



heart of illinois

Down Syndrome Association

Newsletter

October 2019

*Contact Us:*

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The Heart of Illinois Down  
Syndrome Association, Inc. is a  
501(c)3 not-for-profit organization.

*The Heart of Illinois Down Syndrome Association, Inc. is committed to improving the quality of life of persons with Down syndrome by providing support, advocacy, and educational opportunities to those individuals, their families and community advocates.*



**Calendar of Events**

- |                        |  |
|------------------------|--|
| <b>Mon. Nov. 4th</b>   | <b>Board Meeting—6:00pm</b><br>Hy-Vee, Sheridan Rd, Peoria                     |
| <b>Tues. Nov. 12th</b> | <b>Young Adult Cooking Class—7:00-8:30pm</b><br>Bethel Lutheran Church, Morton |
| <b>Sat. Nov 16th</b>   | <b>Coffee Social—Open House - 9:00-11:00am</b><br>The Spot Coffee, Peoria      |
| <b>Mon. Dec. 2nd</b>   | <b>Deadline to make nominations for Board of Directors vacancies</b>           |
| <b>Sun. Dec. 8th</b>   | <b>Family Holiday Party—9:00am-Noon</b><br>Knights of Columbus, Peoria         |
| <b>Tues. Dec. 10th</b> | <b>Grandparent's Group Meeting—6:00pm</b><br>Perdue's, Tremont                 |

This newsletter publishes items of interest relating to Down syndrome and other disability issues. The Heart of Illinois Down Syndrome Association, Inc. (HOISDA) does not promote or recommend any therapy, treatment, institution, professional system, etc. Individuals or organizations referred to are not necessarily endorsed by this publication or its editor. We hope to bring together those interested in Down syndrome and attempt to create an optimistic future and attitude. The editor reserves the right to make corrections as are appropriate and in accord with established editorial practice in material submitted for publication.

# Greetings From The President

Birthdays  
Next  
Month

October 2019

## Happy Down Syndrome Awareness Month!



It's a perfect salutation this month. Wish everyone you see a happy Down syndrome month. It's an easy way to get someone's attention and use the opportunity to explain why we celebrate the abilities of people with Down syndrome.

If "Happy Down syndrome month" isn't in your comfort zone, try wearing mismatched socks, wear a blue and yellow lapel ribbon, take a poster to school that shows people with Ds in every walk of life or explains People First language.

People First language is putting the person first and the descriptor to follow. For instance, she is a person with Down syndrome, not a Down's girl.

Many of our families even have fundraisers to bring attention to the fact our family members have more similarities with their non-disabled peers than differences.

Be creative and enjoy this chance to celebrate Down Syndrome Awareness Month!

Meri

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### November

Steven Knaack  
11/3  
Courion Williams  
11/10  
Reagan Dunaway  
11/15  
Alex Tucker  
11/15  
Uriah Tierra  
11/16  
Logan Serrano  
11/18  
Quinn Hayes  
11/21  
Blade Glover



*Just by shopping at  
smile.amazon.com,  
the AmazonSmile Foundation will  
donate 0.5% of your purchases to  
the Heart of Illinois Down Syndrome  
Association, at no cost to you!*



**Support  
Heart Of Illinois Down  
Syndrome Association Inc.**

When you shop at **smile.amazon.com**,  
Amazon donates.

[Go to smile.amazon.com](https://smile.amazon.com)

**amazon**smile



**COFFEE SOCIAL  
OPEN HOUSE**

Saturday, November 16th  
9:00-11:00am



Join us for a very informal, relaxed social time  
for families to meet other families and little  
ones with Down syndrome.



