

JULY/AUGUST/SEPTEMBER 2014

CONGRATULATIONS, GRADUATES!

Adam Gearhart and Austin Kuszak

DSAF is proud to congratulate Adam Gearhart and Austin Kuszak, who recently graduated from Lincoln Southeast High School.

Prior to graduating, Adam received a letter in Special Olympics basketball. He enjoys playing defense and stealing the ball. Adam still remembers the first time he made a basket during a game. The Lincoln Southeast Special Olympics teams allow graduates to continue to participate, so Adam will continue to be part of the basketball and bowling teams next school year. Adam will also play Homer's Heroes baseball this summer. Adam and his family have been members of DSAF for about 18 years. Adam's favorite DSAF event is the annual Step Up for Down Syndrome Walk and his favorite program is the monthly teen night.

Austin also received a letter in Special Olympics basketball and will continue to participate on the Lincoln Southeast basketball and bowling teams next school year. Austin loves sports and looks forward to weekly practices. Austin believes that especially in sports like basketball, teamwork is very important and enjoys that aspect of the game. Go Knights!



Adam Gearhart



Austin Kuszak

Congratulations to Adam and Austin, their families, and to all DSAF members who graduated in May. We wish them all of the best as they journey on to adulthood!



Austin Kuszak and Adam Gearhart

Teen/Young Adult Group - **Third Tuesday of each month at 6 pm**. Contact Janette Johnson at janettej@windstream.net for more information and to get signed up for the monthly reminder list.

Super Stars (ages 5-12) - **July 10, 2014**, movie "Earth to Eco" at Edgewood Theater, 5200 South 56th Street, Lincoln. Time TBA and will be posted on DSAF's website. Includes 2 admissions, a small pop & popcorn.

Lil' Stars (ages 0-5) - **July 12, 2014**, 9:30 - 11 am, "Meet Me at the Park" at Taylor Park. Playground entrance is off of Taylor Park Drive & Parkvale near 66th and "O" Street. In case of rain, the play date will be held at the nearby home of Deb Sefarik. Contact Kathryn Brockmeier at kathryn.brockmeier@gmail.com for details.

Picnic and Swim Party - **July 27**, **2014 5 pm** at UNI Park (49th and Garland). Drinks. table service, hotdogs, brats, hamburgers and the fixings will be provided. Please bring a family sized side dish or two to share. The UNI Pool is reserved just for our group from 6 - 7:30 pm. Extended family is welcome.

Parents Night Out - August 2, 2014, 6 pm at James Arthur Vineyards. Parents Night Out is for all our parents to come get to know each other and share experiences. There will be a band (Honeyboy Turner Band - Best of Blues) playing and food available for purchase at the winery.

Lil' Stars (ages 0-5) - August 18, 2014, 5:30—7:30 pm at Chet Ager Play Center, 1300 S. 27th St. Pizza included. Need to bring socks and be under 48 in. to play in bigger structure.

Step Up for Down Syndrome Walk - October 4, 2014, at Antelope Park, Lincoln. Teams are forming fast! Go to the DSAF website and click on the Step Up Walk tab for more information.

6th Annual DSAF Pumpkin Patch - October 11, 2014, at Roca Berry Farm in Roca.

Education Conference - November 15, 2014, beginning at 8 am at Country Inn & Suites, 5353 N. 27th St., Lincoln. DSAF will host a number of national and local specialists presented in a multi-track format so you can tailor your conference experience to your current interests. Mark your calendars now, more details to follow.

Lil' Stars (ages 0-5) - **January 21, 2015**, Theatre Event at the Lied Center, Lincoln. Jim Henson's Dinosaur Train Live! This is a Lied "Fam Fest" event so come early for free food and games, show starts at 7 pm. Limited number of tickets (including proximity near stage seating) on sale for \$5 each. Contact Kathryn Brockmeier at kathryn.brockmeier@gmail.com for details.

Registration is recommended for most of these events and is made available on the DSAF website (click on the Events tab).

STEP UP FOR DOWN SYNDROME WALK POSTERS DEADLINE APPROACHING

For every **\$225 raised by August 29**, **2014**, each team may submit one professional photo of their family member with Down syndrome for a fact poster to be used along the walk route (maximum limit of 3 posters per team). These posters are displayed along the entire walk course and contain educational facts about Down syndrome.

The photo sessions this year will be with Erica Thompson at Images for a Lifetime studio in Lincoln. Erica will waive the sitting fee for DSAF members. If you are unable to take advantage of the free photo sessions, we encourage you to have your photographer contact Erica about the design for the posters this year so that we can have a cohesive look. Contact Erica at Images for a Lifetime (402) 325-0057. **Photos need to be taken by early August**.

SPEECH INTELLIGIBILITY: FACTORS AFFECTING UNDERSTANDABLE SPEECH by Libby Kumin, Ph.D., CCC-SLP

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Children, adolescents and adults with Down syndrome have a lot to tell us. But, many times, we cannot understand what they are saying. Speech intelligibility is the term used to describe whether a person's speech is understandable to a listener. Intelligibility sounds like an objective scientific term, but it is not. It is a subjective judgment made by a listener which can be affected by many factors. Not only is the speaker and his speech an important factor, but so are the familiarity of the listener, the type off message being communicated and factors in the environment such as noise. That's why mom, dad, and siblings can understand someone better than someone meeting the person for the first time. That's why an adult with Down syndrome may be understandable saying "hi" and "what's up?", but less understandable when he is trying to tell you about something that happened at school or work. Intelligibility is not static;



it can vary greatly from one situation to another. It is frustrating for a child when we cannot understand what she is trying to tell us. It is also frustrating for parents, families, teachers, and friends to try to guess what the person is saying, to pretend that they understand, nod their heads and respond, when they are not really sure that they got the message right.

