



heart of illinois

Down Syndrome Association

Newsletter

January 2016

Contact Us:

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

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.



2016 Board of Directors

President
Vacancy

Meri Tucker, *Vice President*
309-694-2984
endroad@comcast.net

Milly Howeler, *Treasurer*
309-692-3688
millyhoweler@gmail.com

Laurie Mattheessen

Kim Sarff

Shelli Willoughby

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.

Calendar of Events

- | | |
|-------------------------|--|
| Sat. Jan. 30th | Annual Family Dance Party
6:00pm - 9:30pm
Morton Knights of Columbus Hall
616 David St, Morton |
| Mon. Feb. 1st | Board Meeting - 6:00pm
Bethel Lutheran Church
325 E. Queenwood Rd., Morton |
| Tues. Feb. 9th | Grandparent's Group Meeting - 6:00pm
Cracker Barrel, 150 E Ashland St., Morton |
| Sun. Feb. 14th | Young Athletes Practice - 3:00pm
St. Philomena School, 3216 N Emery, Peoria |
| Tues. Feb. 16th | Young Adults Cooking Class - 7:00pm
Bethel Lutheran Church
325 E. Queenwood Rd., Morton |
| Sun. March 6th | 27th Annual Spaghetti Dinner
11:00am - 6:00pm,
ITOO Hall, 4909 W. Farmington Road, Peoria |
| Tues. March 17th | ACCESS March Madness Experience
FREE Event - see page 8 for details |

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.

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Greetings From Presidential Candidate

January 2016

Hello everyone,
I'd like to take a moment to introduce myself and to let you know how excited I am to be considered for the role of presidency. My name is Shelli Willoughby and I have served on the board during the 2015 year. My family and I have been involved with HOIDSA for many years. My husband previously served on the board for the past ten years. We live in Washington and have three children ages 22, 21 and 15. I work full time at Ameren as a new hire trainer for customer service and have recently gone back to school as well.



Someone once told me, for any organization to have growth it has to get bigger and smaller at the same time. The HOIDSA family is made up of a vast array of diverse and talented members! I'm excited to see what great things we can accomplish together while at the same time, getting to know one another on a deeper level as we support those we love with Down syndrome.

Looking forward to a great year and wishing you all the best,

Shelli Willoughby

Happy New Year
2016



Birthdays
Next
Month



February

Tate Pauli

2/7

Nicolas Carroll

2/8

Abby Reuter

2/8

Andrew Sidwell

2/8

Steven Behrends

2/9

Bo Gill

2/10

Daniel Meyer

2/10

Trevor Kalke

2/19

Jocelyn McDaniels

2/19

David Campbell

2/19

John Deford

2/24

Levi Miller

2/27

9th Annual

HOIDSA



Family Dance Party

Saturday, January 30th, 2016

At the Knights of Columbus Hall, 616 David Street, Morton

6:00 - 9:30 p.m.

FREE ADMISSION*

***Donate non-perishable food items for the local food pantry!**

INCLUSIVE - Casual - Fun for families, teens, kids of all ages!

REFRESHMENTS PROVIDED!



The next
GRANDPARENT'S GROUP *meeting*

Tuesday, February 9, 2016 @ 6pm
Cracker Barrel
150 E Ashland St
Morton IL

an informal evening with casual conversation

Contact Anita with any questions
309-241-8195
hohimer_home@comcast.net

Young Adult Cooking Class

For any member 16 years old and older
3rd Tuesday of the Month

Next class: February 16 7:00-8:30pm
Bethel Lutheran Church
Contact Meri at 309-264-4900



Special Olympics
Young Athletes™

The Young Athletes program is an innovative sports play program for children ages 2-7 with and without intellectual disabilities, designed to introduce them into the world of sports.

