



heart of illinois

Down Syndrome Association

Newsletter

January 2015

Contact Us:

c/o Bethel Lutheran Church
425 N. Missouri Ave.
Morton, IL 61550
309-712-4852
info@hoidsa.org

2015 Board of Directors

Carol Nepolello, *President*
309-243-8414
c.nepolello@comcast.net

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

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

Jamie Czesak
Laurie Mattheessen
Becky McDaniels
Kim Sarff
Shelli Willoughby
Todd Willoughby

Editor: Jamie Czesak
309-303-8475
jamieczesak@gmail.com

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. Feb. 2nd | Board Meeting
6:00pm, Bethel Lutheran Church, Morton |
| Fri. Feb. 6th | My Two Cents
7:00pm, Davis Bros Pizza
2402 E. Washington St., East Peoria |
| Sat. Feb. 7th | Annual Family Dance Party
6:00pm - 9:30pm
Morton Knights of Columbus Hall
616 David St, Morton |
| Sun. Feb. 8th | Young Athletes Practice - 3:00pm
St. Philomena School gymnasium
3216 N Emery, Peoria |
| Sun. March 1st | 26th Annual Spaghetti Dinner
11:00am - 6:00pm,
ITOO Hall
4909 W. Farmington Road, Peoria |
| Sun. March 8th | Young Athletes Practice - 3:00pm
St. Philomena School gymnasium,
3216 N Emery, Peoria |
| Mon. March 9th | Board Meeting
6:00pm, Bethel Lutheran Church, Morton |

Board Meetings are held the first Monday of the month at 6:00 p.m.
at Bethel Lutheran Church in Morton unless otherwise noted.
Child care provided - please call HOIDSA at 309-712-4852.

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.

Inside this Issue

Content	Page
Calendar of Events	1
Greetings from the President	2
My Two Cents	3
Young Athletes	3
Family Dance Party	3
Spaghetti Dinner	4-5
Family Matters Bow-a-thon	6
Memorial Donations	6
Technology Assistance from the Arc of Illinois	7
Feds put new focus on Down syndrome	8
Survey for parents and siblings	8
Post secondary success article and survey	9
HOIDSA on the Web	Back Cover
Editor's Remarks	Back Cover

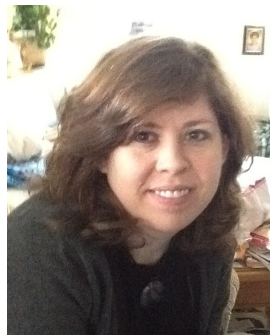


Greetings From The President

January 2015

Happy New Year! I am pleased to welcome Laurie Mattheessen, Kim Sarff, and Shelli Willoughby to the Board of Directors. They all have blossoming boys that keep them busy!!

Kim's son Adam will be starting kindergarten next year in Elmwood. Laurie's son Hayden is in second grade in Bartonville. And Shelli's son Joe is in seventh grade in Washington. They sure grow up fast! With their varying experiences with education, behavior management, medical treatments, service agencies, and extracurricular activities, I look forward to their input on building HOIDSA's programs and service initiatives.



I want to thank Ruth Just and Anita Hohimer for their service on our Board of Directors. Ruth has worked to get adults with disabilities more involved with our activities. We certainly appreciate the work she has done to bring new faces to our events. Anita was instrumental in loading much of the content on our new website and updating it on a regular basis. She has been coordinator of the grandparents group and chairman of the Buddy Walk® for the past 2 years. We are so grateful for all the work she has done for HOIDSA!

Carol

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

Adam Sarff
2/27



My Two Cents

My Two Cents is a time when people with a connection somehow with Down syndrome can get together for camaraderie and laughter in a casual setting. Here we gain insight and information just by sharing our lives with each other. Please join us at the venues below.

Always at 7:00 pm

Friday, February 6 - Davis Bros Pizza
2402 E. Washington St, East Peoria

Can't wait to see you there! Any questions or comments, please contact Todd Willoughby at 309-251-7695.



**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 8, 2015
Sunday, March 8, 2015
Sunday, April 12, 2015
Sunday, May 10, 2015**

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

8th Annual

HOLDSA Family Dance Party

**Saturday, February 7th, 2015
at the Knights of Columbus Hall
616 David Street, Morton, IL
6:00 - 9:30 p.m.**

*Refreshments
provided!*



The Jukebox

(Chuck Tucker will DJ)
Bring your favorite CD's



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

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

SPOTLIGHT ON...