RSVP to Amanda Nauman  
309.360.1133

9901 N. Knoxville, Peoria

*The next*  
**GRANDPARENT'S  
GROUP** *meeting*

Tuesday December 10th @ 6pm

**Perdue's**

201 S. Sampson Street  
Tremont IL

*an informal evening with casual conversation*

Contact Mike King with any questions  
[mwking@rocketmail.com](mailto:mwking@rocketmail.com)

*Save  
the  
Date*

**HOIDSA Family Holiday Party**

Sunday, December 8th  
9:00 am - Noon

Knights of Columbus  
7403 N. Radnor Rd, Peoria

**Memorial/Recognition Donations**

**Our sincerest appreciation to all the family and friends who contributed to the following donations:**

- **Memorial donations in honor of Dave Mattheessen, Hayden Mattheessen's father**
- **Donation from Ellen Palladini**
- **Donation from Jane Wahl, Nathan Parks' grandmother**
- **Donation from Kay Dunn, Robert Bettenhausen's grandmother**

The Heart of Illinois Down Syndrome Association, Inc. warmly accepts memorial donations of any amount. Since we are a volunteer organization, all dollars received go toward fulfilling our mission of improving the quality of life of persons with Down syndrome. The Heart of Illinois Down Syndrome Association, Inc. is a 501(c)3 not-for-profit organization and all contributions are tax deductible.

For more information call 309-712-4852. Pre-printed memorial envelopes are available.





**315 participants  
this year**

## THANK YOU!

### TOP FUNDRAISING TEAMS

The top fundraising teams  
this year are:

Decker's First Dash  
The Caz Crew  
C's Team

### TEAMS WITH THE MOST WALKERS

The top teams with the most  
participants this year are:

Decker's First Dash  
S'Miles Ruder  
The Caz Crew

The Walk committee wants  
to express a sincere  
**THANK YOU** to all our  
sponsors, volunteers,  
families, friends, and the  
surrounding community for  
their support, dedication,  
and work to ensure our walk  
was a huge success!

**Avanti's of Peoria  
Brewers Distributing  
Eastland Suites  
Par-A-Dice Hotel & Casino  
PRP Wine International  
Pizza Ranch  
McDonald's Restaurants –  
Clark Management LLC  
Uftring Auto Group  
Rick and Mary Brown  
John and Christy Getz  
Andrea Eertmoed  
Photography  
ICC Baseball Team**

**Children's  
Hospital  
of Illinois**

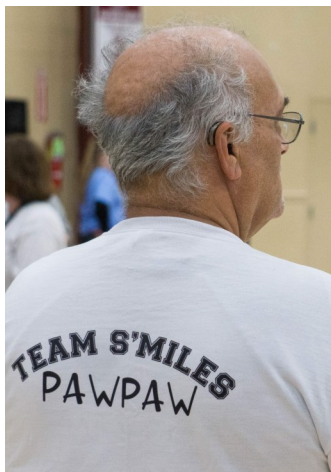
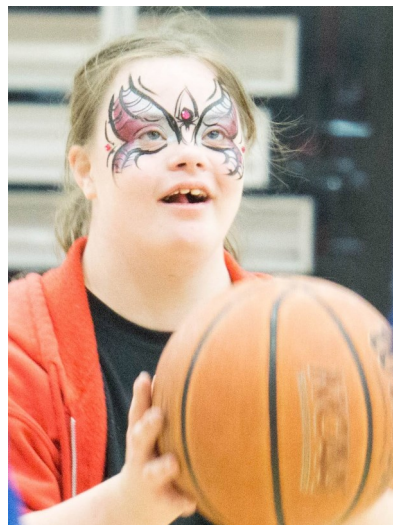


**to ALL our SPONSORS, VOLUNTEERS, and FAMILIES  
for Making HOIDSa's 11th Annual Friends of HOIDSa  
Walk for Down Syndrome a Success!**

Congratulations to Decker's First Dash as the top fundraising  
team and the team with the most walkers!









# Power of the Point: Predictors of Early Language Development in Down Syndrome Research Study

## What are we studying?

We are recruiting mothers and their 18-to-24-month-olds with Down syndrome for a research study on what skills support early language development.

## What will we do?

Toddlers and their mothers will be asked to play with toys, complete an assessment of language & cognitive abilities, & complete questionnaires 3 times over a 1-year period.