All sessions held at
St. Philomena School gymnasium
3216 N Emery, Peoria
3:00 pm – 4:00 pm

Sunday, February 14, 2016
Sunday, March 13, 2016

If interested in participating or volunteering,
e-mail:
youngathletespeoria@yahoo.com

John & Christy Getz
Curt & Amanda Nauman

Board of Directors Nominees

The Heart of Illinois Down Syndrome Association is pleased to announce the following nominees for the Board of Directors:

- Lauren Coyle
- Anita Hohimer
- Anne Hollis
- Christy Sanchez
- Shelli Willoughby for President

Vacancies will be filled by voting at the next board meeting on February 1st at 6:00pm.

Special Recreation Activities: Check Out the Upcoming Activities

HISRA • IRVSRA • Pekin Park District

Contact HISRA at 309-691-1929 for more information or visit www.hisra.org

Contact IRVSRA at 309-699-3923 for information or visit www.fondulacpark.com/specrec.htm

Contact IRVSRA-Pekin Park District at 309-347-7275 or visit <http://www.pekinparkdistrict.org/specialrec>

♦ Calendar of Upcoming Events

♦ Photo Gallery

Visit HOIDSA Online

Website:

www.hoidsa.org

Facebook Page:

<https://www.facebook.com/HOIDSA>

Facebook Discussion Group:

<https://www.facebook.com/groups/HOIDSADiscussionGroup/>



Spotlight on...

We are looking for members to be featured in the "Spotlight On" section of our newsletter.

Let us know if you would like to have your family member with Down syndrome featured in our newsletter. You can write your own article, tell us a story, or answer a few short questions on our interview template.

Send an email to c.nepolello@comcast.net

Memorial/Recognition Donations

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.

Family Matters Workshops Co-Sponsored by HOIDSA

February 23 in Peoria Heights [MAPS - Making Action Plans Helping Us Find Direction](#)

April 19 in Peoria Heights [Examining the Evidence for Inclusion](#)

TIME: 6:00pm to 8:30pm

LOCATION: Heritage Square: Advocates for Access Conference Room Suite C-8

4450 W Prospect Rd, Peoria Heights, IL 61616

Register at <http://www.fmptic.org/events/trainings>

All events are FREE unless noted. Family Matters reserves the right to cancel a training if the minimum requirement of 20 people registered is not met.



Saturday, February 20, 2016
1:00 - 4:00 p.m.
Landmark Recreation Center
Peoria, IL

2ND ANNUAL
**TEAM UP
FOR CHILDREN
WITH DISABILITIES!**

BOWLATHON

Register to bowl by sending an email to info@fmptic.org or you can call 866-436-7842, x3516

Special Education Webinar Series: From Newbie to Ninja

February 4, 2016

Extended School Year Services

Learn what qualifies a student for ESY (Extended School Year services) and what services can be provided.

To Register: <https://attendee.gotowebinar.com/register/7047556543575226882>

March 3, 2016

Productive IEP Meetings

Learn how to prepare for IEP meetings, how to communicate effectively during the meeting, and how to advocate for appropriate services.

To Register: <https://attendee.gotowebinar.com/register/720685162377437953>

Each webinar in the series will be held from 7:00 PM to 8:15 PM.

For questions please call: 1-866-436-7842 x3516

After registering, you will receive a confirmation email containing information about joining the webinar.

Heart of Illinois Down Syndrome Association, Inc.

27th Annual

SPAGHETTI DINNER

Sunday, March 6, 2016 • 11:00 a.m. - 6:00 p.m.



\$7.50/Adult
(13 & up)

\$5.25/Child

Under 3 yrs.
FREE

ITOO Hall

4909 W. Farmington Rd., Peoria, IL

Raffle

Take out orders available

Entertainment

Bake Sale



FUN for the
entire family!

Dinner provided by LaGONDOLA SPAGHETTI HOUSE of Decatur

BAKE SALE: *Calling all bakers - it's that time again!!*

Breads • Brownies • Cookies • Chocolate Treats • Layer Cakes
Pies • Cinnamon Rings • Cupcakes/Muffins • Trail Mix/Chex Mix

We are so grateful for the many goodies you and your families have supplied over the years for our Spaghetti Dinner Bake Sale. We know that we can count on you again to help us raise more funds at this booth! We always have such a nice variety of baked goods, so any of your specialties will be appreciated. If you don't bake, we'll accept goodie bags of candy or feel free to solicit donations from your favorite bakery!

