

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

Late last fall, Deb Safarik and Angie Willey realized that after a year of not being involved with the leadership of a local Down syndrome association, our strengths and abilities were not being fully utilized. We missed helping families and individuals with Down syndrome and being part of the planning and decision making process. When brainstorming about what type of group would best meet the needs of the Down syndrome community, the words *advocates & action* kept coming up.

We decided we want to be 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

Right now [Down Syndrome Advocates in Action Nebraska](#) is a grassroots effort, led by people with a passion to help, some experience under our belt, a [mission statement](#) to guide us, and a history of getting things done. While we have only been serving in our new capacity a short time, we have already accomplished a great deal in the first quarter of 2016.

DSAA Nebraska was not created to replace participation in existing support groups, but rather to give families additional opportunities and support. Please feel free to share our website www.dsaane.org and/or our public 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](#).



Senator Lydia Brasch, Tom Venzor and advocates from the Nebraska Down syndrome community who personally met with senators to talk about LB 891

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From The FOUNDERS



Founders

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:

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Happy Spring! We send this newsletter to you just after a very busy season at DSAA Nebraska. There is much to share about what we've accomplished in the past few months. For example, with your help we have achieved the following:

We started the year by rolling our new support organization complete with website where you can find links to important information and resources. If you have not visited yet, we encourage you to go to www.dsaane.org and check it out. 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.

Next, we are extremely proud to share that YOUR Down Syndrome Advocates in Action hosted our first Down Syndrome Awareness Mall Walk to raise positive awareness about Down syndrome and to promote a healthy lifestyle for those with Down syndrome and their families. It may have been snowing outside, but the weather in the mall was a comfortable 70 degrees.

As you probably know, LB 891 has been signed into law by Governor Ricketts! 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.

Finally, we hosted a parent coffee, Signing Time class and helped put on the ONE Coalition Valentine Day Dance.

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!

Deb Safarik and Angie Willey

DSAA NE 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.

-  Hosted 1st Annual Down Syndrome Awareness Mall Walk
-  Hosted a parent coffee
-  Helped put on the ONE Coalition Valentine's Day Dance
-  Attended the ARC Senatorial Dinner
-  Hosted a free sign language class
-  Spoke to Senators about LB 891
-  Testified on behalf of LB 891
-  Attended Signing Ceremony by Governor Ricketts to declare March 21st as World Down Syndrome Day in the state of Nebraska
-  Attended the Signing Ceremony by Governor Ricketts for LB 891
-  Supported a family by attending their child's IEP
-  Spoke about Down syndrome for World Down Syndrome Day at a local elementary school

Our Mission

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



Advocacy in ACTION

Check Out How We Celebrated World Down Syndrome Day!

Down Syndrome Awareness Mall Walk

Thank you for everyone who came to our first ever Down Syndrome Awareness Mall Walk. The event was held to help spread positive awareness about Down syndrome and to promote a healthy lifestyle by encouraging individuals to walk laps around the mall. For each mall lap completed, walkers were given a raffle ticket to try to win a selection of raffle prizes. Congratulations to Sue, Kira and Tara for winning Royals tickets, a 4 night stay in Branson, and a Down syndrome awareness basket. Individuals with Down syndrome and their families all enjoyed a free ride on the mall carousel and received a random act of kindness card, with a coupon for a free Subway cookie or Applebee's Kids Meal. A Huge thank you to everyone who came and to the following organizations for their generous donations! Applebees, Auntie Anne's, Ben's Brigade, Casey's General Store, Gateway Mall, Indoor Entertainment of Nebraska, The Kansas City Royals, Noodles & Company, Raising Canes, Runza. The Rose Theater, and Subway

Down Syndrome
Advocates in
Action



Would Like To Extend A Huge
Thank You
To Those Who Donated To Our Walk!



WDSO T-Shirts Still Available In A Few Sizes

Get yours while they last! These are not dated or branded and can be worn year after year. Call the office at 402-413-0199 to order yours. Now just \$10 each.

World Down Syndrome Day Awareness Video— <https://youtu.be/o3VAWHQMF8Y>

DSAA Nebraska Down Syndrome Awareness Mall Walk 2016

Thank you for helping us celebrate World Down Syndrome Day!



