



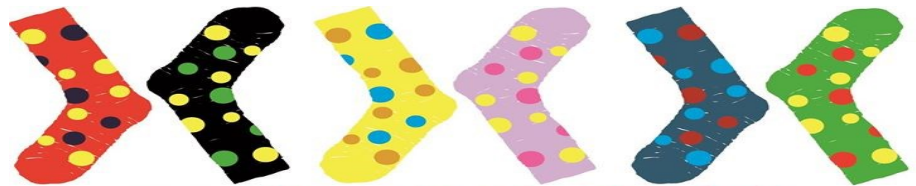
heart of illinois Down Syndrome Association Newsletter

February 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.



www.worlddownsyndromeday.org/lots-of-socks

2016 Board of Directors

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

Calendar of Events

- | | |
|-------------------------|--|
| Sun. March 6th | 27th Annual Spaghetti Dinner
11:00am - 6:00pm,
ITOO Hall, 4909 W. Farmington Road, Peoria |
| Sun. March 13th | Young Athletes Practice - 3:00pm
St. Philomena School, 3216 N Emery, Peoria |
| Mon. March 14th | Board Meeting - 6:00pm
Advocates for Access
4450 N Prospect Rd, Peoria Heights |
| Tues. March 15th | Young Adults Cooking Class - 7:00pm
Bethel Lutheran Church
325 E. Queenwood Rd., Morton |
| Tues. March 15th | ACCESS March Madness Experience
FREE Event - see page 8 for details |
| Mon. March 21st | World Down Syndrome Day |
| Sat. April 9th | Illinois Family Leaders Annual Conference
9:00am-3:00pm Spalding Pastoral Center, Peoria |
| May 5th-6th | Illinois Includes Conference (2-Day Event)
8:00am-4:00pm Double Tree Hotel, Oak Brook IL |

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

Birthdays
Next
Month

Inside this Issue

Content	Page
Calendar of Events	1
Greetings from the President	2
Family Dance Party	3
Spotlight On...	4
Young Adult Cooking Class	5
Young Athletes	5
Spaghetti Dinner	6-7
March Madness Experience	8
Illinois Family Leaders Conference	9
Advocacy Toolkit	10
Illinois Includes Conference	11
New Parent Breakfast	Back Cover
Greetings from Newsletter Editor	Back Cover

February 2016

Happy February everyone! Thanks to everyone who came out for the January dance party! It was a fun filled night of catching up with old friends and meeting some new families. It's just what we all needed on a cold winter night to get us up and moving. I don't know about you, but as much as I enjoy the beautiful winter snow, I'm really looking forward to the warmth of spring and being outdoors.



I'm also looking forward to our upcoming spaghetti dinner and hope you'll be able to join us. For my family, going to the spaghetti dinner is just like going to a family reunion. So many family and friends under one roof it always promises to be a great day! At this year's dinner make sure to stop by the volunteer table to check out opportunities on how you can use your unique talents to serve the HOIDSA community!

Shelli Willoughby



World Down Syndrome Day is annually observed on March 21 to raise public awareness and understanding of Down syndrome. Down Syndrome International encourages our friends all over the world to choose your own activities and events to help raise awareness of what Down syndrome is, what it means to have Down syndrome, and how people with Down syndrome play a vital role in our lives and communities.

March

Janelle Begner
3/1

Chris Bigelow
3/1

Maggie Getz
3/6

Dakota Herold
3/11

Benit Roth
3/13

Jared Hicks
3/14

Jessica Pribble
3/15

Willis Leighty
3/17

Nicholas Stuber
3/18

Jack Robison
3/20

Joseph Zimmerman
3/21

Jamie Martin
3/23

Mercy Thacker
3/24

Ashley Wertz
3/26

Trevor Colby
3/27

Lisa Pattelli
3/30

Jax Gander

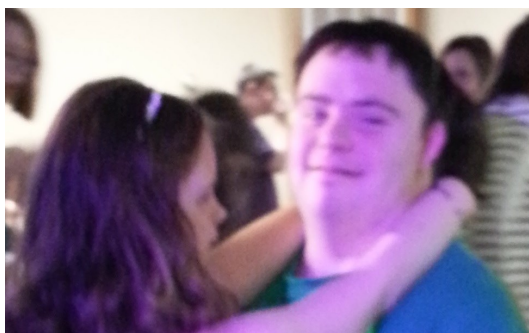




DJ Chuck Tucker did a fantastic job spinning the tunes and keeping the dance floor hopping!



Kaelie Morgan & Brian Howeler



Family Dance Party 2016

Special thanks to Julie Heim, Judy & Dennis Triggs, and Christine & David Almasy for organizing this event, supplying the snacks and goodies, and keeping the pizza coming!