As always, we will be happy to package and price the items on the day of the sale. They will be accepted throughout the day. If you have large quantities, it is best to receive these early in the day. Please mark your containers so we can return them to you. Also, please indicate what flavor the item is if it is not evident. If you cannot attend the dinner but wish to donate to the bake sale, you can arrange to have your items picked up. Please contact Teri Ehrenhardt at (309)467-6113 to arrange for pick up.

Some years we've been sold out before the end of the dinner. Please help keep us supplied throughout the day. Gluten free items and goodies for diabetics are appreciated as well (Chex Mix, Trail Mix, etc.).

PLEASE HELP MAKE OUR 27TH SPAGHETTI DINNER FUNDRAISER A SUCCESS!!!

1. HELP US ADVERTISE!

Download fliers from our website and share with others. Fliers can be found at www.hoidsa.org. Post them at work or on Facebook. Tell everyone you know to come out & have a great meal for a good cause!

2. SELL RAFFLE AND DINNER TICKETS

Please sell dinner and raffle tickets to your family, friends, and co-workers. Tickets are available from Milly Howeler (309) 692-3688.



3. DONATE RAFFLE ITEMS

Raffle items are needed for the main raffle and the baskets. Remember to help by soliciting items and supplying a "theme" basket for the raffle. Please direct all donations through Amanda Nauman at (309)360-1133 or anauman@mtco.com to prevent duplication. Contact Amanda Nauman or Christy Getz at (309)635-7309 or jcgetz94@yahoo.com for more information.

4. DONATE BAKE SALE ITEMS

If you cannot attend the dinner but wish to donate to the bake sale, you can arrange to have your items picked up. Please contact Teri Ehrenhardt at (309) 467-6113 to arrange for pick up.

5. VOLUNTEER

Volunteers needed to help set up, serve, clear tables, and clean up. Send an email to info@hoidsa.org and indicate your preferred job and time slot. Please provide your name, phone number, and email address. (Time slots are 11-1, 1-3, 3-5, 5-7 on March 6th., as well as help setting up at the ITOO Hall on Saturday, March 5th.)

6. MAKE A POSTER TO SHOW OFF YOUR KID

Don't forget to make a poster using a half-size poster board (either horizontal or vertical) with lots of pictures of your child and family for display! Please include your name and contact information on the back if you want your poster returned.



**HEART OF ILLINOIS
SPECIAL RECREATION
ASSOCIATION**



ACCESS the March Madness EXPERIENCE

Come enjoy a special day at the March Madness Experience at the Peoria Civic Center!
HISRA staff and hundreds of volunteers will adapt all of the games and activities in the
March Madness Experience and make them accessible to people with disabilities!

Field Trip Day

Tuesday, March 15, 2016

9:30 am - 2:00 pm

Peoria Civic Center, Peoria, IL

All students with disabilities, group homes residents and members of Special Recreation Associations from around the state of Illinois are invited to join the HISRA staff and volunteers for a day of fun at the March Madness Experience. Doors will open at 9:30 am; come for a few hours or stay and enjoy all of the activities until 2:00 pm. Don't forget to bring sack lunches or money for the concession stand. There are accessible restrooms and a changing area will be set up for your convenience.

Family Night and Special Needs Information Fair

Tuesday, March 15, 2016

5:00 pm - 8:00 pm

Peoria Civic Center, Peoria, IL

Calling all families with children and adult with disabilities from around the state of Illinois! You are invited to join the HISRA staff and volunteers for an evening of fun at the March Madness Experience along with a variety of vendors and support providers who work with people with disabilities! The Special Needs Information Fair is sponsored by the Dunlap and Central Illinois Special Needs Parent Group. The March Madness Experience will be open for this special event from 5:00- 8:00 pm. The concession stand will be open, there are accessible restrooms and a changing area will be set up for your convenience.

