

## REMARKABLE TIMES AT LINCOLN EAST HIGH

By Janette Johnson

As parents of children who look "different," we never really get used to stares from kids and adults alike. But for Jimmy, throughout his school years in the Lincoln Public School District, it has been "Hi, Jimmy." He has loved his high school experience at Lincoln East High School. Football players ask him to sit and eat lunch with them. He can't go down a hallway in school without students and teachers acknowledging him. The football players initiated Jimmy's involvement in running the flag onto the field before home varsity games. Last year, Jimmy was given the "most spirit" award by the students at their fun award night. East was recently recognized for their recycling efforts—Channel 8 news interviewed students about their involvement,



and, yes, they interviewed Jimmy. In September 2015, the students at East voted him as Homecoming King. This is **remarkable** and the students at East are **remarkable**. These students who showcase their talents on the field, in the classroom, on the stage, and in other endeavors, see beyond themselves and chose to share the spotlight and share opportunities with Jimmy. It leaves us speechless. Kudos to Jimmy, Lincoln Public Schools, Lincoln East students, and to all the **remarkable** schools and students in our lives!

## ACADEMIC INFORMATION FOR HIGH SCHOOL SENIORS

Do you have a graduate who wants to pursue further education but does not meet entrance criteria or does not possess the necessary navigational skills? Kennesaw State University Academy for Inclusive Learning and Social Growth has a different path for those who learn differently. Please contact Katherine Rigsby at 470-570-4880 or Jill Sloan at 470-578-2283 for more information.

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## DSAF MEDICAL OUTREACH AWARDED GRANT

On September 11, 2015, the DSAF Medical Outreach program was honored to receive a \$500 grant from the Lincoln South Rotary Club Foundation. The Foundation supports nonprofit organizations promoting youth and education. The Foundation awards grants to organizations that foster and develop the ideal of service in the community. The DSAF Medical Outreach Committee applied for the grant to help offset the expense of supporting more families than expected this year. Due to the Committee's efforts to increase awareness of DSAF in the medical community, we are now getting more calls than ever! This is an excellent example of serving the needs of the community. We are thankful for the generosity of the Lincoln South Rotary Club Foundation and proud of the DSAF Medical Outreach Committee.



DSAF Medical Outreach Committee Chair Alicia Bruning attended a wine tasting hosted by the Lincoln South Rotary Club Foundation where the Committee was awarded a grant to help cover the costs of outreach to families who learn their baby has Down syndrome.

## MEMBER ACCOMPLISHMENTS



Paul Safarik won gold medals in unified doubles tennis and doubles tennis events during the fall 2015 Nebraska Special Olympics. Paul played on a Tennis Buddies Team and his Sharks soccer team also won a silver medal. Way to go, Paul!



Natalie Powers was voted to the 2015 homecoming court at Lincoln North Star high school. Congratulations, Natalie!



## RECENT DSAF EVENTS



July 24, picnic and swim party



Sept. 13, Husker Heroes



July 24, picnic and swim party



Oct. 3, Capital City SUDS walk



Aug. 22, 'Lil Stars at the Ager Center

## UPCOMING DSAF EVENTS

Moms' Night Out - **November 6**, 6:30 pm at Wilderness Ridge, 1800 Wilderness Woods Place, Lincoln.

Lil' Stars (ages 0-5) - **November 13**, Wiggle and giggle with Kindermusik classes with Shawna Gordon at the East Lincoln Christian Church located at 7001 Edenton Rd. There will be a class for ages 0-2 at 6:30 pm and a class for ages 3-5 at 7:10 pm. Registration is free.

Teen/Young Adult Group - **November 17**. We will bowl two games at Parkway Lanes starting around 5:30 pm. Contact Janette Johnson at [janettej@windstream.net](mailto:janettej@windstream.net) for more information and to get signed up for the monthly reminder list.

Christmas Brunch - **December 12** (check calendar for time), at Firespring, 1201 Infinity Ct., Lincoln.

Teen/Young Adult Group - **December 15**. We will bowl two games at Parkway Lanes starting around 5:30 pm. Contact Janette Johnson at [janettej@windstream.net](mailto:janettej@windstream.net) for more information and to get signed up for the monthly reminder list.

