

We Want to Hear - From You

Thank you to those who have already completed our online **Down Syndrome Parent/Caregiver Survey**. We have received a great response so far. Our organization truly wants the input of families like yours, so we can develop new programs and resources to meet the needs of the Nebraska Down syndrome community. This is an anonymous survey as we feel all voices are equally important. If you have not already done so, please complete this survey and help use your voice to advocate for your loved one with Down syndrome. You may choose to answer all the questions, or choose the ones you feel most important. Please base your responses on any organization that provides services or programming for your loved one with Down syndrome. Your voice is important and we want to hear from you!

<https://www.surveymonkey.com/r/V6HYZDQ>

By working together we can accomplish many great things!



Bailey Graham was all smiles at the Mall Walk for Down Syndrome on March 11, 2017

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Deb Safarik—President
 Angie Willey—Vice President,
 Secretary
 Randy Willey—Treasurer
 Advisory Board
 Shauna Graham
 Sue Rogers
 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

From The BOARD

Happy Spring! We certainly hit the ground running in 2017. After a quick celebration of our first anniversary, we continue to work hard to grow our organization to better support the Nebraska Down syndrome community.

This year started out completely different from last year since we have been officially recognized as a 501(c)(3) not for profit organization in the State of Nebraska. We are excited to start planning fundraisers, and hope to have multiple opportunities for you to support the local Down syndrome community throughout the year.











In March we hosted our 2nd Annual Mall Walk for Down Syndrome. This was our first opportunity to fundraise and families were able to form teams and had the chance to win some fun prizes. The forecast on March 11, was for snow that luckily missed us. However, it did not matter as temperature inside Gateway Mall was perfect for a nice walk. We raised over \$4,000 to help further our mission and provide support to families right here in Nebraska.

The Down Syndrome Diagnosis Information and Support Law just celebrated it's first anniversary. Deb was one of the first Down syndrome leaders in the state approached regarding this bill and she is extremely proud to be able to celebrate this milestone. The law is helping to 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. As an organization, we helped review and create and also update the document that new families are given when they receive the news of a new diagnosis. But our work is not done. There are still many doctors in the state to reach out to, to make sure they are accessing and utilizing the information our group helps to provide.

We are working hard to provide your family with additional opportunities to advocate and support your loved one with Down syndrome. By completing our survey, and sharing our website or Facebook information with others you can help us to grow as a community. Thank you for your continued involvement and support to help make your Nebraska Down syndrome community stronger than ever! 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.

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.

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|  Received our 501(c)(3) non profit designation |  Hosted our 2nd Mall Walk for Down Syndrome. |
|  Supported families by attending their child's IEP and MDT meetings |  Sent representatives to ONE Coalition meetings |
|  Provided resources to families at the South-east Community College Provider Fair |  Helped organize, coordinate and volunteered at the ONE Coalition Sensory Friendly Valentines Day Dance |
|  Peer Presentation at a local elementary school |  Networked with other resource groups |
|  Recognized Teachers during Inclusive Schools Week |  Maintain a 321 Resource Library where families can donate no longer used equipment and developmental toys to loan to other families |

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 second annual Mall Walk for Down Syndrome. 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. The walk helped us to raise over \$4,000 to further the efforts of DSAA Nebraska.

Congratulations to the Shada, Ahrens and Kolm families who won the Volleyball Tickets, Branson 4 night stay, and Down syndrome awareness basket. Individuals with Down syndrome and their families also enjoyed a free ride on the mall carousel.

We would like to extend a Huge thank you to everyone who participated and to the following organizations for their generous donations! Terry Rogers, Attorney at Law, Ben's Brigade, EnAble Nebraska, Cornhusker Bank, Gateway Mall, Indoor Entertainment of Nebraska, Auntie Anne's Pretzels, Casey's General Store, Raising Canes, Runza, Dickey's Barbeque, Scooters, Lincoln Children's Museum, Lincoln Children's Zoo, Storm Chasers and Brugger's Bagels.

If you are interested in getting a Down Syndrome Advocate t-shirt we have a limited number available for \$12 each.



THANK YOU TO EVERYONE WHO SUPPORTED THE 2017 MALL WALK FOR DOWN SYNDROME!

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 18th Give to Lincoln Day. Each dollar raised May 1-18th helps DSAA earn a portion of a \$350,000.00 match from the Lincoln Community Foundation.

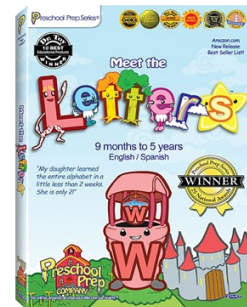
[Donate to Give to Lincoln Day](#)

May 13th, 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 13th 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

June 3 - July 8 Saturdays Homer's Heroes Baseball League, Ages 5-17 Sponsored by Lincoln Optimist Clubs of Lincoln. Register at <http://www.jrsaltdogs.com/divisions/homers-heroes/>

Sibling Workshop— Saturday June 3rd, St. Luke Methodist Church 12-4. [Register here](#)

ONE Coalition Swim Nights— June 9, July 28th and August 11 from 8:30-10 pm. [Register here.](#)



321 Resource Library

The 321 Resource Library is not be a library that only 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 our first items was a Maclaren Major Elite Stroller developed for journeys of short duration for children up to 110 pounds who need minimal postural support. 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.

Education CORNER



JumpStart Learning with Sign Language.

Did you know that by using American Sign Language with your baby, you can help jumpstart their learning and build valuable language skills to help improve literacy and increase verbal speech? While this is true of all babies, it is especially true for our friends with Down syndrome.

