October is DOWN SYNDROME Awareness Month!

The Alaska Down Syndrome Network enjoyed a summer of fun activities, including the Alaska Walk for Down Syndrome and our annual summer picnic at Meyer Lake.

JOIN US FOR OUR ANNUAL MEETING Thursday, Nov 14th

Come for dessert
enjoy the movie shorts
meet your board &
give your input.

What would you like the Alaska DS Network to do?
We love your input!

The meeting is short, so you can get back home on a school night, and it won’t interfere with weekend plans.

7:00 Ice cream & Conversation
7:30 Movie shorts
8:00 Meet your Board and tell us what you would like in the coming year.

Join us at the Anchorage Baptist Temple. Please use the “Church Offices” entrance.
Thank you so much for the generous scholarship this year and last. We used the money to buy Ice Bug studded running shoes and new nordic skis. Being active is helpful to both physical and emotional health, and having the right equipment makes all the difference! Ice Bugs allow Courtney to run and walk even when conditions are icy and dangerous outside. Nordic skis mean that she can stay active all winter long and participate in Special Olympics.

Thanks again for your assistance.

from Wendy Leseman

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**Barnes & Noble Book Fair**

The Alaska Down Syndrome Network and Barnes & Noble Anchorage have a fun day planned for YOU!

**SAT., OCT. 19—10am - 5:00pm**

- 11:00 am & 3:00 pm — Storytime
- 1:00 pm — Craft (to go along with storyline reading of *Paint the Octopus Red*)
- 3:00 pm — Scavenger hunt (for older children & teens).

In addition, from **October 19th through the 24th**, if you purchase something at ANY US Barnes & Noble store and tell the cashier you are shopping for the **AKDS Bookfair**, our organization receives a percentage of the sales! Or place an on-line order and choose the AKDS book fair at check out.

You may purchase from the coffee shop, books, music, games, puzzles, toys, stationary, cards and more.

It’s not too early to get some Christmas shopping done and support the Alaska Down Syndrome Network at the same time. Encourage your families, friends and coworkers to do the same!

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**THOMAS FAMILY!!!**

We are keeping you in our thoughts and prayers; 4-year-old Sarah, her mom, Lisa (our Board VP) and family. Sarah was just diagnosed with complex leukemia. Sarah and Lisa immediately flew to Portland for 5-6 months of treatment. If you would like to send them a card, here is the address:

Sarah and Lisa Thomas
c/o Doembecher Children’s Hospital
700 SW Campus Dr.,
Portland, OR 97239

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**Dear Down Syndrome Congress,**

Thank you so much for my scholarship check for $250.00 to get me a new mattress for my bed in my room. I like it. It is very nice and soft. I love staying in my room. Thanks for buying me my new mattress.

lore

Emily
INDEPENDENT ACTIVITIES
by Jenny Weaver

As a family we search for activities Pearl can do by herself during down time. We enjoy puzzles (with specifications), 300-500 piece jigsaws with lots of different colors and shapes. Puzzles aren’t particularly creative, but they can improve life-skills while providing some solo fun. Puzzles require visual discrimination that enhances reading words and signs. Manipulation of individual pieces uses fine motor skills. Puzzles are a safe, quick downtime activity that Pearl can do solo.

We visit our local thrift stores frequently in search of new puzzles. Anyone interested in a puzzle exchange?

For Pearl’s August birthday she received something new—two beautiful sticker books by Silvio Rebello. These books remind me of paint-by-numbers, but instead of paints they use stickers! The end result is a mosaic-like picture, so little gaps or misplaced pieces somehow fit right in—perfect for Pearly’s style!

Initially, I helped Pearl find each sticker and begin the peel. With each picture she became more patient and more attentive to place the pieces correctly. Pearl now enjoys completing the pictures on her own.

I found these books on Amazon for $9 each. Some of Rebellos stickers are quite small, but I also found books for younger fingers. A “Paint by Sticker” search of the internet reveals a slew of books and publishers. Topics abound including bugs, dinos, zoo animals, Halloween, and much more. Different artists and publishers also available. I just purchased the Beautiful Bugs book for $6.39.

These would make fun Christmas gifts!

Making a PROFILE Page

A how-to article on creating a one-page profile about your child

This method can be used when your child enters a new grade, moves to a new school, if they are transitioning from Early Intervention into the school system, or even going to a new daycare. In any situation where you want your child’s team to have a better understanding about him/her, would be the time to create one. It is one page where you list a vision statement for your child, their strengths, what they love, what works and what doesn’t. You can even add your favorite photo. A nice idea to give teachers just prior to a new school year!