Home Activities: What Can You Do at Home?

- 1. Look in a mirror together with your child and have fun moving your lips and tongue:
 - round your lips
 - blow kisses
 - smack your lips
- 2. Use real or toy musical instruments such as harmonicas or kazoos for work on lip movements, as well as breath control. The recorder is an instrument that many children with Down syndrome play and enjoy.

LEARN ABOUT PEER PRESENTATIONS: AUGUST 4, 6 - 8 PM, LOCATION TBA

A Peer Presentation is a 15 to 20 minute classroom or grade level presentation tailored around your child. It addresses any issues that others in your child's class may need help to understand. Often openly discussing Down syndrome will encourage classmates to understand why another child learns or behaves differently. By teaching kids about disabilities, parents can emphasize the need to include and accept children with Down syndrome and offer suggestions on how to include them. Classroom presentations can address concerns or questions and help set minds at ease and show them they really are more alike than different. Many students demonstrate compassion and kindness when they are fully aware that a classmate has a disability. Caroline Fehlhafer and Liz Echternkamp will be showing parents how to give Peer Presentations to their child's classroom. We think this is a great way to help our children succeed in the classroom. Contact lori@dsafnebraska.org with questions.



2014 Educational Conference Join us on November 15, 2014

8 am - 4 pm at Country Inn & Suites in Lincoln, NE

Presentations include:

Dr. Brian Skotko, M.D., M.P.P., a Board-certified medical geneticist and Co-Director of the Down Syndrome Program at Massachusetts General Hospital, will present on:

- Keeping Children and Adolescents with Down Syndrome Healthy
- Celebrating Life with Down Syndrome
- What Your Other Children with Down Syndrome are Thinking: Sibling Issues for Parents





Dr. Skotko co-authored the national award-winning book, Common Threads: Celebrating Life with Down Syndrome and, most recently, Fasten Your Seatbelt: A Crash Course on Down Syndrome for Brothers and Sisters.

Dr. Sean J. Smith, Ph.D. is the Associate Professor of Special Education at the University of Kansas. Sean will have discussions of innovative solutions for students with disabilities, especially those with Down syndrome. To determine the right solution, the presentation will connect the Universal Design for Learning framework to the specific needs of students with Down syndrome. Resources will include apps, mobile devices, social media application, virtual reality and a number of other innovative solutions.

Dr. Brian Belden, Ph.D. is a developmental and child psychologist; Assistant Professor of Pediatrics, University of Missouri-Kansas City School of Medicine. Dr. Belden along with associates Dr. Cy Nadler, Ph.D. and Dr. Jo Ann Youngblood, Ph.D. will present sessions on:

- Behavior Management
- Toilet training

Additionally we will have sessions on:

- Signing Times
- Music Therapy
- Speech

Helping children with special needs reach their full potential!

Registration opens August 1, 2014, at dsafnebraska.org







DSAF 2014-15 SMART START SERIES BEGINS THIS FALL

Look for application forms on the DSAF website beginning in August and register for one or more of the following workshops:

September 20, 2014; 8:30 to 11:00 AM — *Smart Start*: For families of children with Down syndrome ages 4, 5 and 6 years who are anticipating transition to Kindergarten.

November 18, 2014; 8:30 to 11:00 AM — *School Smart*: For families of children with Down syndrome ages 4 to 12 who want to build healthy relationships with school professionals.

January 10, 2015; 8:30 to 11:00 AM — *Friend Smart*: For families of children with Down syndrome ages 4 to 21 who want to encourage and support their children's friendships and active social life.

February 28, **2015**; 8:30 to 11:00 AM — *IEP Smart*: For families of children with Down syndrome ages 4 to 12 who want to understand the assessment requirements for eligibility and school performance in special education and inclusive programs and how to contribute to development of meaningful Individualized Education Plans (IEPs).

All sessions will be held on UNL's East Campus. Facilitators are DSAF parents and local teachers. Free to DSAF members (annual membership is \$10).

S.E.A.S. SCHOLARSHIPS AVAILABLE

DSAF's S.E.A.S. program provides scholarship reimbursement for paraprofessional support so a child with Down syndrome can attend a summer workshop or camp. For program details please refer to the Guidelines for the S.E.A.S Program and Application for S.E.A.S Scholarship Reimbursement accessible from DSAF's website or contact DSAF.

<u>CONTACTS</u>

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UPCOMING STEP UP WALK DEADLINES

For every **\$225 raised by August 29**, **2014**, each team may submit one professional photo of their family member with Down syndrome for a fact poster to be used along the walk route (maximum limit of 3 posters per team). For details, see article on page ### of this newsletter.

Corporate donations and logos will be accepted until August 31, 2014.

Each person who registers as an Adult, Virtual Adult, Child or Virtual child and submits payment before **September 14**, **2014**, will receive a free limited edition 2014 Step Up Walk t-shirt. Each shirt will have the team name in large letters on the top back of the shirt at no additional cost. The color of the shirts have not yet been decided.

Submit a Stars Tent bio and photo by September 14, 2014.

Please browse the Step Up website, http://www.ezeventsolutions.com/fr/DSAF/StepUp2014, utilize our resources, read our e-mail blasts, and join the Facebook group (https://www.facebook.com/groups/dsafnebraska/).