The "Spotlight On" section of our newsletters will now be completed in a standard interview type format which should be easier for families to complete. More information about this new format will be posted in the February newsletter.

Heart of Illinois Down Syndrome Association, Inc.

26th Annual

SPAGHETTI DINNER

Sunday, March 1, 2015 • 11:00 a.m. - 6:00 p.m.



\$7.00/Adult
(13 & up)

\$5.00/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

PLEASE HELP MAKE OUR 26TH SPAGHETTI DINNER FUNDRAISER A SUCCESS!!!

VOLUNTEERS NEEDED!!!

We're using VolunteerSpot to organize volunteers for the Spaghetti Dinner.

Here's how it works in 3 easy steps:

1. Click this link to go to our invitation page on VolunteerSpot: <http://vols.pt/VT3g51>
2. Enter your email address: (You will NOT need to register an account on VolunteerSpot)
3. Sign up! Choose your spots - VolunteerSpot will send you an automated confirmation and reminders.

Note: VolunteerSpot does not share your email address with anyone.

If you prefer not to use your email address, please contact Anne Hollis at (309)219-5899 or anne.mc.hollis@gmail.com to sign up manually.

Set Up

We are in need of volunteers to help us set up on Saturday, February 28th at the ITOO Hall beginning at 9:00am.

Clean Up

The Spaghetti Dinner committee also needs help with loading and clean up from 6:00-8:00pm after the dinner.

HELP US ADVERTISE!

Download fliers from our website and share with others. Fliers can be found at www.hoidsa.org.

RAFFLE AND TICKETS

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.

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



POSTERS - 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!

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.).

Saturday, April 25, 2015

1:00 - 4:00 p.m.

**Landmark Recreation Center
Peoria, IL**



Sign up today for family matters bowl-a-thon! Teams need to register by March 15th.

Sign up at: <http://www.firstgiving.com/FamilyMatters>

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/specialrecreation.html>

Memorial/Recognition Donations

- **Memorial donations in the name of Judy Gill.**
- **Memorial donations in the name of Vernon “Gene” Watkins.**

*Our sincere
appreciation.*

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.

The Arc of Illinois Presents

Technology Assistance

Who Can Apply?

- A person with an intellectual or developmental disability
- Family member on behalf of a person with an intellectual or developmental disability
- Must be an Illinois resident

How Do I Apply?

- The application form must be completed and returned to The Arc of Illinois
- You must include a copy of an evaluation/assessment to show the need for the assistive technology device and what type of device is needed.

CONTACT

The Arc of Illinois
20901 S. LaGrange Rd.
Suite 209
Frankfort, IL 60423
Phone 815-464-1832
Fax 815-464-5292
Email: janet@thearcofil.org



The Arc of Illinois, through a generous donation, has developed a new *Assistive Technology Program*. This program will fund, or partially fund, the purchase of assistive technology for individuals with intellectual and/or developmental disabilities who have received an evaluation/assessment from a qualified provider but the purchase is not subsidized by Medicaid, Medicare or Private Insurance.

Our goal through the Assistive Technology Program, is to enhance and improve the quality of life for persons with intellectual/developmental disabilities by providing opportunities for individuals to receive technology to help with education, employment, community living and independence.

The maximum amount funded will be \$500.00 per person or family. Upon approval, the device will be shipped directly to the applicant.

The application form can be accessed by visiting:

https://gallery.mailchimp.com/bcec73d19574f43e0b9ab00c1/files/AT_Flyer_01.pdf

ODDS AND ENDS

Feds Put New Focus on Down Syndrome

from disabilityscoop

As people with Down syndrome live longer than ever before, the National Institutes of Health is looking to reshape its efforts related to the chromosomal disorder.

The federal agency is tweaking its Down syndrome research priorities and adding a new focus on life's later years and associated conditions.

The changes come in the first-ever update to the NIH's Down Syndrome Research Plan. Originally issued in 2007, the revised plan was released last month.

With statistics showing that life expectancy for people with Down syndrome has increased fourfold since 1960, the update includes a new section with goals related to aging with Down syndrome.

Additional areas of emphasis include understanding the progression of Down syndrome, options for treatment and management as well as objectives related to conditions like Alzheimer's disease, congenital heart disease, hearing and vision problems, gastrointestinal problems, thyroid dysfunction and immune disorders that often co-occur.

