

*Bridget Gillson of Wasilla, sings during her talent showcase for Alaska Miss Amazing.*

*The Sun is Always Rising*

MAY 2015

## Young Ladies We Know Participate in Alaska Miss Amazing

Congratulations to Darci Owens, Lexie Wooster, Bridget Gillson, and Alex Schudel for their participation in the Alaska Miss Amazing Pageant.

The Miss Amazing Pageant began in 2007 and now includes 26 states. Alaska joined in 2014, under the leadership of Angela Pugh.

Last year six ladies participated. On March 21st at Dimond High,



*Darcy Owens strikes a lovely pose in her sash, crown and rose corsage. Photo submitted by Dana Owens*

13 contestants entered this year's pageant in four age divisions and paid the five cans of food that would be donated to local charities.

Darci Owens, from Chugiak, claimed the Teen Crown for ages 16-19. She performed a cup routine for her 2-minute talent showcase.

Lexie Wooster, of Anchorage participated and won royalty status in the Jr. Miss division for ages 20 to 23. She performed a hip-hop dance.

Bridget Gillson, of Wasilla also competed in the Jr. Miss division. Bridget sang a song for her talent.

As part of their honors as Queens, Darci and Lexie have the opportunity to attend the National Miss Amazing pageant in Los Angeles in July. In addition, they will represent at the World Special Olympics Summer Games happening in LA at the same time.



*Lexie Wooster radiates royalty decked out in her Queen ensemble with Right Hand Man, and friend, Alex Schudel. Karen Schudel photo.*

## From the Editor: Spring!

by Jenny Weaver

As usual Spring motivates me to clean up my act and change my ways. I feel especially empowered to do new things. Somehow in my old(er) age, I have this urge to help bring about positive change to my Palmer community. I want to represent for the Matanuska-Susitna Valley and bring together families who experience Down syndrome.

But I'm not quite sure what to do. I plan to attend the film festival we are hosting in Anchorage on May 9 (thank you Wendy Leseman!) to see if those films might provide the beginning of a more structured discussion on Down syndrome in the valley. Time will tell. A dessert social may be a good place to start. I am open to suggestions.

Spring also brings blossoming and great growth as evident in the talents and accomplishments of Darci, Lexie, Bridget, and all the brave contestants in the Alaska Miss Amazing Pageant.

Spring heralds the arrival of new developments like when Donna Davidson and Jennifer Gross recently returned from a national conference in Las Vegas, both brimming with motivation and excitement from ideas and contacts they made. It's easy to understand Jennifer's enthusiasm as the new treasurer; setting up first-time accounts on new equipment. The surprise is that after years and years of work for our organization, Donna Davidson returns full of energy and new ways to help and bring together Alaskan families who experience DS. How very lucky are we to have them both on board and so willing to learn and try new things? How very fortunate to have Donna at the helm! Thank you SO much.

And lastly, with such sadness I report the passing of Linda Wooster, long time supporter and board member of our Alaska Chapter, and mom of Lexie. Surely she is worthy of far more than mere mention in the editor's column, but to be quite frank Linda's death is so sudden that I just can't put into words the disbelief and sincere loss. Our most heartfelt condolences to the Wooster family. How thankful am I to think she spent a portion of her last Christmas working to provide such a wonderful party for us all. We have lost a friend.

Make the most of your Alaska summer! And

## From the President:

by Donna Davidson



### YOUR BOARD AT WORK

The Board sent Jennifer Gross and me outside to a DS Leadership conference in March. It was a wonderful opportunity, and I am so thankful to have been able to go. It gave me many ideas for doing a better job for the Chapter. There is so much "out there" now with technology; it was wonderful for us to connect with people, groups and activities from around the country. In this newsletter and the next I will pass on much of the information collected (we came home with a couple boxes worth of info/books/pamphlets I think!)

The conference was put on by *DS Affiliates in Action* (DSAIA). This is a fairly new group for DS leaders around the country. Its mission is "to support and advance the growth of local DS organizations; to be the conduit of value-driven programs, training and best practices." There were three days full of workshops on leadership, strategic planning, research, learning, fundraising, etc. etc. No time to enjoy the sun, but we sure ate a lot of good food! We also were able to speak with companies that set up on-line fundraising and websites. After teleconferencing later with three companies, the Board decided to setup with STRIDE again, the company that we used last year that works with Buddy Walks only.