Request your FREE TICKETS and FREE PARKING PASSES via e-mail : jwahl@peoriaparks.org

O'Neill Tabani Enrichment Fund

Empowering People with
Down Syndrome to Pursue
Postsecondary Education



Zeshan Tabani + Joshua O'Neill

The O'Neill Tabani Enrichment Fund was established in January 2005 by the O'Neill family to create postsecondary opportunities for people with Down syndrome. Named after their son Joshua, who happens to have Down syndrome, and his friend Zeshan Tabani, the Fund has been able to provide scholarships to more than **110 people** in the last **10 years**.

The mission of the O'Neill Tabani Enrichment Fund is to offer financial assistance to young adults with Down syndrome – 18 and older – who are continuing to enrich their lives by taking classes or enrolling in postsecondary educational programs.

Post-secondary Facts:

- There are 240 college programs for students with intellectual disabilities
- Inclusive higher education opportunities for student with Down syndrome have gained tremendous strides in the past few years
- Benefits to students with Down syndrome, like with any college student, include expanding social networks and increased employment options
- Some student take academic classes for credit while others take classes informally
- All students can learn and benefit from the opportunity to attend college!

In 2015, the O'Neill Tabani Enrichment Fund awarded **21 grants** to students in 16 states

Applications are available now!
To learn more, visit
www.ndss.org/OTEF or email
otef@ndss.org



www.ndss.org



Education News

Governmental Affairs Newsline



Every Student Succeeds Act

The Every Student Succeeds Act (ESSA) replaced the No Child Left Behind Act (NCLB) when the President signed ESSA into law on December 10, 2015. NDSC, representing the Down syndrome community, worked in collaboration with a broad coalition of national advocacy organizations and Hill staff to advocate for the same opportunities afforded non-disabled students.

After 14 years we will have a new law for elementary and secondary education funding that gives the states and districts a great deal of discretion in determining how to hold themselves and their schools accountable for improving student achievement

State and local advocacy and collaboration will be critical to ensure that EVERY student, including those with intellectual disabilities, really do have an equal opportunity to succeed.

Of particular interest to our members, ESSA seeks to prevent the overuse of alternate assessments, while ensuring that students who do take alternate assessments have the opportunity to make progress in the general education curriculum and work towards a regular high school diploma. ESSA incorporates concepts of Universal Design for Learning, requires states to address how they will reduce incidents of bullying and harassment and reduce the use of aversive practices such as restraint and seclusion.

Click here to see the letter NDSC sent to Congressional leadership in support of the law.
(http://www.ndsccenter.org/wp-content/uploads/ESSA-Letter-12.3.15.pdf?blm_aid=2252600)

The fact that NDSC supported ESSA does not mean we do not have significant concerns about how well this law will be implemented to protect the civil rights of students. However, the consensus of disability groups, and most other civil rights groups, is that this law is stronger than what we would get if we opposed ESSA and tried again next year in this political climate. Also, ESSA is stronger than the combination of current law and ESEA waivers that would continue to be used indefinitely by the states without the new law.

Another reason that NDSC supported ESSA is that with the help of your advocacy, and collaboration with other organizations, we were able to use ESSA as a vehicle for changing significant problems in the rules that have governed alternate assessments for more than a decade. NDSC is proud of its leadership role in such an important victory for students with Down syndrome and other intellectual disabilities. The letter in the link above provides a brief description of some of the new alternate assessment provisions, as well as UDL provisions and language that applies to restraint and seclusion. Many of these changes can be used at Individualized Education Program (IEP) meetings to raise academic expectations and increase inclusion for students with Down syndrome. NDSC will be developing a resource on this topic, which includes greater details on the provisions, as well as tips for families on how to use them to advocate for their children.

To view this full article, visit:

<http://www.ndsccenter.org/page-category/resources-for-families/>



New Effort To Boost Down Syndrome Research

by Shaun Heasley | December 11, 2015

Research on Down syndrome has long lagged behind other conditions, but a new effort is underway to make it easier to study the chromosomal disorder.

For the first time, a biobank is being established specifically to collect and manage blood samples from people with Down syndrome.