This profile, originally posted on a graphic design website called CANNA is no longer available on the site. An actual profile page example is reprinted here. For full instructions on “how to,” request a hard copy from Donna Davidson dkdavidson@gci.net.
The Sun is Always Rising

OCTOBER 2019

FUN AT THE MUSEUM

During a recent trip to Anchorage for car repairs, we decided to lessen our pain and spend a portion of our day at the Anchorage Museum. We were not disappointed. This day we found an interactive kitchen display that allowed Pearl to open cupboards to see what Alaskans store inside. We also discovered two huge modern sculptures of a polar bear and walrus. The tideland display reminded us of the Seward Sealife Center.

We found Molly from Denali, part of an exhibit on media and Alaska. (Unfortunately, this exhibit ends Sunday, October 13th.) Molly the TV shows airs through PBS KIDS, and represents the first Alaskan native as the main character in a nationally distributed show. The PBS.org website claims their “programming is rooted in education and inclusion.”

Invariably and as a family, we end up in the Discovery Center, making bubbles, creating earthquakes, and watching volcanoes blow off. Interactive fun!

The museum offers several programs specifically for people with disabilities. Did you know that admission is free for professional caregivers in the company of their client who pays admission? The museum also offers audio/visual descriptions for selected art, and both drop-in and structured workshops for children and adults. Of special note are the museums SENSORY-FRIENDLY AND ACCESS MORNINGS described here and on their website anchoragemuseum.org:

“Self-directed, drop-in sessions are offered monthly October through April and are opportunities for families and adults who experience a range of developmental and physical disabilities and those on the autism spectrum to visit a specific museum gallery when the museum is closed to the general public. Museum staff help facilitate and support visitors with opportunities for close looking and tactile activities specifically designed for these sessions. A safe space is available, and an adult must accompany visitors under age 18.

Sensory-Friendly and Access Mornings are $5 per family or group. Advance registration is appreciated.

Though these opportunities are created by museum staff for certain times, visitors experiencing sensory sensitivities and disabilities may visit the museum anytime during open hours for independent exploration.”

Halloween night at the Museum runs 3 to 6 pm and includes fun for all ages. Come in costume, trick-or-treat, Hear local storytellers, watch shadow puppets, visit treat station, explore spooky science, and experience Halloween music in a new way.

In addition, the museum offers free admission to everyone from 6:00 to 9:00 pm on the first Friday of each month.

Thanks to Michelle Hoffacker and family for their continued coordination and support for the Alaska Walk for Down Syndrome.
AK WALK FOR DOWN SYNDROME

Our annual Buddy Walk, renamed Alaska Walk for Down Syndrome, was celebrated on August 10 at the Anchorage Park Strip. Over 400 in attendance, with some new faces! Activities included face painting and a climbing wall (blow-up style, which was always busy of course!) Professional organizations tended booths, one of which had a fun bean-bag game.

There were about 30 give-away items: attendees put their tickets in a jar in front of the item wanted, and a winner was drawn from each jar.

As you can see from the photos, our yellow shirts really stood out!

What a wonderful day for a picnic!

A BIG THANK YOU to all of our generous sponsors:
- Pediatric Cardiology of Alaska
- Alaska Wholesale Flower Market
- All for Kids Pediatric Therapy Clinic
- The Children's Clinic
- Mylords Floral
- Debenham Properties
- Michael Korupp Orthodontics
- Denali Peak
- Tons of Fun Entertainment
- Over the Top Tents
- Klondike Promotions
- Nutritionist Grace Schumacher
- DJ Janet McKnight
- Alaska Railroad
- Anchorage True Value Hardware
- Bells Nursery

Big Hole by Nancy Davenport. What makes this book different is that the young adult adventure is told through the eyes and mind of a boy with Down Syndrome. He and his brother Jack find themselves on an unexpected adventure down a flooded creek without even a real paddle. Although not quite large print, the text is spaced and easy to read. It’s on my list to read, but let me know if you’d like it first and I’ll send it your way! As a librarian, I love the idea of adding more and more books to libraries that have authentic characters with Down Syndrome.

And finally, as a quick refresher I’m including the link to our library. I haven’t added books lately, so be sure to send me titles you own and are willing to loan out, or that you feel the chapter should purchase. https://www.librarycat.org/lib/AKDSN.

Once you find a book you are interested, you can check to see where it is housed. The other option is to contact me directly through email or text and I’ll figure out how to get the book to you. Wendyleseman@gmail.com or 907-244-8303.

2 NEW BOOKS in our Library by Wendy Leseman

Two books came across my desk a while back, and rather than waiting until I’ve read them both completely, I’m writing an introduction to both in case you might be interested in borrowing them and reading for yourself.