This will take 1.5–2 hours at your home, our lab at the University of Illinois, or a location near you.



## Are there any benefits?

You and your child will receive \$20 for each visit.

You will contribute to a growing body of research looking at early language development in Down syndrome.

## Find out more!

For more information, contact the Development in Neurogenetic Disorders Lab:



[thedndlab@illinois.edu](mailto:thedndlab@illinois.edu)



(217) 265-8043



Development in Neurogenetic Disorders

**I ILLINOIS**

Speech & Hearing Science  
COLLEGE OF APPLIED HEALTH SCIENCES

IRB #20065



## **Board of Directors Vacancies**

*The Heart of Illinois Down Syndrome Association would like to add at least 4 people to our Board of Directors to fill vacancies and expand our leadership. The Nomination Committee seeks candidates that are passionate about helping people with Down syndrome reach their full potential.*

*Board members will*

- serve a three-year term*
- attend monthly board meetings*
- participate on at least one committee*
- help develop and oversee the operating budget*
- provide input to direct the Board's efforts*

*HOIDSA is specifically looking for candidates in the following areas:*

- representing adults with disabilities*
- families with young children*
- educational expertise/school districts*
- relationship with the medical community*

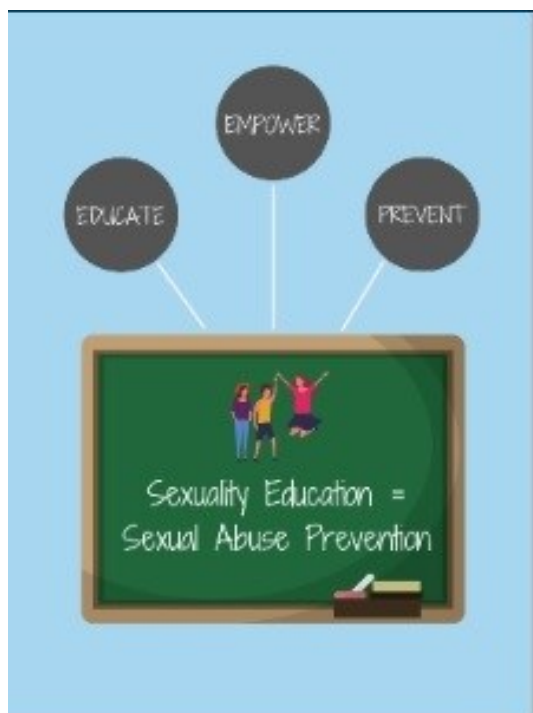
We will accept nominations through December 2<sup>nd</sup>. Vacancies will be filled at a later board meeting after all candidates have been considered. If you are interested, or know someone who would be a great addition to our Board, please contact us at 309.712.4852 or [info@hoidsa.org](mailto:info@hoidsa.org).

## **Education Committee Volunteers**

HOIDSA is looking for a few dedicated volunteers to take the reins of our Education Committee. The position requires the Chair and Committee to secure speakers, facilities and complete the necessary paperwork.

HOIDSA is fortunate to have many experienced former Committee members who have offered support with planning. With so many successful conferences under our belts, there are many templates available to the Committee to follow or edit.

If you are interested or have any questions, please contact us at 309.712.4852 or [info@hoidsa.org](mailto:info@hoidsa.org).



**ELEVATUS TRAINING**

LEADERS IN SEXUALITY AND DEVELOPMENTAL DISABILITY



## ONLINE WORKSHOP SERIES

### **Preventing Abuse: Helping Self-Advocates Become Sexual Self-Advocates**

FOR EDUCATORS, PROFESSIONALS  
AND SUPPORT PEOPLE

**You are invited to attend:**

### **Preventing Abuse: Helping Self-Advocates Become Sexual Self Advocates**

**Thursday, November 21, 2019 from 2:00 PM - 3:30 PM  
(eastern)**

**Online Workshop Series:**

**Preventing Abuse: Helping Self-Advocates Become Sexual Self-Advocates**

We know the rate of sexual abuse among people with I/DD is very high, 7 times higher than the general population. And, we also want people with I/DD to lead full, healthy lives and have relationships that are enriching, supportive, and not exploitative. One way to help prevent abuse, and support healthy, satisfying relationships is with sexuality education that teaches self-advocates to become sexual self-advocates.