Housed at Nationwide Children's Hospital in Columbus, Ohio, the biobank will offer researchers a centralized source to study Down syndrome and other conditions common in those with the developmental disorder including congenital heart disease, childhood leukemia and Alzheimer's disease, organizers said.

"Biobanks have been around since the 1990s," said Lito Ramirez, founder of DownSyndrome Achieves, which is working with Nationwide Children's to create the new resource. "Nearly every research category except Down syndrome has had a centralized biobank. Now, we are able to support researchers by providing a national, centralized repository of samples donated by people with Down syndrome."

Initially, organizers said the biobank will store blood samples collected at Nationwide Children's, but plans are in the works to eventually source from other facilities and accept various tissue types.

Brian Skotko, co-director of the Down Syndrome Program at Massachusetts General Hospital and a leading researcher in the field, said the biobank is much needed.

"A biobank provides researchers with the potential to unlock some of the mysteries associated with Down syndrome," Skotko said. "Currently, researchers do not have readily available and curated blood and tissue samples to advance our understandings of the conditions that co-occur with Down syndrome. I am excited that the Down syndrome community will have this national resource, which is long overdue."

To view this full article, visit:

<https://www.disabilityscoop.com/2015/12/11/new-boost-down-syndrome/21672/>

Pediatricians Told To Bone Up On IDEA

by Michelle Diamant | December 8, 2015

A major physicians' group is urging doctors to learn more about special education services and to take a hands-on role in advocating for kids with disabilities.

In a clinical report published this month in the journal *Pediatrics*, the American Academy of Pediatrics says that doctors have a significant role to play in ensuring that children with disabilities get the services they need from schools. The 13-page report offers pediatricians a primer on the Individuals with Disabilities Education Act, detailing school districts' responsibilities to provide help for young children all the way through the transition to adulthood.

"Although providers are advised to respect the educational expertise of school professionals, they can safeguard that children with disabilities and other health or behavioral issues receive appropriate services from (early intervention) and school programs throughout their childhood years," the report states.

Specifically, the American Academy of Pediatrics said doctors should identify and refer children who ought to qualify for special education services and communicate effectively with school-based programs about kids' needs.

By becoming involved in a child's school planning – through written communication, calls or in-person meetings – doctors can help promote better medication monitoring, improved behavioral outcomes and they can advocate against the use of restraint and corporal punishment, among other concerns, the pediatrics group said.

This type of support from pediatricians is particularly important during transition periods in a child's life including moving from one program or school to another, the group indicated.

"This is an update for pediatricians, given the changes in IDEA, since they are commonly asked for help and advice by parents about ways to help their child with developmental and/or special educational needs," said Paul Lipkin of the Kennedy Krieger Institute and Johns Hopkins University School of Medicine who was a lead author of the new report.

To view this full article, visit:

<https://www.disabilityscoop.com/2015/12/08/pediatricians-bone-up-idea/21657/>



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

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EDITOR'S REMARKS

Hello Everyone!

One of HOIDSA's largest fund-raisers is right around the corner: the annual Spaghetti Dinner. Please take some time to review the information on pages 6 and 7. We need lots of help to make this Spaghetti Dinner another successful fundraising event. There are many ways you can help contribute to the success of the Spaghetti Dinner: volunteer your time the day of the dinner, solicit donations for the raffle, bake goodies for the bake sale, help advertise by hanging up fliers, or sell dinner tickets to your friends and family.

I hope to see everyone at our 9th Annual Family Dance Party! This is a very popular event and always lots of fun! See page 3 for more information.

Hope you and your family are off to a great start to 2016!

Carol Nepolello c.nepolello@comcast.net

NEW PARENT OPEN HOUSE

This is a very informal, relaxed social time for newer parents to meet other families and little ones with Down syndrome.

Coffee, juice and snacks will be served.

Take home gifts for everyone!



Next Open House
Friday, February 12th
9:00am - 10:30am



New Location:

Bethel Lutheran Church
325 E. Queenwood Rd., Morton

*Please call Milly for additional information
at 309-231-3689*