

### heart of illinois

### **Down Syndrome Association**

### **Newsletter**

November 2019

Contact Us: c/o Bethel Lutheran Church 325 E. Queenwood Rd. Morton, IL 61550 309-712-4852 info@hoidsa.org

#### 2019 Board of Directors

Meri Tucker, Interim President 309.694.2984 endroad@comcast.net

Nick DeTrempe, Vice President 309.868.5810 ndetrempe@gmail.com

Renee Hayes, *Secretary* 309.453.3115 renoslife@yahoo.com

Milly Howeler, *Treasurer* 309.692.3688 millyhoweler@gmail.com

John Getz Mike King Laurie Mattheessen

Trisha Romero

Dianna Shoemaker

Alex Tucker

Editor: Carol Nepolello 309.243.8414 c.nepolello@comcast.net

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

Mon. Dec. 2nd Deadline to make nominations for

**Board of Directors vacancies** 

Mon. Dec. 2nd Adult Holiday Social—6:00pm

Lariat Steakhouse, Peoria

Sun. Dec. 8th Family Holiday Party—9:00am-Noon

Knights of Columbus, Peoria

Tues. Dec. 10th Grandparent's Group Meeting—6:00pm

Perdue's, Tremont

Tues. Dec. 17th Young Adult Cooking Class—7:00-8:30pm

Bethel Lutheran Church, Morton

Mon. Jan. 6th Board Meeting—6:00pm

Fondulac Library, East Peoria

This newsletter publishes items of interest relating to Down syndrome and other disability issues. The Heart of Illinois Down Syndrome Association, Inc. (HOIDSA) 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

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#### November 2019

This time of year, we take a moment to be thankful for all the people who enrich our lives.

29 years ago, this month, we began an unexpected journey with the birth of a child with Down syndrome. We were so unprepared! Fortunately, we were surrounded by people who were.



We were given contact information to a parent group by some of the professionals working with our family. That group has grown into the non-profit of which you are now a member. The Heart of Illinois Down Syndrome Association, Inc. has been the backbone of our education, support and activism. Some of the best people in the world are members of this wonderful organization.

You are encouraged to engage with HOIDSA on any level you can. You will be enriched for it with knowledge, inspiration, support and camaraderie.

Many years have passed since we traveled down this path. We couldn't have imagined how fulfilling and rich HOIDSA has helped make it. Thank you to all of you!

Happy Thanksgiving!

Meri

Birthdays Next Month

#### December

Dan Schwenk 12/4 Evan Loring 12/6 Jobee Artis 12/7 Justin McCunn 12/9 Victoria Williams 12/15 Christopher Moore 12/19 Annie Perkins 12/23 Kaitlin Moore 12/25 Brett Campbell 12/27 Elinn Hooker 12/30 Cameron Booth

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!



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### <u>Inside this Issue</u>

Content	Page
Calendar of Event	s 1
Adult Holiday Social	3
Family Holiday Party	3
Grandparents' Group	3
Volunteer Opportunity	4
DS Research Stud	у 6
DS Diagnosis Survey	7
Greetings from Newsletter Editor	Back Cover
Deadline for Stipends	Back Cover

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'Tis the Sesson for

Celebration

and

Fellowship



for guests high school age and older

Monday, December 2nd

Doors open at 6:00 pm Annual Board Meeting 6:30-7:00 pm

Lariat Steakhouse, 2232 W Glen Ave, Peoria

Variety of Appetizers Will Be Served, Cash Bar \$10 per person will be collected at the door

Dress as your Favorite Holiday Movie Character and have fun playing Holiday Movie Trivia

Please email your reservations by November 25th

to Milly Howeler millyhoweler@gmail.com



### HOIDSA Family Holiday Party

Sunday, December 8th 9:00 am—Noon

Knights of Columbus 7403 N. Radnor Rd, Peoria

Questions?

Contact Meri Tucker endroad@comcast.net or Milly Howeler millyhoweler@gmail.com

# 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



Next cooking class:

December 17th

Bethel Lutheran Church, Morton

7:00-8:30pm

Page 3





### **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.



Join the Registry

Set up a Professional Account

Información en español

### DS-Connect® is a powerful resource where people with Down syndrome and their families can:

- · Connect with researchers and health care providers.
- · Express interest in participating in certain clinical studies on Down Syndrome, including studies of new medications and other treatments.
- Take confidential health-related surveys. These surveys are aimed at better understanding of the health of people with Down Syndrome across their lifespans.

Visit the website at <u>dsconnect.nih.gov</u> for more information





Board members, Alex Tucker, Meri Tucker, and Renee Hayes with son Quinn, picked up a donation check from the Morton Police Department. Sergeant Brock and his fellow officers had a No Shave November campaign in honor of Beth Ruder and her son Miles pictured on the far left.

### **Memorial/Recognition Donations**

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

- No-Shave-November at Morton Police Department (see picture above)
- Maggie Getz's Family Fundraiser
- T-shirt sale at Central School Dist. 51, Washington
- Jeans Day at Pleasant Valley Elementary School

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.

# 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 Neurogentic Disorders Lab:



thedndlab@illinois.edu



(217) 265-8043



Development in Neurogenetic Disorders

### **I**ILLINOIS

Speech & Hearing Science COLLEGE OF APPLIED HEALTH SCIENCES

# SYNDROME DIAGNOSIS SURVEY



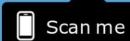
# Your feedback can help shape the future of how parents receive a diagnosis!

This study aims to reassess the information parents deem essential when receiving a prenatal or postnatal diagnosis of Down syndrome. Participation in this study will take approximately 10-15 minutes.

# PARENT SURVEY LINK:

https://uofsc.co1.qualtrics. com/jfe/form/SV\_5hGOU3k gPA2zqcJ





Scan this QR code to automatically load the survey on your phone!

If you have any questions, please contact Meg
Wilkes at
margaret.wilkes@uscmed.
sc.edu or by phone at
(704) 995-0912.

Thank you for your participation!



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EDITOR'S REMARKS

Hello Everyone!

In the spirit of Thanksgiving, I would like to express how thankful I am for HOIDSA and all the great things that this organization does for the Down syndrome community.

HOIDSA is a 100% volunteer-driven organization and could not operate without the dedicated volunteers we have. Please consider serving on the Board of Directors. We need talented individuals who share our passion for improving the lives of people with Down syndrome. You can make a difference!

Wishing you all a Happy Thanksgiving!

Carol Nepolello

c.nepolello@comcast.net

# DEADLINE FOR 2019 STIPENDS

HOIDSA offers each person with Down syndrome a yearly stipend for a recreational activity. Please turn in proof of payment for activities from 2019 to Milly Howeler by December 20th. If you have any questions or concerns, please contact Milly at 309-692-3688 or millyhoweler@gmail.com.

You can request a reimbursement by sending a copy of your receipt to: Milly Howeler 5624 N. Graceland Dr. Peoria IL 61614

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 <u>www.hisra.org</u>/programs

Contact IRVSRA at 309-201-4005 for information or visit <u>www.irvsra.org/</u>