(See related articles on pages 4 and 6.)

### National Down Syndrome Adoption Network



Multiply Your Blessings!

The NDSAN would like to add more families like yours to their Adoptive Family Registry.

If you are interested in adopting a child with Down syndrome, contact us today.

National Down Syndrome Adoption Network

Mission: To ensure that every child with Down syndrome has the opportunity to grow up in a loving family.

[www.ndsan.org](http://www.ndsan.org) • [www.facebook.com/dsadoption](https://www.facebook.com/dsadoption)

Adoptive Parent Contact: Stephanie Thompson - [stephanie@ndsan.org](mailto:stephanie@ndsan.org)



# Darci Owens

## Alaska Teen



*submitted by Darci's mom, Dana Owens.*



*Queen Darci poses with sisters, Dani and Drea.  
photo submitted by Dana Owens.*

When Darci was first introduced to the idea of competing in the Alaska Miss Amazing Pageant, she was “interested in giving it a try”. Although Darci is self-proclaimed as “not a girlie girl”, the idea of being on stage, performing her cup stacking routine, making new friends, and experiencing new things are ALL things she definitely enjoys. Her first experience of winning a crown came when she was voted Prom Queen at Eagle River High School in 2014. This positive experience catapulted her confidence and willingness to try new things.

The experience of a Miss Amazing Pageant is, well.... Amazing! So many volunteers make all the girls feel welcome, beautiful, talented, and empowered. All the contestants had a chance to shine in the spotlight. They also were able to practice their communication skills during the interview portion of the evening. The organization truly lives up to its mission statement: Celebrating the abilities of girls and women with disabilities.

After participating in the Interview, Talent, and Evening Wear portions of the competition, Darci won the Teen division. She is looking forward to representing Alaska in the National Miss Amaz-

ing Competition in Los Angeles in late July. While there, Miss Amazing Pageant winners from around the country will also participate in the Opening ceremonies of the World Special Olympic Games. It looks to be a very exciting (and busy) week.

Darci will have a one year reign as Alaska Miss Amazing Teen. During that time, she will participate in community service projects, fund raisers, and make appearances on behalf of the Miss Amazing organization. If anyone has opportuni-

*Girls with disabilities  
can do anything they want.  
They can change the world”.*  
Darci Owens, Alaska Miss Amazing Teen

ties for the Alaska Miss Amazing title holders, please contact Dana @ 242-7867.

After winning her title, The Alaska Star, a local Eagle River paper, interviewed Darci about her experience. When asked what she would like people to know about the Miss Amazing Pageant, Darci gave such an inspiring response; “Girls with disabilities can do anything they want. They can change the world.” Awesome!



*Queen Lexie and Queen Darci with escort Alex Schudel  
at the AK Miss Amazing Pageant.*

*Karen Schudel photo.*

Next year's Alaska Miss Amazing Pageant will take place in March or April of 2016. For more information contact AngelaPugh at [akmissamazing.com](http://akmissamazing.com)



## *The Grant*

“It’s the President Calling!”

by *Donna Davidson*

Early April I called as many out-of-town families as I could to assess Chapter interest in a “Netflix-type” of library. DVDs / thumb drives would be new, state-of-the-art educational information on a variety of topics, mailed out upon request for a few days. Content would be from recent webinars and conferences given by national and international speakers. This program would be a special set-up just for Alaska, by a group called 3 2 1 eLearning.

321 eLearning is an on-line program for “families, educators, and researchers from around the world to connect, share, and learn about Down Syndrome.....a personalized virtual learning for the Down syndrome community.” (For more information visit <http://www.321elearning.net/about-us/>).

All programs are fee based. This program does not work well for Alaska as webinars and conferences are live-streaming. They are not downloadable. Also the time differences can be difficult, though the 2015 eConference was three full days (80 webinars) with speakers from around the world.

3 2 1 eLearning leader Dr. Jennifer Smolka and I wrote a grant to cover the costs of getting content from webinars put onto thumb drives, which would then be sent to us. I would send out a “menu” of all topic titles, and ask people to request what interested them. They would be mailed out to you for several days, then you would need to send it back in a prepaid mailer.

The grant was submitted to the Global Down Syndrome Foundation. We will hear which grant requests are chosen, in June at the NDSC national conference. Karen and Alex Schudel will attend and be our representatives should we prove successful! Also, if successful, you will receive a letter with much more information about how our program will work. There are a number of issues to be worked out yet.