You may already know that individuals with Down syndrome tend to be visual learners. For years, I always thought that meant they learned better when they were shown something rather than being told something. While this statement is essentially true, I did not really understand it, until I met a young lady with Down syndrome, who is now a certified ASL interpreter, at the Phoenix NDSC convention. She told me via sign language that, “People with 46 chromosomes primarily think in words while people with 47 chromosomes think in movies and pictures. Therefore sign language is a more natural language for individuals with Down syndrome.” Wow! Talk about a wake-up call. For my son to recall information, he needs to have a photo or visual memory that he can access. So what was I doing to give him that visual image?

It is all about teaching to a person’s strength. When you teach language using sign language, it gives an individual with Down syndrome a picture or a video clip they can access at a later time to help them learn and recall language at a much faster rate. Add in the written and spoken word along with the sign language and you are teaching what is known as “Total Communication”. You may have heard this term from your Early Intervention Team, but it is just as possible you have not. You are your child’s first and best teacher. Don’t be afraid to start them on the right path by doing educational activities like teaching sign to build their language.

When is the best time to start teaching Total Communication to your child? You can start exposing your child to sign language and the written word, as soon as they are able to sit up. You may not see any results for a while, but be assured, your message is getting in. Kids with Down syndrome typically have a much larger receptive vocabulary, than expressive vocabulary. Young children also have the ability to control their hands far sooner than they can control their voice. Beginning signs won’t be perfect, so expect approximations. A great first sign to start with is the sign [More](#). In very young children this sign often looks like a clap. It is important for you to continue to say the word and model the sign correctly, and not copy your child’s approximation. Soon their signs will start to look like yours.

It only takes a few signs to get started. Other first signs include [Mom](#), [Dad](#), [Eat](#) and [Milk](#). You can focus on just a few signs that work within your daily routine or sign as many words as you know all the time. Once you master the first few signs check out this [free video dictionary](#) to learn up to 500 more signs that you can teach your baby or young child.

A great tool for teaching total communication in a fun and musical video format is Signing Time. Videos that can be re-played over and over again, can give a child the repetition which is needed to move the information to their long term memory. Some kids with Down syndrome even learn to sight read from Signing Time videos. These are such a great resource, I want to make sure everyone in the Nebraska Down syndrome community gets a chance to try it. **From now until the end of 2017, I am offering a free, digital Baby Signing Time, Volume One video.** You can keep it for yourself, or share it with someone with a new baby. [Click here](#) and use **Coupon Code: *stabst1*** to get the free video, you can download and watch instantly on a phone, computer or tablet.

ABC Signing Kids



Advanced Instructor

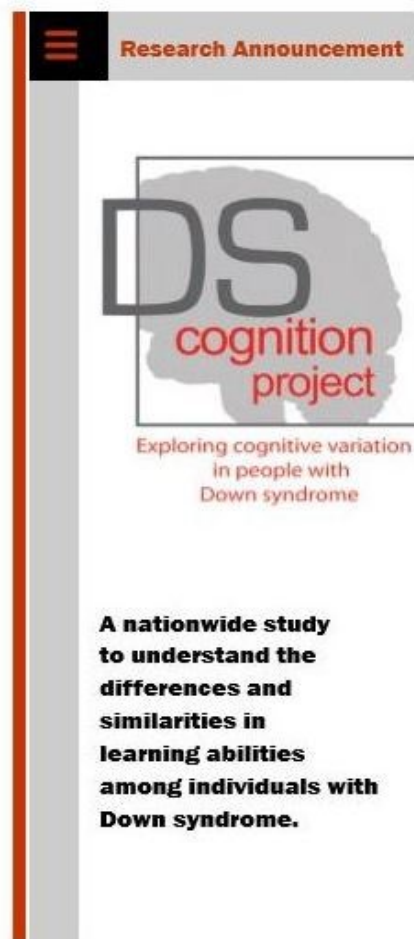
I am happy to answer any questions you might have about teaching sign language to your child! Feel free to contact me at abcsigningkids@signingtimeacademy.com

Angie Willey, Advanced Signing Time Instructor and Mom to Ben, age 9 with Down syndrome.

RESEARCH OPPORTUNITY

How much does genetics influence learning and behavior in children with Down syndrome?

The Down Syndrome Cognition project is a large scale, multi site, national research study being funded by the LuMind Foundation. The goal of this study is to understand more about how children with Down syndrome learn and problem solve. They are also gathering information about certain medical conditions related to Down syndrome to determine how they may affect learning abilities



Who can participate in the study? Individuals with Down syndrome who are between the ages of 6 and 25 years. A short eligibility screen will determine participation.

What will participants be asked to do for the study?

Parents will be asked to complete short questionnaires on medical history and their child's adaptive (self help) skills. These may be completed online.

Mothers will be asked to complete a 45-minute phone interview covering medical and family history and environmental exposures.

Participants will provide a small blood sample which can be coordinated with a medically necessary blood draw, and parents will be asked to give a small saliva sample.

Participants will be asked to attend an in-person (2-2 1/2 hours) testing session. Most of the testing is done on the computer and will seem like computer games.

If a minimum of 5 local families get chosen to participate, they can send a representative to the Lincoln area to do the personal interviews here.

Are you interested in applying to be a part of this exciting research?
For more information contact:

Debra Rose Hamilton, MA, PsyS
Emory University School of Medicine
Atlanta, GA 30322
Office: 404.778.8481
drhamil@emory.edu

Tracie Rosser
Emory University School of Medicine
Atlanta, GA 30322
404-778-8474
trosser@emory.edu



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!