Since 2007, the NIH said scientists have published nearly 350 papers addressing items outlined in the original plan.

For the full story, visit: <http://www.disabilityscoop.com/2015/01/20/feds-focus-down-syndrome/19976/>

The Institute on Disabilities and The Sibling Leadership Network Survey

The Institute on Disabilities at Temple University is working together with the Sibling Leadership Network to study the support needs of siblings of individuals with disabilities. This project is funded by the Pennsylvania Developmental Disabilities Council.

We invite you complete this survey and to encourage other individuals you know to participate in this national survey about siblings of individuals with disabilities, their support needs, and their families. We are looking for people to share their perspectives.

The survey is for the following individuals to complete:

- Siblings of people with disabilities
- People with disabilities
- Parents of people with disabilities
- Professionals working with people with disabilities and their families

This is an online survey; it will take less than 30 minutes to complete.

The survey can be accessed at: http://survey.col.qualtrics.com/jfe/form/SV_3WCwrRZwGMzCHtj

Study Finds Postsecondary Programs Boost Outcomes

from disabilityscoop

Individuals with intellectual disabilities who attend postsecondary programs are finding greater success in the job market than those who do not pursue further education, a new study suggests.

Graduates of postsecondary programs reported higher rates of employment since completing high school, according to findings published online this month in the Journal of Intellectual Disabilities. The research offers support for a growing number of programs at colleges and universities specifically geared toward young adults with developmental disabilities.

For the [study](#), researchers interviewed administrators and surveyed 34 graduates from two postsecondary programs — one focused on providing supports so students can participate in typical college classes and the other offering a more specialized program just for those with disabilities. Researchers asked about the work experiences of the graduates who completed postsecondary programs between 2011 and 2013.

The graduates' experiences were then compared to data from the federally-funded National Longitudinal Transition Study 2 on the post-high school outcomes of individuals with intellectual disabilities who did not attend postsecondary programs.

Researchers found “steep gains” for individuals in both the specialized and inclusive postsecondary offerings.

Slightly over half of those who did not seek additional education after high school said they had been employed in the last two years. By comparison, roughly 9 in 10 of those who graduated from a postsecondary program reported that they had worked outside their home or former school in the same time period.

“There is a growing body of evidence that suggests that (postsecondary education) programs for individuals with (intellectual disabilities) are highly effective as a means to increase employment rates for such individuals,” wrote Eric J. Moore of the University of Tennessee and Amy Schelling of Grand Valley State University in their findings. “Such data can and should be used to encourage further propagation of (postsecondary) programs for individuals with IDs and provides justification for pilot programs of similar kinds in countries wherein (postsecondary) programs have not yet been made available for individuals with IDs.”

For the full story, visit: <http://www.disabilityscoop.com/2015/01/20/study-postsecondary-outcomes/19972/>

Participate in the National Online Dialogue on Families, Disability and Postsecondary Success

Are you a family member of a young adult with a disability who's currently or recently enrolled in a postsecondary education program (e.g., certificate, apprenticeship, community college, college or university)? Participate in ePolicyWorks' upcoming online dialogue, Connecting Families: Supporting Postsecondary Success of Young Adults with Disabilities.

The dialogue is open for participation now and will continue through February 6, 2015.

Register and join the discussion at: <http://connectingfamiliespost2ndsucccess.epolicyworks.org/>



c/o Bethel Lutheran Church
425 N Missouri Ave Morton IL 61550

NONPROFIT
U.S. POSTAGE
PAID
PEORIA, IL
PERMIT NO. 455

EDITOR'S REMARKS



Hello Everyone!

This time of year means that the Spaghetti Dinner committee is busy preparing for one of HOIDSA's largest fundraisers: the annual Spaghetti Dinner. Please take some time to review the information on pages 4 and 5. We need lots of help to make this Spaghetti Dinner another successful fundraising event. There are many ways that 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 8th Annual Family Dance Party! This event is my favorite HOIDSA event of the year. See page 3 for more information about this event.

Hope you and your family are off to a great start to 2015!

Jamie Czesak jamieczesak@gmail.com

HOIDSA ON THE WEB

Check out HOIDSA's website and Facebook page!!!

Visit www.hoidsa.org

"Like" us on Facebook at

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

Join our Facebook discussion group at

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