

The Sun is Always Rising

Newsletter of the



OCTOBER 2019



October is DOWN SYNDROME Awareness Month!



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 would 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.

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

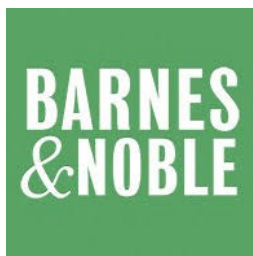




Thank you so much for the generous scholarship this year and last. We used the money to buy Ice Bug studded running shoes and new nordic skis. Being active is helpful to both physical and emotional health, and having the right equipment makes all the difference! Ice Bugs allow Courtney to run and walk 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



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

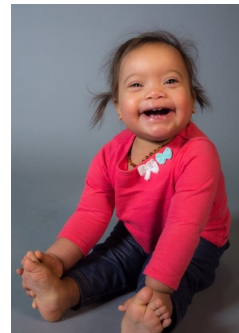
(to go along with storytime reading of *Paint the Octopus Red'*)

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.

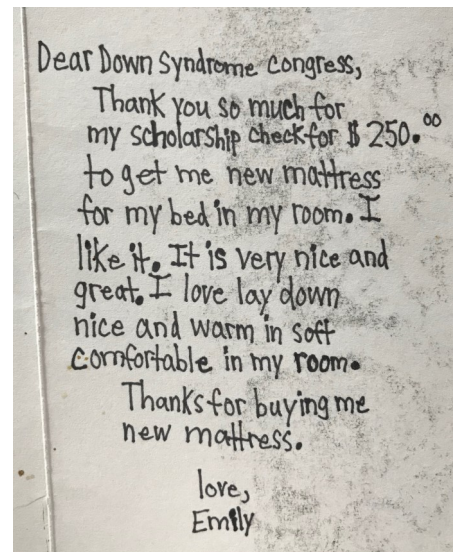
It's not too early to get some Christmas shopping done and support the Alaska Down Syndrome Network at the same time. Encourage your families, friends and coworkers to do the same!



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 di-

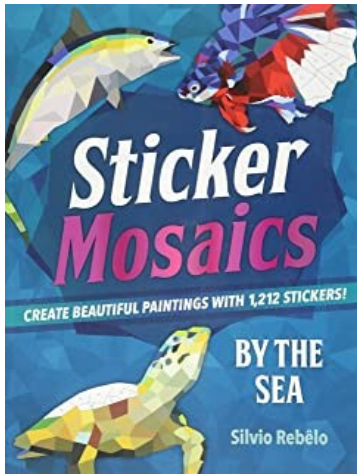
agnosed with complex leukemia. Sarah and Lisa immediately flew to Portland for 5-6 months of treatment. If you would like to send them a card, here is the address

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



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 re-



quire 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 Pearl'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!





ELLIE STAFFORD
AGE 5
KINDERGARTEN

Teach me to soar and I will
-Katie Hampton

VISION STATEMENT

We envision our daughter living a life of choice. We envision her having relationships she feels are valuable. In her future we envision her doing work that she enjoys and that makes her feel productive. We envision our daughter living a happy and meaningful life surrounded by love and support.

STRENGTHS

- Visual learner
- Advanced Reader
- Knows ABC's and Letter Sounds
- Can count to 30
- Social and Kind
- Funny
- Smart
- Great Friend
- Fast Learner
- Excellent Memory

WHAT DOESN'T WORK

- Being Rushed
- Sudden Change in Activity
- Negative Talk
- Yelling
- Assuming I Don't Understand

WHAT WORKS FOR ME

- Patience
- Peer Modeling
- Schedule and Routines
- First/Then Visuals
- Picture Cues for Tasks
- Believe in My Abilities
- Praise Me For My Achievements
- Warn Me About Transitions

WHAT I'M WORKING ON

- Talking in Sentences
- Fine Motor Skills, like Writing, Cutting Paper and Coloring!
- Gross Motor Skills, like Running!
- Following Directions
- Conversational Speech

I LOVE: My Parents, My Brothers
Will and Luke, Taco Bell,
Dancing and Rap Music.

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



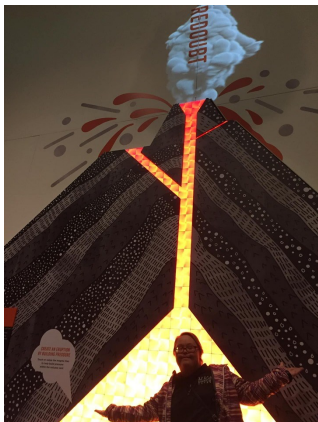
FUN AT THE MUSEUM

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 au-

dio/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 anchagemuseum.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.

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.

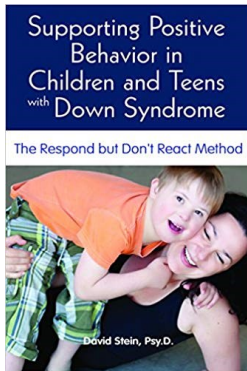
Has your child ever done the "Stop and Flop"? Has your

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*

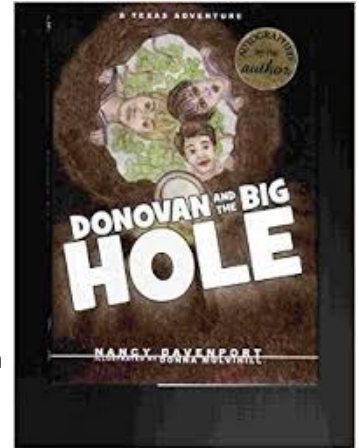


Big Hole by Nancy Davenport. What makes this book different is that the young adult adventure is told through the eyes and mind of a boy with Down Syndrome. He and his brother Jack find themselves on an unexpected adventure down a flooded creek without even a real paddle. Although not quite large print, 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.



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
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Klondike Promotions
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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.





The Alaska Down Syndrome Network Annual Picnic was held at *Mirror Lake Park, in Peters Creek* on June 28. Jennifer Gross reports that nearly 40 people attended including families from Anchorage, Eagle River, and the Valley. The weather was great and the lake provided for much fun. Enchanted Alaska was there with a whole cast of characters who were enjoyed by everyone on the lake that day. According to Jennifer, "Everyone seemed to enjoy visiting and hanging out."

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."

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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!