This online workshop will cover the knowledge and skills needed to achieve this goal. We will explore the latest statistics regarding abuse and learn useful tips and tools for helping people become sexual self-advocates. We will discuss topics to include when working with self-advocates, such as: body parts and body autonomy, skills for saying no, and the difference between a healthy, unhealthy, and abusive relationships.

**For more information or to register, go to**

**<https://www.eventbrite.com/e/preventing-abuse-helping-self-advocates-become-sexual-self-advocates-tickets-74291408603?aff=mcivte>**





## Illinois Life Span Webinars

Join us for lunch time webinars.

November 5, 2019, noon - 1:00 p.m. - **Special Needs Trusts and ABLE Accounts.** Presented by Brian Rubin, Rubin Law.

**REGISTER** for November 5th Webinar

November 19, 2019, 11:00 a.m. - **IL DHS DDD Update and Q & A.** Hosted by the LFA Program and Presented by Allison Stark, IL DHS DDD Director; Ronnie Cohn, Ligas Court Monitor; Donna Frownfelter, Chair, Ligas Advisory Committee; Shirley Perez, Director, Ligas Family Advocate Program

**REGISTER** for November 19th Webinar

**For more information or to register, go to**

[https://thearcfillinois.salsalabs.org/biweeklyeventsemail0\\_copy1\\_copy2\\_copy1\\_copy1\\_copy1\\_copy1\\_copy1\\_copy1?wvpld=b455977c-0f06-448f-801c-b325d0aa4c51](https://thearcfillinois.salsalabs.org/biweeklyeventsemail0_copy1_copy2_copy1_copy1_copy1_copy1_copy1_copy1?wvpld=b455977c-0f06-448f-801c-b325d0aa4c51)

## Know Your Options in Developmental Disability Support

November 14, 2019 in Oak Park, IL

We can help you understand how to build a living arrangement that works best for you and is in line with your hopes and goals. We can answer questions about how CILA or Home-based Waiver funding works, how the PUNS list is utilized, and how support services can be tailored to meet your needs. We can also provide positive examples of how individuals and families have utilized the funding to build the life that they want within their community.

**For more information or to register, go to**

<https://thearcfillinois.salsalabs.org/kyo2019/index.html?eType=EmailBlastContent&eld=1153e764-baf0-4371-bae9-dcd293ffb946>

## Planning for the Future for Children and Adults with Intellectual and/or Developmental Disabilities

Presented by  
Brian Rubin, Attorney/Parent  
Sherri Schneider, QIDP/Parent  
Benjamin Rubin, Attorney/Sibling  
Join us for one of four dates throughout the year to learn more about:

- Government benefits and programs in Illinois for children and adults with special needs and how to navigate the "maze"
- Appropriate special needs estate planning, necessary to qualify for, and in order not to lose, government benefits
- Guardianship and alternatives
- Guidance on preparing instructions and thoughts for future care providers

**For more information:**

<https://thearcfillinois.salsalabs.org/planningforthefuture2019-2020/index.html?eType=EmailBlastContent&eld=1153e764-baf0-4371-bae9-dcd293ffb946>

# Dad with Down syndrome inspires his son — and teaches us all to re-examine our assumptions

Matthew Green | Jun 04, 2019

*Jad Issa's son Sader is studying dentistry and is proud of his father's achievements.*

Jad Issa has Down syndrome, but his life isn't what you might expect. Just ask his wife (who doesn't have Down syndrome)—or his son, who is studying to be a dentist.



