys saying the word 'door' and frequently opens and closes them. He also gets a kick out of throwing items off of any accessible surface. Like his older brother, Coda likes to laugh and play pranks which include sneaking out the front door and crawling away as fast as he can. Luckily, he can't walk yet, but we're working on that skill. Even more terrifying is when his tricycle is left out (ten times the distance in a fraction of the time)). Coda has Down syndrome and he is this family's induction into the world of special needs.

I work as a nurse at Providence Hospital in the Emergency Department and enjoy my work most of the time. I am an outdoor enthusiast and have been my whole life. Starting from cub scouts as a kid, I moved on to become a ski instructor during high school; and later learned the ropes of rock climbing and joining my college's outdoor program as a climbing instructor. Currently I coach Jr. Nordic skiing in the winter and youth mountain bike in the summer. My newest seasonal activity is hunting. This year I went for a caribou twice to date and still my freezer is half full of fish and blueberries only.

When getting my family out in the natural world I liken myself to the role of 'alpine guide on Mount Everest', except my clients (kids) cry often, bicker endlessly, need help going to the bathroom, and don't pay me.

WELCOME TO THE BOARD!



The Bagg Family, left to right, Chris, Kyle, Sheryl, Nicole, and Charlie.

Meet Sheryl Bagg who joined the board as Social Chair some months ago. Her family includes husband, Charlie, a real estate agent with Keller Williams in Anchorage, and children Nicole, Christopher and Kyle.

Sheryl's brother lives in Anchorage so with job and recreational opportunities awaiting, they made the move from Illinois to Alaska in 2010.

Nicole graduated from Dimond High and now majors in Criminal Justice at UAF. Chris graduated from Service High

School and attends the ACT program. Kyle is a sophomore at Dimond who races motocross.

As a family, the Braggs like to hike, snow machine, and sight see.

Karen Schudel invited Sheryl to the Board and upon consideration Sheryl knew it was a good time to join and give back to the group. As Social Chair, she looks forward to planning fun activities for the group.



PHOTOS IN THIS ISSUE *(not identified in a story)*

Page 1, The Lipse children from Wasilla, Angler 6, Hadassah 1 1/2 and Rill 4.

Page 2, Courtney Fleischman at the rowing machine. Pearl Weaver, during a piano lesson. Both young ladies using their ADSN scholarship.

Back page, Nixon Lane, age 4, excited about his find along Kachemak Bay. Hadassah the little leaf girl.

Dylan Harrop with Rosie, look at those smiles!

Kyle Petersen safely seated for a family UTV ride.

Ashley Baker presents steak dinner.

Alex Davison enjoying a sunny summer kayak.

Tyler Bennetts of Anchorage with his first spruce hen.

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BARNES & NOBLE
Bookfairs
 October 17 at 10am (AKDT) through
 October 23 at 10 pm (AKDT)

Bookfair for AK Down Syndrome Network

Our annual book fair is happening! It will look a little different this year. No in-store festivities but you can support our group at ANY Barnes & Noble. Shop in-store, call and arrange curbside pick-up, order online at <https://www.barnesandnoble.com> and use the, "Buy Online Pickup In-Store" option, or have your purchase shipped to you. Please use our book fair ID #12599973 when ordering online or mention our book fair at the register when shopping in person or on the phone.

