

Down Syndrome Advocates in Action; A New Down Syndrome Support Group

It is hard to believe that just one year ago, Down Syndrome Advocates in Action had not even been thought of. Yet here we are, a year later, and we are now incorporated, have a board, officers, a new website and a passion for helping families and individuals who are part of the Nebraska Down syndrome community.

It was during October last year that we sat down and decided what kind of group we as parents would like to be a part of. A group:

- where individuals with Down syndrome are encouraged to be self-advocates
- that supports families with younger children who are still in school or about to start school
- that acts on ideas and gets projects done in a timely manner
- that engages community members with current information from the Down syndrome community
- that makes decisions about the programming events they offer based on input from families.
- that is an active advocate in local and state government
- that works with other support groups who serve the disability community to achieve common goals
- that welcomes individuals with Down syndrome of any age

DSAA Nebraska was not created to replace participation in existing support groups, but rather to give families additional resources and support. Please feel free to share our website www.dsaane.org and/or our Facebook page [Down Syndrome Advocates in Action Nebraska](#) with anyone who might be interested in finding out more about the group. You can also join our new private Facebook group [DSAA NE](#).



In This Issue

- ◆ The New Support Group
- ◆ National Down Syndrome Awareness Month
- ◆ 321 Resource Library
- ◆ NDSC Convention
- ◆ LB-891

From The BOARD



Deb Safarik & Angie Willey

We are currently working towards becoming a 501(c)3 organization. If you are interested in becoming part of our advisory board, please contact us at:

DSAA Nebraska

6425 Taylor Park Dr.

Lincoln, NE 68510

402-413-0199

dsaaofne@gmail.com

www.dsaane.org

Happy Fall! It may have seemed like it was a quiet and relaxed summer, but let us assure you that we have been working hard to put the pieces in place to move forward as an organization. There is much to share about what we've accomplished in the past few months.

The most exciting news is that we have officially incorporated as a Non Profit in the State of Nebraska. We are no longer just a grass roots movement, and are excited to make this announcement.











As you probably know, LB 891 has been signed into law by Governor Ricketts this past spring. This law will help ensure that any family receiving a new diagnosis of Down syndrome will receive accurate, up-to-date and non-biased information, anywhere in the state. We helped review and create the document that new families will be given when they receive the news of a new diagnosis. Finally, we hosted a Pot Luck Picnic, and helped put on the ONE Coalition swim parties and Husker Heroes Event.

We are proud to provide your family with additional opportunities to advocate and support your loved one with Down syndrome. By sharing our website and Facebook information with others you help us to grow as a community so we can plan additional opportunities for support and advocacy. Thank you for your continued involvement and support to your Nebraska Down syndrome community! If you have not visited yet, we encourage you to go to www.dsaane.org and check out our new website. DSAA Nebraska is an organization for families by families, and we invite you to share any ideas or suggestions for information you would like to see on the website.

*Deb Safarik, President DSAA and
Angie Willey Vice President, Secretary DSAA*

DSAA Out and About

DSAA leaders have been busy welcoming new members, offering programs, hosting fun events and promoting awareness in the community. Check out what we've been up to.

- | | |
|------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|  Officially Incorporated as an Organization |  Sent representatives to ONE Coalition meetings |
|  Supported families by attending their child's IEP |  Helped organize and volunteered at the ONE Coalition Husker Heroes Event |
|  Provided resources to families at the ARC Transition Workshop |  Networked with other resource groups at the NDSC Convention |
|  Provided resources to families at the Eastern Nebraska Transition Conference |  Created a 321 Resource Library where families donate no longer used equipment and developmental toys to loan to other families |
|  Hosted a Pot Luck Picnic | |
|  Peer Presentation at a local elementary school | |

Our Mission

is to advocate for the value, acceptance and inclusion of people with Down syndrome.

Advocacy in ACTION

OCTOBER IS
DOWN SYNDROME
AWARENESS MONTH.
THERE ARE LOTS OF MYTHS
ABOUT DOWN SYNDROME.
GET EDUCATED, BE INSPIRED!



Go to www.dsaaane.org to learn more.

OCTOBER IS...

DOWN SYNDROME
ACCEPTANCE MONTH

Proud participants
in the 31 for 21
challenge to blog
about individuals
with Down syndrome
every day during the
month of October. CLICK
HERE to find out more.

Sponsor a Poster

Just \$10 will sponsor a poster to be displayed in a local business, library, church or school, to promote Down syndrome advocacy & acceptance during the month of October. If you would like your child featured on a poster, just email a photo to us at dsaaofne@gmail.com, and let us know which poster you like best. We will send you a digital version to share socially.

Printed posters will be ready in just a couple days and you can choose to post them in your favorite establishments, or let us post them in various spots around Lincoln. You can see posters at the ARC, Nebraska VR, Easterday Rec Center, Libraries and schools and more.