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

May 14th, Saturday—Transition Workshop If you know someone ready to leave high school and go out in the world or someone who already made the transition, this workshop is for you. Join the ARC and AFN on May 14th from 10am - 4pm at the Bryan Plaza and hear from Courtney Miller, Director for the Division of Developmental Disabilities and members of the Lincoln Public Schools Transition Staff. There will also be 3 breakout presentations about Social Security, guardianship/power of attorney, & Able accounts/Special needs trusts.

June 4 - July 16 Saturdays Homer's Heroes Baseball League, Sponsored by Lincoln Optimist Clubs of Lincoln. Register by May 19th to get a t-shirt. <http://www.jrsaltdogs.com/divisions/homers-heroes/>

ONE Coalition Swim Nights, Star City Shores, Lincoln NE. June 4th 8:30-10 pm, July 2nd 8:30-10 pm, August 20th 6:30-8 Pm. These will be sensory friendly swim events without loud whistles or music. Register at <http://onecoalition.weebly.com>

ADVOCATING AND WHAT IT MEANS TO BE AN ADVOCATE BY Deb Safarik

We've been talking a lot about advocating and what it means to be an advocate. Too many times we think that advocating is synonymous with fighting. Fighting for our child's rights. We fight for opportunities, for curriculum accommodations or modifications. We fight for our children to be included with their peers. We fight for meaningful ways to test just what our kids have learned and understand.

All of this advocating/fighting is real, legitimate and important. But there are other ways to advocate that don't have to make us feel like we are sometimes "at war" with the whole world.

We advocate for our kids when we include them in our day to day activities, take them on errands with us, go to their siblings games or concerts, enroll them in typical activities like swimming lessons, summer programs, sports programs, going to the library story time, or going out to eat, etc. Taking advantage of age appropriate activities for our kids helps create awareness, it allows the public to see and be around our kids, we build awareness and advocate that they are a part of our community.

Of course sometimes it's not easy. Sometimes these experiences need some modification and extra support. We need to teach our kids how to act appropriately in public. There needs to be consequences if a behavior problem occurs; natural consequences are best. I told all my kids, including Paul, if they wanted to come back to somewhere they had to be willing to leave. I made up this great scenario that the next time they asked me to say, go to the park, I needed to have a good memory of how nicely they left when it was time to go. Otherwise, I said, if I remembered how they kicked, screamed and ran away, I certainly wouldn't want to go through that again! (I told the story with great drama. I think it made an impression.)

Parents are the experts on their kids. We know how they react in new situations, but they can also learn and grow from being exposed to different opportunities. Pre-practicing how to act in a challenging situation really helps. Pre-talking how things will go helps. Being sure you have favorite toys, snacks, friends or family along will help your kids feel more comfortable.

It's important to not always take "no" for an answer. I remember if I was reasonably sure I was putting Paul in a situation I knew he would enjoy I either didn't give him a choice or if he said, "no" we still did it. Getting comfortable in a new situation takes a little practice for any of us, even more so for our kids.

Advocating can be a fight but it can also be a way to bring awareness to others so they know how great our kids are, what they can do, and how they are more alike than different!

Education CORNER



Summer Safety and Atlantoaxial Instability

With the warmer weather, many families find themselves spending an increased amount of time outside. There are balls to be thrown, bubbles to be blown and sidewalks that need decorated with colored chalk masterpieces. Just like their typically developing peers, individuals with Down syndrome want to go out and enjoy the nice weather. As parents this can some time cause concern, since some kids with Down syndrome don't always recognize dangerous situations. There are also popular outdoor activities that can pose an extra danger to individuals who have Trisomy 21. Here are a couple things to think about before you and your family head outside to play this spring and summer.

Individuals with Down syndrome are at an increased risk of **atlantoaxial instability**, a serious disorder where there is increased mobility between the first and second cervical vertebrae (atlantoaxial joint). Injuries to this area can result in spinal cord damage. The most recent [2011 Guidelines for Individuals with Down Syndrome](#), published in the journal *Pediatrics*, now recommends that regular x-rays are not accurate for diagnosing AAI and instead the parents should be educated about the symptoms to watch for and high risk activities should only be attempted with direct professional supervision. Symptom include neck stiffness and pain, reduced balance, vertigo, gait disorder and paralysis. High risk activities include contact sports, gymnastics, diving, horseback riding, trampolines and bouncy houses.

For further details, we reached out to Dr. Maegen J. Wallace, Pediatric Orthopaedics, Children's Hospital & Medical Center Asst. Professor, University of Nebraska Medical Center who gave us the following details; "As pediatric orthopaedic surgeons we commonly see injuries from trampoline use. These injuries are often sprains and fractures from falls on the trampoline, falls off of the trampoline and collisions with other trampoline users. Most injuries occur in children ages 5 to 14 years of age when unsupervised and 2/3 occur when two or more children are on the trampoline at the same time.

