

# The Sun is Always Rising

Newsletter of the



NOVEMBER 2018

## Glacier Morrow Saves the Day

Do you know Glacier Morrow? He lives in Wasilla. Glacier is a Broncos fan. He is also a huge country western music fan and aspires to lead his own band. Glacier enjoys Special Olympics and competes in several sports including bowling and floor hockey. Glacier works at Smash Burger in Wasilla. If you live in the Valley, you know Glacier.

This story is about how Glacier saved his mom, Jana, and her boyfriend from a house fire. It's true! One late September night, Glacier got up to get a drink of water, and to check his phone, when he noticed something very strange happening to his house. Glacier woke his mom and they all escaped the fire. Glacier is credited with saving their lives.



Although their house still stands, there is much work to do, both demolition and reconstruction. Glacier and his mom are staying in an apartment until work can be done on their house. Jana says that might not be until spring.

In the meantime, an account has been set up for donations at Denali Federal Credit Union account #211971. We will keep you posted on future plans to help Glacier and his family.

**Glacier, you are awesome!!!**

## ANNUAL MEETING

*Alaska Down Syndrome Network*  
*Saturday, November 10, 2018*

Anchorage Christian School  
6575 E. Northern Lights Blvd, Anchorage

**9:30 am**

Good Morning, Welcome!

**10:00 am—11:30**

"The Language of Toys:  
The Right Toy at the Right Stage"  
*Molly Thompson, Speech therapist*

**11:30**

**Lunch**

*Sandwiches from House of Bread*  
*(gluten free options provided)*  
*Fruit & Cookies*

**Noon—1:00 pm**

Business Meeting & Lunch continues

**1:00-3:00 pm**

"Nutrition in Down syndrome,"  
*Kim Wilcox, board member & nutritionist*

Attend one or both sessions  
with lunch and meeting in-between

RSVP for babysitting to  
Michelle 854-2754  
*polarmom4@gmailcom*

Watch Constant contact messages for further  
info or call Donna Davidson 907.694.2545.



## Thank you for the Donation!

*We received a donation of \$500 from a gentleman in Juneau. Here is the story of how he happened to give to us. Submitted by Gary Timothy, Juneau Board Member*

I met with Mr. Ron Maus and we talked about many of the old timers here in Juneau, and then he shared with me how he came up with the \$500 for our group.

As you may or may not know, all cruise ships coming into US waters must have a local skipper onboard. For us in Juneau, that means that the cruise ships slow down (but don't stop) just as they enter the 'Inside Waters' and the skipper takes over the navigation. This is what Ron does.

So, as Ron shared with us, onboard there was a pregnant woman about ready to give birth. To speed up her travel time to the hospital, they got her onto Ron's vessel, which is much faster than the cruise ship. The woman was so pregnant that she could not fit through the doorway on his vessel, so they made her comfortable on his back deck and raced to the hospital.

All went well and she gave birth to a baby with Down syndrome. The folks on the cruise ship got a collection going for her. They raised \$500 and gave it to Ron. Ron never met up with the lady again, so he felt it would be appropriate to donate it to the AK DS network.

## THE WISDOM OF FRIENDS *Alaskans* *Parent Adult Children with Ds*

This summer I had the fortune of reconnecting with three women who impacted my life as the mother of Pearl.

Sue Behnert, one of my first contacts with another parent of a child with Down syndrome, belonged to a group of moms in Juneau. They arranged with local physicians to provide information to new families of children with Ds. Upon the birth of Pearl, my family received that information. I hesitantly made contact, not really knowing what to expect. With Pearl only two weeks old, I returned from Pelican to Juneau and met Barbara Knolls, Lori Mallinger and Sue. I witnessed kids with Downs at play, and talked with these wonderful moms full of hope and good will. This meeting proved a precious gift of positive support that launched me on a path of education and advocacy.

Sue and I talked as her son, Karl, and my daughter, Pearl, competed in Special Olympics Alaska (SOAK) State Track. Sue mentioned our newsletter and how a recent article resonated with her. Certain she was referring to the center-spread story (Mar 2018) by Evelyn Luna about the birth of dear Angelina it surprised me that Sue was remarking upon the article by Cheryl Erickson (Dec 2017). Cheryl related her trip to the National Down syndrome Congress Conference and what she had learned regarding future and estate planning for her daughter.

Sue told me the article helped her realize that she still had more to consider for Karl's future. She shared concerns that family assistance might come at the cost of Karl moving, even out of state. Karl's employment, friends, and nearly all other supports would require time and effort to rebuild. She claimed she is forced to re-think Karl's options.

Sue's concerns mirror our own. We have no family close by. Who will care for Pearl when we are gone? Where? Pearl's brothers live out of state. What does that mean for her system of supports? How can we make that transition easier?