[Sader Issa | Facebook](#)

Jad's story recently made headlines when his son Sader spoke about his father in a video published on Facebook, which led to a series of stories and interviews about this remarkable family.

## **A loving father and a responsible provider**

Sader—a strapping young man who enjoys swimming, bodybuilding, studying, and spending time with his friends—lives with his parents in Syria. He's proud of his father; in the video, he says that even if he could, he'd never want to pick someone else to be his father. "I'm proud of him, the same way he is proud of me," he says. This feeling is well-founded; Jad is the family's main breadwinner, and despite the difficulties of his condition, he "tried to do everything to secure a normal life for [me] like any other child," Sader says. "During my studies, he was the biggest supporter economically, psychologically, and in all respects."

As Sader explains in the video, the pride is mutual: "One of the things that I am proud of is when he introduces me to a new person for the first time, and he says, 'My son is a doctor.' You can see the pride and joy in his eyes. It's like he's saying: 'I have Down syndrome, but I raised my son and did everything to help him become a doctor who treats people. I'm proud of him ...'"

Clearly, Jad and his wife were able to provide a more than adequate environment for Sader to grow up healthy, happy, and smart. In Sader's own words, "A child who grows up in the lap of a person with Down syndrome will have all the love and tenderness that anyone can offer. This will lead up



to a person who is emotionally and socially well balanced and is able to achieve anything he wants ... When you see a person, perceived by the community as a vulnerable person or a person who is dependent on the community, who is working hard and trying to do everything to secure everything I need as a small kid ... This will of course push me to do all I can to be the best person [I can be].”

#### **A husband and a friend**

Jad hasn’t only been a good father; according to his son, he’s also a good husband. In his relationship with his wife, “They may disagree sometimes, or not. They have a life full of love, simplicity, and humility in all respects.” In short, Sada says, their relationship is like that of any other couple.

Outside the home, Jad has been working at a local wheat mill for 25 years, and he has good relations with his neighbors and coworkers. “His social relations are simple and pure because he loves everyone and anyone, and in return, all people love and respect him, and treat him like any ordinary person,” Sader explains.

#### **Re-examining what Down syndrome means**

All of this should make us think twice. When most people think of Down syndrome, they think of a life full of mental and physical disabilities, of social isolation, of total dependence on other people’s care, of being a burden ... In short, a life they consider not worth living.

Yet, this view is profoundly and tragically mistaken.

The assumption that people with Down syndrome are doomed. People with this condition can have a wide range of abilities and the fact that he was able to have a son is highly exceptional. However, there’s no way for us to know ahead of time what a person with Down syndrome—or anybody else, for that matter, with or without disabilities, money, social privilege, etc.—will be able to achieve.

Again, Sader says it best: “As a child who grew up with a father with Down syndrome, I know exactly how pure hearted and loving they are but also that they have ambition and drive and deserve a decent life.”





c/o Bethel Lutheran Church  
325 E Queenwood Rd Morton IL 61550

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## EDITOR'S REMARKS

Hello Everyone!

As you know, October is Down Syndrome Awareness month. Our Walk committee did a fantastic job putting together the Walk this year! Thank you to everyone who came out to show their support. I know it's not always easy to take time out of our busy lives, so we appreciate all efforts, big or small, to increase Down syndrome awareness and raise money for our organization. Thank you for making this such a successful event!

If you would like to share pictures of any of your activities for Down Syndrome Awareness month in the next newsletter, please email them to me by November 8th.

*Carol Nepolello*

c.nepolello@comcast.net

## THINGS TO DO

Don't forget to utilize special recreation associations like HISRA and IRVSRA all year around:

**Contact HISRA at 309-691-1929 for more information or visit**  
**[www.hisra.org/programs](http://www.hisra.org/programs)**

**Contact IRVSRA at 309-201-4005 for information or visit**  
**[www.irvsra.org/](http://www.irvsra.org/)**

Follow the Illinois River Valley  
Special Recreation Association on Facebook  
for more information about upcoming events