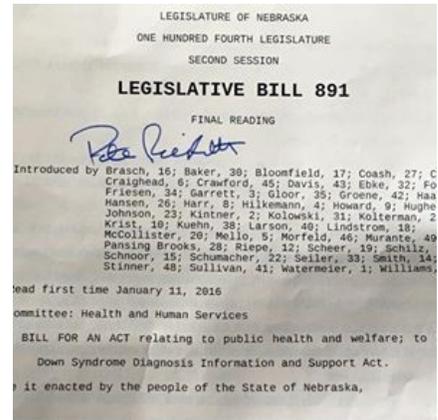
The American Academy of Orthopaedic Surgeons has felt that injuries from trampoline use are so common that it has published a position statement on trampoline use in children. The highlights of the position statement are to not allow trampolines to be used unsupervised by an adult, only one person on the trampoline at a time, the trampoline jumping surface should be at ground level, protective padding on bars and springs should be in place, and no children under the age of 6 should use trampolines.

Other high risk activities include bouncy houses and even monkey bars. The biggest thing parents can do to help prevent injuries is to supervise their children during activities and not allow more than one child on equipment at a time. Parents have to remember that being vigilant in supervising their children is important but even the most vigilant parent cannot prevent all injuries from occurring."

As always, it is up to us as parents to determine the level of risk we are comfortable with for our children. Part of being a strong advocate, involves educating ourselves about the risks involved with the activities our kids participate in, so we can provide appropriate levels of support and make informed decisions that align with our values. If you would like additional information to help you advocate for your child, go to <http://orthokids.org>



LB-891 - A Pro Information Bill



LB891 Down Syndrome Diagnosis Information and Support Act has passed and been signed by Governor Ricketts!

We would like to thank everyone in the Nebraska Down Syndrome Community who advocated on behalf of families yet to receive a diagnosis of Down syndrome. Nebraska joins 12 other states who have passed a similar law. A special thank you goes to Tom Venzor, for proposing the idea, to Senator Lydia Brasch who sponsored the bill and to the 43 other senators who signed on as co-sponsors.

When meeting with Senators to discuss the bill, almost all asked why this needed to be a law. They each felt that accurate, non-biased and immediate information should already be provided to families receiving a diagnosis or screening test results.. Unfortunately, far too many of us know this is not happening. Previously, a prenatal diagnosis was most often delivered by a specialist who dealt with high risk pregnancies and had experience delivering an unexpected diagnosis. Even with all that experience many families still report receiving out of date information or being pressured to terminate their pregnancies. Now, however, a new screening is available called Cell Free DNA screening. This checks for genetic issues, but also allows an expectant couple to find out the sex of the baby very early in pregnancy. For this reason, obstetricians and family practice physicians are being asked to order the tests, but they may not be prepared or equipped to deliver the news that a baby has a high likelihood of having Down syndrome. This law will make it easier for any physician who orders the test to deliver results and provide up to date, non-biased information and allow families to be better informed so they can make decisions that align with their values.

Now that the law is passed, the Nebraska Down syndrome community must again work together to get the information on the Health and Human Services website so that doctors can access the information. Until that time, our website lists some of the best resources for medical professionals who want to learn more about delivering a new diagnosis. <http://www.dsaane.org/medical-professionals.html>

The passage of this law shows that by actively advocating and collaborating with others in the Down syndrome community we can accomplish great things!

For details about the LB 891, please refer to the following information about the Down Syndrome Diagnosis Information and Support Act.

[Legislative Summary](#)
[Official Bill as Introduced](#)



You Spoke - We Listened

Thank you to everyone who took the time to become a member 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 organization. We want you to know we take your responses very seriously. Here are the areas DSAA members are most interested in, based on the number of responses each received:

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. 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.

By working together we can accomplish many great things!





WISH LIST

Office Supplies

- Forever stamps
- Bubble/padded mailing envelopes
- General office supplies
- Paper goods (plates, towels, etc.)
- iTunes gift card (app-downloads)
- The following items will be used to support families experiencing hospital stays:
- Gift cards to local grocery stores
- Gift cards to local gas stations
- Gift cards to local restaurants

STAY CONNECTED

E-News Blast

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 contact our members via e-mail 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!

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!