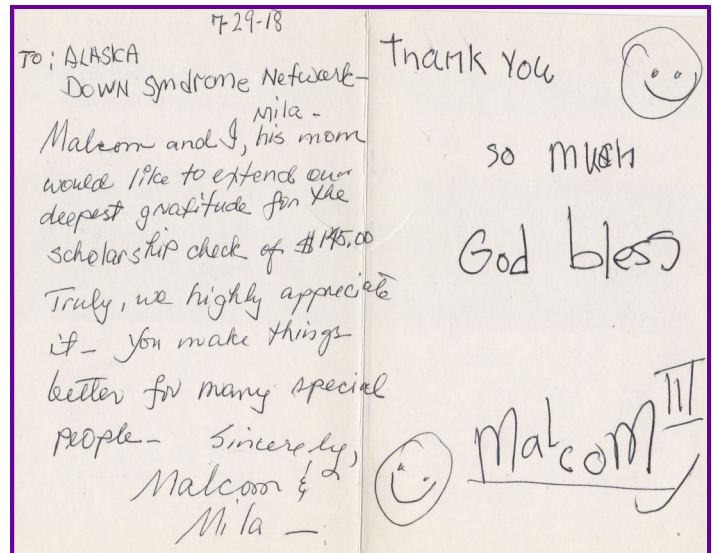
At the same SOAK event, I bumped into my friend, Cathy Olson, a single mom who lives in Glennallen, with her adult son Cathy and I met years ago at a PATHWAYS Conference. Cathy worked for PARENTS, taught as a special ed aide, attended college, served as an EMT, and now works for FEMA! Cathy has been a constant advocate and volunteer for people who experience disabilities.

Cathy explained how her work for FEMA required out-of-state travel for extended periods of time. But Cathy can't go anywhere unless Chris receives support. She explained the time, effort, and evolution of that process. Friends, community members, and employers came together to help Chris get where he needs to be and to help him provide for himself when Cathy travels. Necessity provided motivation to step up Chris' independence from mom. My husband and I also work to build a community of natural supports for Pearl. Timing isn't always convenient. Things happen. I know we need to get busy. Cathy's work and Chris' success fuel our own efforts.

And lastly, while trying to entice a good story for our next edition...I connected with Gayla Valle. You might have met her as Yakutat teacher extraordinaire, world traveler, mom to Max and Joey, former PARENTS Board or Governor's Council member or perhaps as an agent with a Yakutat-serving air service. Gayla's son, Max, lives in Juneau. Most exciting, Max had a grand adventure this year as he embarked on a journey from Juneau to Hoonah via traditional Tlingit boat.

Gayla shared her ideas for Max and as always, her advocacy focused quickly on Max's wishes. Gayla spoke to what MAX enjoys, what HE sees his life like-- what he needs, but also what he wants. Gayla reminded me that at the forefront our efforts, and to the greatest extent possible, we must include our children's desires and consider how they envision their own lives.

Fortunate for me to reconnect with these three insightful women; all parents of older Alaskan children with Down syndrome. All still advocating for their child. All still seeking solid information and positive options, sharing good information and, in the process, providing a profound reality check for me!



These intelligent, hard-working Alaskan women, accomplished in their own right, certainly entitled to retirement and self-fulfillment, each admitted they don't have the all answers for their adult child with disabilities. And they continue to search. Their thoughtfulness and dedication blew me away!

We are all different. Even in our Down syndrome, no two individuals or families are exactly alike. We DO have many similar needs, questions, and concerns. We search for answers as we plan each day. We explore options for the future and make choices, sometimes life-altering, for our children and our families. And we are Alaskans, by golly! So whenever possible, we do this on our own...

This summer, I was strengthened and encouraged by three dear friends. I was reminded that my strongest supports come from the experience of families who walk this similar path right now, and those who passed here just before me.





## VOLUNTEER BELL RINGERS NEEDED!

Ring a bell...Take a Stand Help Others



*A way for our children to give back!*

**\*\* JOIN THE CONTEST \*\***

*A goal this year was to give back to our community by participating in fun volunteer activities. We are setting up the first event – ringing bells for the Salvation Army Christmas fundraiser!!*

**FRIDAY DECEMBER 7**

**5:00 – 7:00pm**

*There are two locations in Anchorage, one in Eagle River, and one in Juneau. We would love to have other towns join in (Wasilla, Palmer, Kodiak, Fairbanks??).*

*Sign up for a 30 min. stint or the full two hours.*

*Salvation Army will count the money from each location to see which spot brought in the most.*

*Who can woo the shoppers the best??*

*We will have Santa hats for all and we encourage everyone to wear a Buddy Walk t-shirt, especially a red or green one if you have those.*

*Let's go ring those bells!*

*To sign up to ring bells visit this website.*

[www.volunteersignup.org/EWWMY](http://www.volunteersignup.org/EWWMY)

*For more information*

*Call Kim Wilcox at (907)306-7324.*



## Are you a Mutant???

submitted by member, Cheryl Peyton

I've been researching genetics a bit lately, and have found that, in fact, most of us are mutants. Pretty much everyone has a few genes that have mutated over the ages. Of significant relevance to mothers of Down Syndrome children, though, are genes related to MTHFR. No, its not an abbreviation for a bad word.