There is a new t-shirt design popping up on our Facebook feed that says "October is Down syndrome awareness month, but for us, it is also January, February, March, April, May, June, July August, September, November and December". This statement is true for many of us. We don't get to take a break from advocating for our loved one with Down syndrome, and we don't want to. We have come far, but there is still more work to be done to achieve acceptance for our friends and loved ones with Down syndrome. There are many stories of discrimination against people with disabilities; many stories of lives not being valued as they should be. So, however we choose to advocate, it is so important that we do. Because it's not just about being aware of a syndrome. It is about looking past the stereotypes to see that each person with Down syndrome has hopes, dreams and abilities and are worthy members of society.

So even though we advocate all year long, and will continue to do so, October is a great month to put a little extra into our efforts. This year we will be participating in the 31 for 21 blogging challenge. Every day in October, we will be sharing a fact or story to help promote acceptance. We encourage you to check out the daily posts and share them to help spread even more awareness.

Be sure to check out the Down Syndrome Awareness Poster Campaign on the left side of the page that describes how your child can be featured on a poster that can spread positive awareness in a local establishment during the entire month of October. We will also run a few contests on our face book page, so be sure to like our page and connect with us on our website. You might win a prize that will help you spread Down syndrome awareness.

Finally, on October 28, 2016 we will be wrap up our month long advocating campaign with a Down Syndrome Awareness Month Ball Night at St. Mark's church. Families and extended families are invited to join us for a free night of basketball, pizza, karaoke, pumpkin decorating and more! The event runs from 5:30 to 8:00 pm and will be fun for the whole family.

We encourage every family touched by Down syndrome to do something a "little extra" to celebrate Down syndrome Awareness Month in October. If you need ideas, or suggestions, please contact us, we would be glad to help!

Education CORNER

National Down Syndrome Congress Convention 2016 by Angie Willey

The Willey family was once again blessed to be able to take part in the NDSC Annual Convention held in Orlando, Florida near the end of July. There were over 80 sessions available for families to help them learn the latest information to become better advocates for our loved ones with Down syndrome. I presented and shared information about the benefits of using Sign Language with hearing children to build language and communication, and also got to spend some time in the Kids Camp, where the little ones had fun singing songs and signing along with them.

Our family's favorite part of the NDSC convention, is the feeling that it is a big family reunion. From catching up with families that you met during previous conventions, to connecting with a new families facing similar issues, everyone at the convention does a great job at making you feel like you are part of the family.

One of the highlights this year was meeting the cast of "Born This Way".

Megan, John and Sean all had self advocate booths in the exhibitor hall (across the aisle from my Signing Time booth) and it was fun to watch the cast members and their families interact with each other on a personal level without cameras around. They also did a some speaking at the convention, signed autographs and took lots of photos with their many fans. Many of the fans were star struck and rightly so. The show recently won an Emmy for their efforts. Each and every one of these kids were fully included in school and it shows. It was inspirational to see them in person.



Another, high point of the week for us was the food. This might seem strange, but with Ben's recent diagnosis of Celiac Disease, having safe food readily available, was such a blessing. The NDSC purposely chose a venue that had excellent chefs that understood Celiac Disease, gluten free diets, and cross contamination. The current estimate is that up to 1/3 of

individuals with Down syndrome also have Celiac Disease. The newest recommendation is that individuals with Ds get a blood test for Celiac every year along with their Thyroid blood tests. While the blood test alone is not the sole method of diagnosis, it can indicate if further testing is required.

The 2017 convention is going to be held in Sacramento on July 20-23rd. Many local agencies are able to offer scholarships. Contact us if you would like more information. If the convention is something you can fit in your summer schedule, I highly recommend it.



Share it!

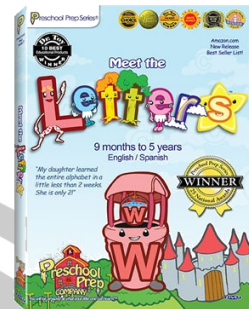
If you know of an event, activity or social outing that might interest other families in the area, let us know! E-mail dsaaofne@gmail.com with all the info so we can share it with our community.

Mark Your CALENDAR

October is Down Syndrome Awareness Month- follow our blog to see daily posts about Down syndrome, and feel free to share them and spread awareness throughout the month.

Trick or Treat Resource Fair. October 27, 2016 5-7 pm at the Firefighter Hall at 241 Victory Lane, Lincoln NE. Trick or Treating for the kids and Resources for parents. Bring a dish to share at the pot luck dinner.