So, back to my original phone calls. It was great having the opportunity to connect and chat with 22 of you. I learned a lot. Of the 22, 20 families were actually very positive about this idea, saying they would be interested in using such a program. That gave me confidence to go ahead and write the grant. I also realized by counting our children’s ages, that almost exactly half of our children with DS are over the age of 22 ! So there is a huge need for adult-oriented information. To those I was able to reach, thank you for taking time with me.

*Karen Schudel and Kim Ferko at the recent Baby Fair in Anchorage at the Egan Ctr. Saturday April 18th.*

*Thanks to all our volunteers for their time and energy.*

*Our booth looked great!*



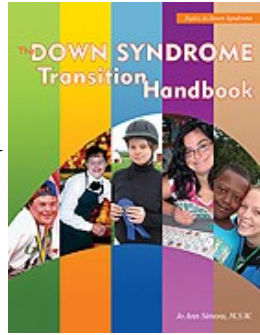
## BOOK REVIEW

### DOWN SYNDROME TRANSITION HANDBOOK

*Charting Your Child's  
Course to Adulthood.*

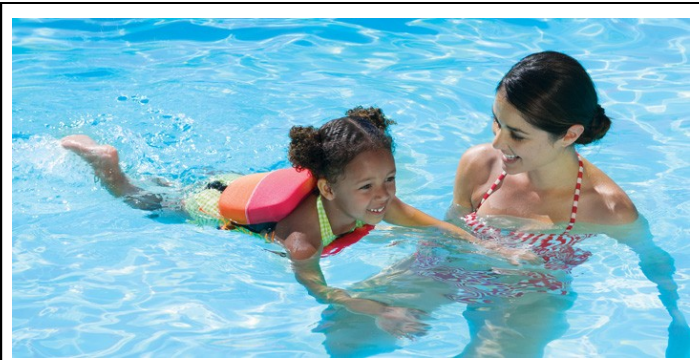
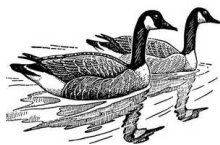
by Jo Ann Simons, MSW.

Submitted by Donna Davidson



This is another of the good books put out by Woodbine House – the publisher that has so many wonderful family-friendly books about DS as well as a variety of other disabilities. Those of us who have been through the transition-to-adulthood or who are now experiencing it, know that it can be a rather scary time – a time of knowing you don't know much! Or at least it feels that way. I remember always having ideas of goals and how to achieve them for my son, until we got to the end of schooling. Then it felt like I was on the precipice of a huge void that I had to jump into – or was falling into. I wish I had had this book available.

The writing is NOT textbook style. It is clear, well-organized and full of practical information, making you want to read it all. It will help a family envision and create a future for their child, then develop a transition plan. The first chapter starts with a concise list of steps in transition beginning at ages 13-15. The second chapter is all about getting the most out of high school as you prepare for transition. The following chapters discuss post high school education options, testing pros and cons, legal issues, money concerns, living arrangement options, health, social networks, technology, and the family's role in the child's adulthood. This book will carry you well into adulthood with all the topics that it covers. I believe this is a must-have book – I bought one for myself as there are a few chapters I think I need to read. Available from [www.woodbinehouse.com](http://www.woodbinehouse.com) or Amazon.



## Nifty New Item

Submitted by Julianna Montooth of Dillingham

**POWERSWIMR** - by SwimWays . This is a swim "vest" that advances swim ability at the child's own pace. It has a foam pad at the chest and the back, which cinch snug with side cords. A strap between the legs keeps it from riding up. It leaves arms completely free for swimming, and helps hold the child in a proper swim position unlike a life vest. The two foam pads are actually nine thin pads inside two cases, so one pad (or one each side) can be taken out as the swimmer gains confidence, until all nine are gone! It comes in three sizes and is available through amazing

Alaska Chapter DS Congress Annual

## Family Fun Picnic



**Thursday, June 11**

5:00-9:00 pm

Abbott Loop Community Park on Elmore Rd.

Bring a food item (salad or dessert) to share.

Main course will be chili.

Climb the rock wall.

Enjoy music by the "Main Squeeze."

## Board of Directors

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## Organizations to Note!