MTHFR is short for Methylenetetrahydrofolate reductase. The MTHFR gene is located on the 1st chromosome. Most mothers of children with Down syndrome (DS) have one or more mutations relating to the MTHFR gene. The polymorphism (another word for mutation) that is primarily indicated in DS is 677C>T or C677T (the nucleotide cytosine is replaced with the nucleotide thymine at position 677).

The MTHFR 677 gene (for you other researchers out there, the SNP is rs1801133) encodes the protein MTHFR. Its job is to convert one form of folate (5,10-Methylenetetrahydrofolate) to another form of folate (5-Methyltetrahydrofolate, i.e., 5-MTHF). Essentially, the mutation interferes with the affected individual's ability to use folic acid. Depending on whether they have one copy (heterozygous) or two copies (homozygous) of the mutation, their ability to use folic acid is either impaired or relatively non-existent.

Women with the mutation are more at risk for pregnancy loss and having babies with Down Syndrome and neural tube defects. This occurs for a couple of reasons. The first is that we have problems with "non-disjunction" when our eggs are formed – we tend to form eggs that have not divided properly more than most – eggs with two copies of one chromosome or another instead of just one. These will become trisomy once fertilized. Then, if we do conceive a child with DS, our bodies don't "auto abort" as is typical.

Well, that's all well and good, but my precious child with DS is hear now, alive and well – so why does it matter? The answer, is, like most things, genes affect more than one process in our bodies. So, we mutated MTHFR folks are more at risk for elevated homocysteine, cancer, heart disease,

stroke, coronary artery disease, depression, anxiety, Alzheimer's Disease, memory loss, retinal vein occlusion and a number of other maladies. We tend to have difficulty with processes involving the entire B vitamin group, in fact. And, our children (DS and otherwise) have at least a 50% chance of carrying the same mutation.

But, there is good news! There are supplements now for 5-MTHF. You can take folate directly and not have to rely on your body's ability to produce it. Over the counter supplements are available under many names and with many dosages. A few are:

5\_MTHF Thorne <https://www.thorne.com/products/dp/5-mthf-1-mg>

Methylfolate 5 Methyl Life <https://methyl-life.com/product/methylfolate-5/>

Bio-active folate numerous

How do you know if you have the mutation? If you have a child with DS, you probably do. But, to find out for sure, and to determine if you are homozygous or heterozygous, you need to do genetic testing. Your health care provider may be able to help. You can find out on your own, though. A number of organizations offer genetic testing direct to consumer, such as 23&me, Ancestry, CRI Genetics, Family Tree DNA, and many more. While many testing services provide the data directly to the consumer, sometimes the specific information you are looking for can be difficult to tease out. There are secondary services, though, such as Promethease (Promethease.com) that can import your data and digest it into more understandable reports. Each company seems to have slightly different research as to the effects of various genes. So, getting multiple reports is helpful.

One last note – Bryan Jepson, M.D., reports a number of polymorphisms associated with autism. The MTHFR C677T is one. This may explain why children with DS are at a higher risk of developing autism spectrum disorders as well.

So, yes, you probably are a mutant – we all are. It is well worth finding out if you have any MTHFR mutations, C677T in particular, though. Your health and possibly the health of your children may be greatly improved by 5-MTHF supplement-

ation. Do some research and talk to your health care provider if you would like to know more. While I've read a lot, I am not a health care professional. There are many out there better informed than myself. Sources:

Jepson, Bryan, M.D. with Jane Johnson, *Changing the Course of Autism*, Sentient Publications, Boulder, CO, 2007.

O'Leary, V.B., et al., *MTRR and MTHFR Polymorphism: Link to Down Syndrome?*, American Journal of Medical Genetics, January 15, 2002, volume 107, number 2, pages 151-155.

Rosenblatt, David S., *Folate and homocysteine metabolism and gene polymorphisms in the etiology of Down Syndrome*, American Journal of Clinical Nutrition 1999;70:429–30.

Scala, I., et al., *Analysis of Seven Maternal Polymorphisms of Genes Involved in Homocysteine/Folate Metabolism and Risk of Down Syndrome*, Genetics in Medicine, volume 8, number 7, July 2006, pages 409-416.

