

# ALASKAN ADVENTURE

Imagine someone grants you a gift -the gift of an Alaskan adventure to wherever you like to include your entire family—even your youngest child, who experiences Down syndrome. In fact, imagine that you receive this offer

**BECAUSE your child has Down syndrome!**

Enter the Gorski family; Tristan, Alaskan born, and his wife, Wendy, who live in Eagle River with their four children; Atticus, 11, Tesla, nearly 9, Wren, 7 and young Coda.

“I’ll be honest,” says Wendy, “Coda’s diagnosis clobbered us over the head. And his tenacious medical issues kept us on our knees a while longer as we strove to stand again.”

Visits with a physical therapist eventually put the Gorski family on a rather round-about path to meet the Redfields; Dan, Kristen and Ava. The Gorski family used a therapist to help Coda. The Redfields, used the same therapist for little Ava, who at 18 months began to exhibit signs of Tay-Sachs disease. What transpires here is both sad and wonderful, for



little Ava’s growing limitations made way for an awareness and purpose that the Redfields transformed into Adventure for Ava. (See article page 3.)

Don Redfield approached the Gorskis in the spring of 2019 with simple terms; a daytrip anywhere in Alaska the family wanted, if they allowed him to film

the excursion for his new project Adventure for Ava.

The Gorskis opted for bears. Crescent Lake at the edge of the massive Lake Clark National Park and Reserve became the chosen destination. The adventure, months in the making, required a host of friends and business contacts. Redfield arranged an amazing trip, complete with treehouse lodging, floatplane flights, boat rides, and bears.

Lots and lots of bears!

On a rainy day in late September, the Gorski family crammed into their Toyota Tundra and began the long drive from Eagle River to Homer. Travel along with them now, through this story and photos, which continues to the center page spread.

For Wendy Gorski’s heartfelt blog on the family trip, visit <https://unfinishedadventure.com/2019/11/19/chinan-thank-you/>





## SUPER SARAH UPDATE



From Lisa Thomas, 2/3/20

Greetings to all our amazing friends in Alaska!

Sarah just finished her third round of chemo treatment. We currently have a week break!

The plan is to start her fourth round February 11th. Three treatments remain and each should take 4-6 weeks. At this pace, we hope to arrive back in Alaska in May, possibly June.

We appreciate all the love, prayers, support and gifts sent from everyone. This journey has been very difficult, but Sarah is a champ! She brightens the oncology floor with her dancing, running for the doors, giving fist bumps and teaching everyone sign language. She is a rock star.

Please continue to pray. We can't wait to see and hug you all again soon,

The Thomas Family

**Write Sarah and Family at:**  
Ronald McDonald House  
3410 SW Bond Ave  
Portland, OR 97239

World Down Syndrome Day



## World Down syndrome Day

is just around the corner!

In Anchorage, Rugged Brews, RaeRaes, Goldie's, and PerkUp Espresso will offer our WSDS coffee sleeves to their customers on 3.21.

Do YOU have a favorite coffeeshop that might do the same?

Contact us at [alaskads@gmail.com](mailto:alaskads@gmail.com).

Tell us how many sleeves you need and where to deliver!

**Help Spread the Word about Down syndrome!**



Our **Annual Christmas Party** took place December 6, at the Bayshore Clubhouse in Anchorage. Tickets sold out (150) for the gala event that included a lovely setting, delicious dinner, short concert by the Midnight Sons Barbershop Singers, dancing, and of course a visit by Santa!

### THANK YOU!

**Boy Scout Troups 26 and 2026** who provided set-up, **All for Kids** volunteers helped with Santa time, and beautiful flower arrangements by **Alaska Wholesale Flower Market**.

Thank you to all you contributed, volunteered and attended!



The handsome Broyles brothers, Ben and Brendan, at the Christmas Party.

# PEOPLE FIRST LANGUAGE

## An Evolution of Language

By Jenny Weaver

My family has grown and changed since Pearl's birth nearly 34 years ago. Societal norms and the language we use to communicate with and about people who experience disabilities has also evolved during this time.

As a special education college student in the early 70's, I remember awful terms like "trainable" and "educable." Since then, our practices evolved from "segregated" special education settings, to "integration" and "inclusion."

As practices change, so does our language. When our language changes, so do our attitudes. Language should always be respectful and kind.

Our family members have or experience Down syndrome. They are not Down syndrome kids or Downs adults.

We should no more recognize their disability first than we should introduce me as the always-late-with-the-newsletter editor. If your husband experiences diabetes do you introduce him as your "diabetic spouse?" Of course not. It's entirely unnecessary and rude!

This may seem like a trifle to some. But the difference is huge!