Ball Night Down Syndrome Awareness Month Celebration October 28, 5:30 –8:00 pm , St. Mark's Church. Let's celebrate all the great advocating we have done during October with a Party! Join us for a fun night of pizza, basketball, karaoke, pumpkin decorating, and more! Register at dsaane.org so we make sure to have enough pizza!

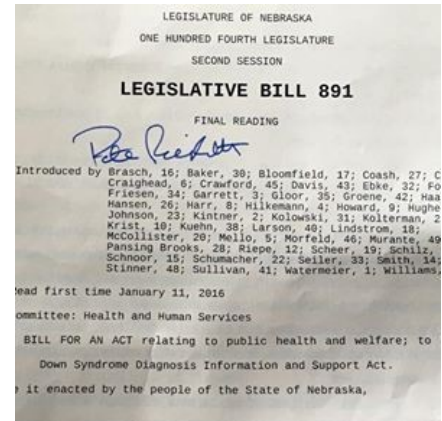
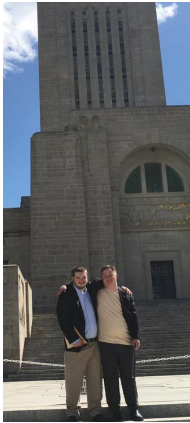


321 Resource Library

We have a new program for the families in the Nebraska Down Syndrome Community. The 321 Resource Library will not be a library that houses books, but instead will have gently used therapy items, large strollers, education materials and more. We are currently looking for donations for items that were especially helpful for your child when they were younger, but might not be of use any more. DSAA will store these items and loan them to families when needed (deposits may be required for large ticket items). One of first and most exciting items we already have, is a Maclaren Major Elite Stroller developed for journeys of short duration for children up to 110 pounds who need minimal postural support. Thank you to the Rohrer family for donating it. This item will be available to check out for short periods of time and is perfect for vacations where extra walking might make fun days difficult for our kids. We also have a weighted exercise ball great for babies who need to work on trunk strength and some educational videos for kiddos wanting to work on sight words. Please contact us 402-413-0199 if you have items you would like to donate or if you are interested in checking something out.

ADVOCATE

LB-891 - A Pro Information Bill



As you may know, LB891 Down Syndrome Diagnosis Information and Support Act passed the Nebraska legislature and was signed by Governor Ricketts!. That meant that the Nebraska Down syndrome community had to work together to create the document that is posted on the Department of Health and Human Services website. The due date was July 22, 2016 and the website and printable PDF went live on that date. Here is a link to the [web page http://dhhs.ne.gov/publichealth/Pages/DownSyndrome.aspx](http://dhhs.ne.gov/publichealth/Pages/DownSyndrome.aspx) and the [PDF document](#) that families who receive a new diagnosis of Down syndrome will be receiving in the State of Nebraska. You may recognize a few familiar faces in the photos. We are always looking for more photos for this document, please contact us if you would like more information about the photo requirements.

You Spoke - We Listened

Thank you to everyone who took the time to connect with us on our website www.dsaane.org. The questions you answered will help us develop programs and activities as we continue to grow our organization. Families in Nebraska deserve an organization that really listens to what they need and want from a support group. We want you to know we take your responses very seriously. The families that have connected with DSAA are most interested in these areas:

1. Educational Opportunities
2. Local Events & Activities
3. Advocating Opportunities
4. Peer Presentations
4. IEP Support
5. Networking Opportunities
6. General Down Syndrome Information
7. Parent to Parent Support

However, we know that as your loved one grows, priorities change. But don't worry, we will keep asking. If you have not connected with us on our website, go to www.dsaane.org and let your voice be heard. Look for future surveys and please take the time to answer and let us know how our efforts can best be put to use to serve you. You are also welcome to contact us at any time with suggestions, ideas, or if you would like support at your IEP or a presentation for your child's peers.



WISH LIST

STAY CONNECTED

E-News Blast

Office Supplies

Forever stamps
Bubble/padded mailing envelopes
Paper goods (plates, towels, etc.)
iTunes gift card (app-downloads)

321 Family Support Items-

To be gifted to families experiencing hospital stays.
Gift cards to local grocery stores
Gift cards to local gas stations
Gift cards to local restaurants

321 Resource Library Items-

Strollers, therapy items, developmental toys
that your child has outgrown, that can be
loaned to another family and put to good use.

Are you receiving our e-mails? We send out an e-news blast several times a month filled with information, reminders and upcoming events. We also send e-mails when we have last minute special opportunities that you won't want to miss. Please contact us with your current e-mail address so you don't miss out on anything!

BLOG STORIES

We would love to be able to share some of your personal stories on our blog. Have you thought to yourself that you would love to share you family's story? E-mail dsaaofne@gmail.com and we will be happy to publish it for you. Your story may be inspiring to another family. We can provide prompt answers to your questions and all the help you need to help write it!