*The above article was written and researched by our member, Cheryl Peyton. References attached. The article is presented here for your information and review.*

## MEMBERSHIP RENEWAL

Your membership renewal form, a scholarship form, and a survey will be in the mail soon (and available at the annual meeting).

**PLEASE** fill out and return the survey with your membership. Keep the scholarship form on file for the upcoming year, as we will not mail out another one.

*Memberships are due by*

**JANUARY 10, 2019**

*to be included on the 2019 membership roster.*





## Board of Directors

### PRESIDENT:

Donna Davidson  
dkdavidson@gci.net  
694.2545

### VICE PRESIDENT:

Lisa Thomas  
lthomas907@gmail.com  
315.5482

### SECRETARY & BUDDY WALK

Michelle Hofacker  
polarmom4@gmail.com  
980.7205

### TREASURER:

Jennifer Gross  
stormyluna@gci.net  
227-0389

### SOCIAL CHAIR

*In transition*

### MEMBERSHIP:

Karen Schudel  
schudelk@hotmail.com  
346.3191

### PROFESSIONAL LIAISON

Sam Thompson  
sam.thompson503@yahoo.com  
503.949.2663

### SOCIAL MEDIA

Facebook and website  
Julie Broyles  
[akbroyles@yahoo.com](mailto:akbroyles@yahoo.com)  
222.1199

### MEMBERS AT LARGE

(\* denotes committee chair)

Rachel Robinson  
Self-advocate

Wendy Leseman  
wendyleseman@gmail.com

## YOUR BOARD AT WORK

### Meet *Lisa Thomas*

our board Vice President.

“Born and raised Alaskan, my husband Tim and I have 2 boys (10 & 8) and our daughter Sarah (3) who has Ds. I joined the board 2 years ago.

I enjoyed helping to plan events, fundraising, and set up the play group for our babies and toddlers.

I also put together gift baskets for new babies. We are partnering with Project Linus. They make and donate blankets to hospitals for kids with an illness and those born with health issues.

Donna Davidson and a coworker of mine made some blankets for our baby baskets. Assistance from Project Linus will help us out a lot! For more information visit

<http://m.projectlinus.org/>

*Thank you* to **Michelle Hoyt** for working with us!

Currently I am working on gathering information for our new website and the Down Syndrome Diagnosis Network.





*Tristan Gorski* serves on the board as an At-Large member. She has also been very busy with board duties and reports the following; "I recently completed a current list of rural hubs and accurate contact information; including: rural hospitals, social workers and ILP contacts. I further contacted all listed parties and informed them of the AK DS Network, what we work to accomplish locally, and what we strive to offer for our chapter members with an emphasis on potential options for rural families.

Lastly I notified the rural contacts of our intent to send current contact information, including an up-to-date website with many electronic resources.

My son Coda Fin Gorski turned two on October 14th and recently started signing. His favorite signs are "music" and "more." He has learned to crawl up stairs, and to get down those same steps, we set up a slide. He sends himself head first down to a carpeted landing. Though our therapy friends remind us this habit will be hard to break, they too fall prey to the charms of a toddler and his smile.



## Board of Directors

Tristin Gorski  
wendy0gorski@gmail.com  
317.1546

Gary Timothy  
gftimothy@hotmail.com  
321.5523

### ADVOCACY

Kim Wilcox  
jkwilcox@gci.net  
344.9249

### EDUCATION

Molly McCarthy  
akmollymac@gmail.com  
346.3475

### NEWSLETTER:

Jenny Weaver  
jweaver@mtaonline.net  
982.5446

### PARENT PACKETS:

Rose Fitch  
rosemariam@gci.net  
231.2360

### PULL-TABS

Dave Alzheimer

### CHRISTMAS PARTY

Jennifer Curtis  
djcurtis@gci.net  
344-5830

### CHAPTER CONTACTS:

#### WEBSITE

akdownsyndrome.org

#### Facebook

Alaska Down Syndrome Group

#### EMAIL

Alaskads@gmail.com

#### PHONE

(907) 677.6677





AK Chapter National Down Syndrome Congress  
P.O. Box 241886  
Anchorage, AK 99524-1886

wishing you and your family

*a Happy  
Thanksgiving*



### *Help Us Use Bulk Mail*

In order to use the bulk mail rate for our newsletter and other mailings, we need to send out a minimum of 200 pieces. Our membership falls below that by nearly 30. Please consider joining if you aren't currently a member. Or gift a membership to family, friends, or providers.

If you received this newsletter and are not a member of our group. Someone gifted you this newsletter.



## *Annual Christmas Party*

*Saturday, December 1st*  
**3:00 to 6:00 pm**  
Anchorage Christian School  
6575 E. Northern Lights  
Anchorage

*See Constant Contact for  
developing info  
or call Donna Davidson  
with questions  
907.694.2545.*