Has your child ever done the “Stop and Flop”? Has your child “bolted” or displayed lack of “stranger danger”? If so, you might find the book Supporting Positive Behavior in Children and Teens with Down Syndrome by David S Stein, Psy.D very helpful. The subtitle “The Respond but Don’t React Method” gives the reader a very accurate idea of what to expect. Understanding why certain behaviors manifest in our children and young adults is the first step in being able to help them come up with more effective ways of coping with their environment. This resource was published in 2016, so you can expect current research has informed the ideas presented in the book.

The other book I haven’t actually read, but since it has the endorsement of The National Down Syndrome Congress, it’s worth taking a look at. It’s called Donovan the Big Hole by Nancy Davenport.
NATIONAL INSTITUTE OF HEALTH (NIH) AWARDS MILLIONS FOR DS RESEARCH

“The National Institutes of Health has awarded approximately $35 million in new grants in fiscal year (FY) 2019 to advance research on Down syndrome through the Investigation of Co-occurring Conditions Across the Lifespan to Understand Down Syndrome (INCLUDE) project. These awards bolster total funding for Down syndrome research in FY 2019 to an estimated $77 million. INCLUDE is a trans-NIH effort with participation from many NIH institutes and centers. Research funded by INCLUDE will investigate critical health and quality-of-life needs for individuals with Down syndrome, while at the same time explore co-occurring conditions with individuals who do not have Down syndrome.

Individuals with Down syndrome are both affected by and protected against many of the conditions that afflict the general population,” said NIH Director Francis S. Collins, M.D., Ph.D. “By improving our understanding of the basic biological mechanisms of Down syndrome, and making clinical trials more accessible and specifically tailored to individuals with Down Syndrome, we expect that research from the INCLUDE project will benefit everyone.’

..Individuals with Down syndrome experience, “in later years, dementia resembling Alzheimer’s disease, as well as hearing loss, congenital heart defects and sleep apnea. Autism and epilepsy are prevalent in the population, as are autoimmune disorders such as celiac disease. However, individuals with Down syndrome infrequently develop solid tumors, such as breast or prostate cancer, or have heart attacks despite having multiple risk factors, such as obesity and type 1 diabetes.”

Research funding includes studies on Down syndrome and brain development, resistance of people in Ds to solid tumors, their predisposition to leukemias, congenital heart defects, and sleep apnea.

A portion of the grant goes to research to ensure medications commonly used in children with Down syndrome are tailored to them and a study that will set the stage for testing a treatment for Alzheimer’s disease specifically for individuals with Down syndrome.

NICHD also is launching a physician training program to raise awareness of the unique care needs for children with Down syndrome.

A chunk of the funding focuses on how to ready young adults for clinical trials. Included are the establishment of outcome measures. For more information about NIH and its programs, visit www.nih.gov.
Social Security Income Changes Proposed by Shaun Heasely

“A bill introduced in Congress would give more flexibility to people receiving Supplemental Security Income benefits.

People with disabilities who receive Supplemental Security Income would be allowed to keep substantially more assets and would no longer be penalized for marrying under a new proposal.

Currently, in order to retain benefits, SSI recipients generally can have no more than $2,000 to their name at any given time.

Lawmakers in the U.S. House of Representatives are looking to significantly increase that ceiling, with a bill introduced this month that would raise SSI’s asset limit to $10,000 for an individual and $20,000 for couples.

In addition, the Supplemental Security Income Restoration Act, or H.R. 4280, would increase the amount of disregarded income that beneficiaries can take in each month. And, the bill would repeal penalties for marrying or receiving financial, food and housing assistance from family members.

Backers say the time has come to update Social Security’s SSI program, which has remained largely static since 1972.

“This issue is one I have heard about directly from autism advocates and families in our district, particularly parents preparing for children with disabilities to transition into adulthood,” said Rep. Elissa Slotkin, D-Mich., who introduced the measure along with Rep. Raúl Grijalva, D-Ariz. “This bill brings the Supplemental Security Income (SSI) program’s outdated limits up to speed with inflation — a common-sense adjustment that will make a huge difference for individuals and families caring for someone with disabilities.”

Article printed September 23, 2019 in Disability Scoop
On the Calendar....

October 19 - Bookfair 10 am—5 pm
Barnes & Noble, Anchorage
(more info on page 2)

October 19-24 - Nationwide Bookfair

November 14  (Thursday), 7 pm
Annual AKDS Network Meeting
Anchorage Baptist Temple
(more info page 1)

DECEMBER 6 (Friday), 5:30 pm
Christmas Party
Bayshare Clubhouse, Anchorage
(see info opposite)

April 2020—Regional Conference
(more on this exciting event soon!)

Save those dates!