*Submitted by Donna Davidson*

**Camp PALS** - a relatively new program, this is a one-week sleep away camp for individuals with DS and their peers. It is a unified camp similar to Camp Shriver – individuals are paired with volunteer peers for an experience of a lifetime. Currently there are 6 locations across the country, and take campers ages 12-18, 14-21, or 21-30 depending on location. One project at the camp is for campers to write letters of congratulations and welcome for new parents of babies with DS. Email [jenni@palsprograms.org](mailto:jenni@palsprograms.org) for info.

**TRIPS, Inc.** - all-inclusive vacation packages for travelers ages 16 and up. They have been in business 24 years. One chaperone for every 3 to 4 travelers. Wide variety of vacation locations. A bit spendy, but apparently quite amazing. [www.TRIPSINC.com](http://www.TRIPSINC.com)

**International DS Coalition (IDSC)** - “support for families.” This group connects people via small chat groups on Facebook. There are groups for a variety of ages, or interests, including brand new parents. They also have an ebook “*Real Families, Real Stories: Celebrating Life with Down Syndrome.*” The book is also available at Amazon. [www.groups.theidsc.org](http://www.groups.theidsc.org)

**Down Syndrome Diagnosis Network (DSDN)** - strong support for families with a new diagnosis, either pre or post birth. They organize small online groups for new families, and have excellent information for physicians about how to deliver the diagnosis and connect families. [www.dsdiagnosisnetwork.org](http://www.dsdiagnosisnetwork.org)

**DSA of Queensland, Australia** – they have a great looking reading program, that would be good for homeschooling or extra support at home. Numerous other resources as well, such as articles on behavior as communication and how to help your child learn and info for new grandparents. Well worth perusing this website. [www.dsaq.org.au](http://www.dsaq.org.au)

**International mDSa** = a group for Mosaic DS. An online information source, though personal connections are made. It is the only group for mosaic DS. [www.imdsa.org](http://www.imdsa.org)

*Thanks to all who contributed to this edition of The Sun. Please remember that we relay information here, but you must make your own choices regarding organizations, their mission, and their intent. We appreciate any and all feedback! Apologies in advance for all errors! The editor*

## #15in2015 Passes 100



### Changing the Face of Beauty <sup>co</sup>

-founded by Katie Arends Driscoll of Illinois, launched a social media campaign called #15in2015 on Nov 1st, 2014. The program grew from her desire to see her daughter's disability represented in retail ad campaigns. She publically challenged Ellen DeGeneres, family, and friends to call out their favorite retailers with a video or a picture and ask them to include models of all abilities in their advertising. She believed the more consumers ask for change, the greater possibility change will actually happen. She hoped to convince 15 businesses to embrace her idea in 2015.

In December, after cutie pie Izzy Bradley was featured in a Target ad, her mom, Heather Bradley of Down Syndrome Diagnosis Network (NSDN), reached out to push this campaign further. It eventually went global. In mid April, Driscoll announced that the campaign received verbal commitments from over 100 companies to include models with disabilities in their 2015 campaigns.

For more information visit <http://5boysand1girlmake6.com/>



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*Anchorage vs. Mat-Su in Special O state floor hockey. Bobby Hill #20 in the goal, Glacier Morrow from Mat-Su #15 in blue.*

## *Upcoming Events*

### ***FAMILY PICNIC***

Thursday, JUNE 11 5-9  
*Abbott Loop Community Park*

### ***BUDDY WALK***

Saturday, AUGUST 1 10:00 am

### ***ANNUAL MTG***

Friday & Saturday, NOV. 13 & 14  
*Changepoint Church*  
Multiple workshops covering all age groups.  
*Featuring Sue Buckley of England.*

### ***CHRISTMAS PARTY***

Saturday, DECEMBER 5  
*Changepoint Church*

## **Fall Workshop with Sue**

Our November workshop with Sue Buckley is shaping into an excitingly inclusive event. Buckley is interested in presenting a Friday workshop on ages 5-15 to cover effective education for children with Down syndrome. Teachers, related professionals, paraprofessionals, and of course, parents are invited. Friday night we will host a late-teen/adult discussion group for parents and youth 16 and above. Saturday, Buckley will look at supporting development in children ages 0-5 for parents, early intervention and preschool professionals. Although these are general guidelines, Buckley claims anyone can attend any and all. Stay tuned for updates and registration info. *Begin now to plan for possible travel to Anchorage and join us for this unique opportunity!*