**Registration** is recommended for most of these events and is made available on the DSAF website, [www.dsafnebraska.org](http://www.dsafnebraska.org) (click on the Events tab).

## DS-CONNECT®: THE DOWN SYNDROME REGISTRY

DS-Connect® is for people with Down syndrome. We hope that DS-Connect® will answer two important needs. First, doctors taking care of people with DS and scientists studying DS need first-hand information to understand how DS affects people. Second, they need to find new educational, behavioral, and drug treatments and study whether they are effective in people with DS. This Registry will help to find those people who might be eligible to take part in these studies.

There are several ways DS-Connect® can help people with DS and their families and caregivers. The Registry can connect its members with information about the larger DS community, including DS family organizations. DS-Connect® can provide information about DS to people with DS and their family members. It can also provide yearly updates about the medical care that is recommended at the current age of the person with DS. DS-Connect® can give people with DS and their family members information about new findings and treatments for DS. It can provide a list of doctors and other healthcare providers in their local community. In addition, DS-Connect® can let people with DS (or their family members) know when they may be eligible for new research studies. Any DS-Connect® participant can look at the grouped results to learn how often a response is given by other members of the Registry. Finally, DS-Connect® can be a useful way to store medical information about the person with DS, including growth charts and summary reports that can be shared with doctors.

By collecting information about people with DS, the Registry may be a catalyst for research that benefits people with DS. A registry can:

- Help connect people with DS who may be interested in participating in research to scientists who study DS.
- Speed up research in DS by collecting information that scientists can use.
- Help scientists learn why people with DS have different symptoms.
- Help healthcare providers improve how they treat people with DS.
- Advance our understanding about how and why certain treatments work or don't work by quickly publicizing the results of studies on DS.
- Help scientists develop and test new treatments for people with DS
- Encourage new scientists to conduct research on DS

For more information about this National Institutes of Health (NIH) sponsored program, visit <https://dsconnect.nih.gov/>.

## ABLE ACT UPDATE

The Nebraska Legislature quickly responded to the recent historic passage of the federal Achieving a Better Life Experience ("ABLE") Act. The Nebraska Achieving a Better Life Experience Program ("Nebraska ABLE") was signed into law on May 27, 2015. These new laws will allow Nebraskans with certain disabilities, for example Down syndrome, and their families to open tax-advantaged savings accounts to pay for certain disability-related expenses. Subject to certain conditions and within specified limits, funds in these Nebraska ABLE accounts will also have the advantage of not effecting eligibility for SSI, Medicaid, and other public benefits. The Federal Treasury has proposed new federal tax regulations related to the ABLE Act and had a public hearing on its proposed rules on October 14, 2015. The Nebraska State Treasurer, who is trustee of the Nebraska ABLE, is moving forward and hopes to have ABLE accounts available to Nebraskans as soon as possible in 2016. The Nebraska Treasurer issued a Request for Proposals (RFP) for investment and administrative services for the ABLE Program and is currently working through the RFP process. We anticipate that Nebraskans will use ABLE accounts as affordable and beneficial tools for financial planning for individuals with Down syndrome.

### CONTACT US

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DSAF is seeking new board members and volunteers. Please contact Jodi White, Program Director, to express your interest in becoming involved.



**Down Syndrome Association  
for Families (DSAF)**

P.O. Box 57362  
Lincoln, NE 68505

Return Service Requested

Mission Statement: The Down Syndrome Association for Families is a Lincoln based non-profit organization that provides support for individuals with Down syndrome, their families, friends, educators and professionals who share in their lives.

Every person with Down syndrome is an individual who has a unique purpose and abilities. DSAF provides networking and a positive vision for the future.

Website: [www.dsafnebraska.org](http://www.dsafnebraska.org)  
Telephone: 402-421-1338

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**CAPITAL CITY STEP UP FOR DOWN SYNDROME WALK - OCT. 3, 2015**

**Estimates — Raised: \$81,000+**  
**Teams: 77 Registered walkers: 1,700+**



It was a beautiful day! A big thanks to the families, friends, co-chairs Jennifer Brill and Jamie Bertucci, volunteers, fundraisers, donors, and sponsors who participated! Look for additional information and results in upcoming DSAF publications.