**Recognize  
the uniquely  
individual  
person  
FIRST!**



The National Down syndrome Society (NDSS) posted the following *Preferred Language Guide* on their website [www.ndss.org](http://www.ndss.org)

### "USE THIS LANGUAGE WHEN REFERRING TO DOWN SYNDROME AND PEOPLE WHO HAVE DOWN SYNDROME"

- People with Down syndrome should always be referred to as people first.
- Instead of "a Down syndrome child," he/she should be "a child with Down syndrome." Also avoid "Down's child" and describing the condition as "Down's," as in, "He has Down's."
- Down syndrome is a condition or a syndrome, not a disease.
- People "have" Down syndrome, they do not "suffer from" it and are not "afflicted by" it.
- "Typically developing" or "typical" is preferred over "normal."
- "Intellectual disability" or "cognitive disability" has replaced "mental retardation" as the appropriate term
- NDSS strongly condemns the use of the word "retarded" in any derogatory context. Using this word is hurtful and suggests that people with disabilities are not competent."



## Adventure for Ava

After 18 months rejoicing in their new family and daughter Ava's growth, parents Dan and Kristen Redfield, of Anchorage, watched little Ava begin to regress. With an eventual diagnosis of Tay-Sachs disease, and the complications associated with it, the family's ability to even venture outside disappeared.

The Redfields recently established Adventure for Ava, "a non-profit initiative helping families with special needs create memories...The best memories are those made outside," claims their website, "However for families with special needs, getting there can be difficult."

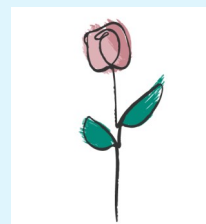
In 2020, Adventure for Ava plans to host four families on an Alaska adventure of a lifetime. They currently seek sponsors for all levels and types of support. The Stone Soup Group will process applications and donations.

For more information see their website at

<https://www.avasstory.org/>

Thank you, Dan, professional photo-adventurer, for permission to use of you photos on the front page and center page spread. You can visit Dan's website at

<https://www.alaskaphotoventures.com/>





# ALASKA ADVENTURE



The Gorskis made their way south, through the eerie, smoldering remains of the Kenai wildfires, and finally arrived in Homer. There they checked into unique accommodations donated by Cottonwood Cabins complete with greenhouses and chickens. Homer's beautiful 40-acre Karen Hornaday Park added the perfect antidote for a family who rode in a cramped car all day.



The next morning brought sunshine as the family arrived at Beluga Air to board their first floatplane. Owners Angela and Wes Head arranged much of the Gorski's adventure, in addition to flights to and from Crescent Lake. (See info on Beluga Air on back page).

After a quick tour and orientation, including how to walk on airplane floats, the family flew across the inlet to Redoubt Mountain Lodge at the edge of Crescent Lake. Here the family and photographer made their way onto a pontoon boat and motored into a day they will never forget.

They spent the morning hours on the water, drifting back and forth along the shore watching for bears.



Our second bear, a young, energetic male the kids dubbed 'Fisher', because of his numerous failures. We silently cheered him on for quite a while, until he finally scooped one up.

We rested with this mother and cubs (Sky, Bramble and Berry) for a long time. We learned bears yawn when nervous or threatened. We saw her catch wind of and alert to a nearby, lone bear. We watched her move the cubs down the shore to nurse them, something our guide informed us is pretty rare to witness as the mother must be very comfortable in order to relax enough.





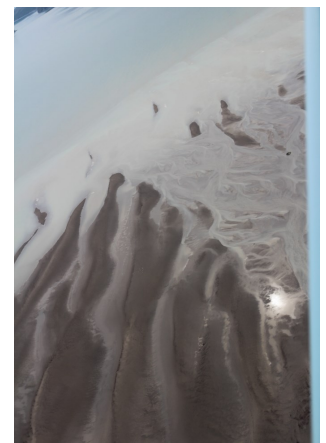
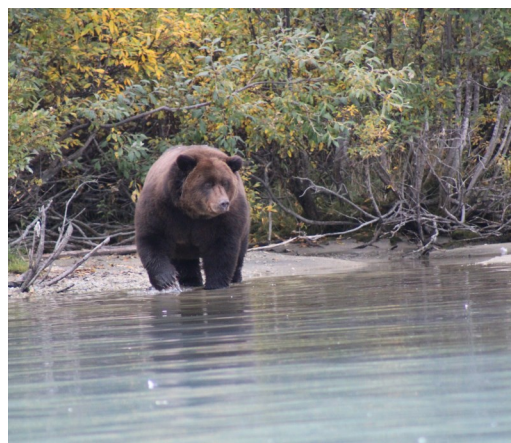
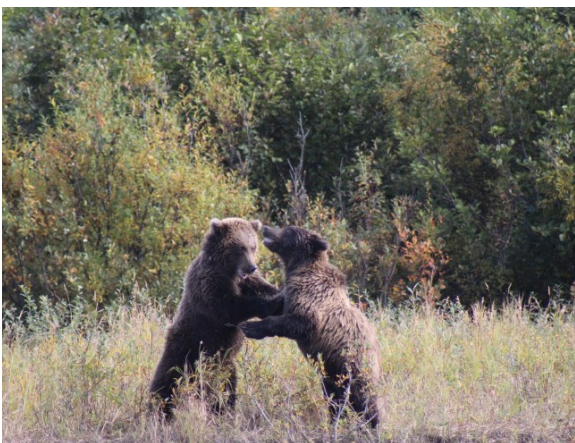
... OF A LIFETIME!



*(Wendy's bear notes are included along with the photos below)*  
 After a delicious salmon lunch at the lodge, the family returned to the boat and continued to search for bear. They then made a last jet across the lake where they spied Big Ben. At the end of day the family flew back to Homer, exhausted from the sights, fresh air, fine food and excitement of the experience.

In her blog, Wendy reflects upon the multiple blessings her family received on this journey. The logistics of their adventure— flights, a boat ride, lodging, boat guide; all donations of time and livelihood. Some intangibles shared included kindness, patience, and understanding. And what an Alaskan experience! In reflection, Wendy shares a moment of a clarity—

*“(There are) myriads of reasons our family is thankful this season. The most stunning one being that we stumbled upon a gift. And that gift has given our family a wider, warmer view, deeper perspective and sharper focus since Coda was born.”*



*These two newly ousted siblings were such a gift to see! In their mischievousness and banter, our children saw themselves, their cousins, friends, and even our cats and dog. In short, they saw that we living creatures share far more than we differ.*

*Big Ben made us all laugh in amazement and wonder how he/she would make it up into the mountains to hibernate. We later read about Holly, the winner of Fat Bear Week, and realized Ben didn't quite compare, but from the bears we met, this guy seemed to make the best use of the circle of life.*



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**CONGRATULATIONS TO NEWLY ELECTED PRESIDENT,  
MICHELLE HOFACKER**

Michelle joined our Board of Directors in 2011 as Secretary. In that role, she always provided prompt and accurate minutes and followed through on all and any manner of chapter business. Michelle's biggest claim to fame (and always involving the entire Hofacker family) is her coordination of the annual Buddy Walk.



Michelle begins her President's column next edition. Until then, here is Michelle's straight-up bio, which true to form, emphasizes her family instead of herself.

Michelle has lived in Anchorage for 24 years married to husband, Jason. The Hofackers have four children, "Joel, 21, band director at Anchorage Christian Schools; Makenzie, 19, just completed a year's fellowship at Barnabas Prep (college experience for adults with special needs; Makenzie was a caregiver); Luke, 17, will be entering his senior year at Anchorage Christian Schools; Seth (with Ds) 14, homeschooled since 6th grade, will be entering his freshman year with Denali Peak Home-school Program."

Michelle's strongest traits; her fierce love of all things family and a special devotion to her son, Seth, make her a perfect candidate for president. Her track record of undying advocacy for individuals and families who experience Down syndrome speaks for itself.

Michelle now commands the helm of our amazing state-wide non-profit, with a lot on her agenda, and rather huge shoes to fill! Thank you for volunteering Michelle. We all wish you the best and we are here to help! We look forward to the next chapter of the Alaska Down syndrome Network!

**THANK YOU**

to all who participated in the Barnes & Noble Book Fair in October.

At the Anchorage store families listened to story time and made a craft project. The in-store event, along with on-line purchases, made our DSN over \$500!

We thank Barnes & Noble's friendly and helpful staff for their assistance with this event.

Saturday, April 18, 2-4 pm  
 Hearts and Hands  
 7521 Brayton Dr., Anchorage

## WELCOME TO THE BOARD!



The Franz Family, mom, Karlan, Sterling (in the back), Harvey, and Dean.

Meet Karlan Franz, newly-elected Board Secretary. Aunt to Sophia Kamilos, Karlan, has lived in Anchorage for 25 years. Along with husband Dean, she parents two young boys ages one and three. Karlan enjoys camping and hiking.

Karlan joined the board "to contribute to a wonderful community of amazing people!"

In addition to her duties as secretary, Karlan volunteered to coordinate the annual Walk for Down syndrome. She says she would like to make this year's walk the biggest yet!

## "Organization is a process, not a project."



What a terrific workshop on

### ORGANIZATION!

Lisa Witzleben from **Unclutter Me** provided 18 participants with some great tips, tools, & techniques for managing our busy lives.

You can learn more about Lisa's services through her website [www.uncluttermeak.com](http://www.uncluttermeak.com) or her Facebook page <https://www.facebook.com/uncluttermeak/>.

*This workshop was provided for our members at no cost and is just one way our fundraising dollars benefit our members. Do you have an idea for a workshop, educational speaker, or activity that you think would benefit our membership? Contact us at [alaskads@gmail.com](mailto:alaskads@gmail.com).*

Have a photo you would like to publish? A story to share? A thank you to deliver? Send it directly to this newsletter at :

[newsletter@akdownsyndrome.org](mailto:newsletter@akdownsyndrome.org)

The clearest photos make the best reprints. Jpegs please!

*Help make our paper better by sharing your news, photos, and events.*

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*Hi there, Esther Kwon!*



## On the Calendar....

March 21st - **World Down Syndrome Day**

April 18, Saturday—**Polka Dot Dance**

June 26, Friday —**Annual Picnic**  
4-8 p.m. Mirror Lake

Aug.—**Alaska Walk for Down syndrome**  
Delany Park Strip

September —**Regional Conference**



**Beluga Air**  
invites families to  
contact them for  
their flight and tour  
needs out of Homer.

Contact Angela at 235-8256 or email  
[angela@belugaair.com](mailto:angela@belugaair.com).