Dylan Lundy (middle) with his biological brother (left)



The Morgan Sisters

Brianna, Linsy, Jamie Czesak, and Kaelie

Food and monetary donations collected that night were given to Sophia's Kitchen who feed the hungry at St. Joseph's Hall
103 S. Richard Pryor Place
Peoria IL 61605



Spotlight on... Alex Tucker



Greetings From Alex Tucker

February 2016

Hello everyone, My name is Alexander Edward Tucker. I have Down Syndrome and I'm 25 years old. I'm a self Advocate of the Heart of Illinois Down Syndrome Association. I went to Washington D.C. with my mom "Meri Tucker" and lobbied about the ABLE Act, the Able Act means that individuals with Down syndrome can save money for buying a house, a car, and not to live in poverty. Here some fun facts about me. I like to Read, listen to playways, learning about Egypt, singing, work at morton mission mart, and I wish to be on board of the Down Syndrome Association. Having down Syndrome doesn't stop me from doing theater and dancing. I Have a older sister who is engaged and a younger brother who is in college at Augustana. I'm in the Young Adult Cooking class and it is fun to do. I like to help others with down syndrome if they need help. I support those who are self Advocates with down syndrome. I send out a happy 2016 to All.

Alexander Tucker

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.

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.

♦ Calendar of Upcoming Events

♦ Photo Gallery

Visit HOIDSA Online

Website:

www.hoidsa.org

Facebook Page:

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

Facebook Discussion Group:

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

Young Adult Cooking Class

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

Next class: March 15th 7:00-8:30pm

Bethel Lutheran Church

Contact Meri at 309-264-4900

NEW LOTTERY TICKET FOR 2016

The Illinois Lottery has released a new scratch-off lottery ticket to support Special Olympics programs throughout the state.



Purchase a Special Olympics Illinois Lottery Ticket and have the chance to win up to \$50,000! Plus, 100 percent of the profits from the \$3 ticket benefit Special Olympics training programs!

Last year, more than 950,000 tickets were sold raising almost \$1 million for our athletes! Help us sell even more this year by visiting your local Illinois Lottery retailer and purchasing your ticket today!



The Young Athletes program is an innovative sports play program for children ages 2-9 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, March 13, 2016
Sunday, April 10, 2016
Sunday, May 8, 2016

If interested in participating or volunteering,
e-mail:

youngathletespeoria@yahoo.com

John & Christy Getz
Curt & Amanda Nauman

Page 5

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

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

1. VOLUNTEER

Volunteers are needed to help set up, serve, clear tables, and clean up. There are still several spots left to fill. Please sign up at Volunteer Spot.

Here's how it works in 3 easy steps:

1. Click this link to go to our invitation page

<https://www.volunteerspot.com/login/entry/406614418050>

2. Enter your email address: (You will NOT need to register an account on VolunteerSpot)

3. Sign up! Choose your spots - You will see what spots are still available and you'll be able to choose the job and time slot you want. VolunteerSpot will send you an automated confirmation and reminders.

If you don't have access to the internet, contact Anne Hollis at (309)219-5899 or anne.mc.hollis@gmail.com

On the day of the dinner, volunteers are asked to park across the street at Midwest Implement or at least on the far end of the parking lot and leave the close spots for our guests.

2. DONATE ITEMS FOR THE RAFFLE & SILENT AUCTION

Raffle items are needed for the main raffle and kids raffle.

We would also love for you to donate a basket for the silent auction, but we welcome single items and will create baskets for them. Please direct all donations through Amanda Nauman at (309)360-1133 or anauman@mtco.com to prevent duplication.

We welcome your help soliciting items from businesses and small business owners. This is also a great way for them to advertise their products and make a contribution to a 501(C)(3) nonprofit organization. Tax-deductible receipts are available.

Contact Amanda Nauman or Christy Getz at (309)635-7309 or jcgetz94@yahoo.com for more information.

3. DONATE BAKE SALE ITEMS

Bake sale items will be accepted throughout the day. We will be happy to package and price the items for you. Please indicate what flavor the item is if it is not evident. **Gluten free items and goodies for diabetics are greatly appreciated.**

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.

4. 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!

The meal includes ALL-YOU-CAN-EAT LaGondola spaghetti, salad, garlic bread, and a drink.

5. SELL RAFFLE AND DINNER TICKETS

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

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

Illinois Family Leaders Collaboration presents the 10th Annual Family Conference

Saturday, April 9th, 2016
Spalding Pastoral Center
419 NE Madison Ave, Peoria, Illinois

Registration: 8:30am to 9:00am

Conference: 9:00am to 3:00pm

Featuring Nancy Brown, Bridget Brown, & Tyson Bedford

Design Life with Direction and Purpose

Learn from veteran parent, Nancy Brown, and self-advocates Bridget Brown and Tyson Bedford, how you can start designing a purposeful life for your child with a disability beginning in preschool, and how to use person-centered planning to empower youth of any age to self-advocate (age 14 and over are encouraged to attend). You will gain inspiration from others who have achieved their dreams and acquire tools you can use to reach your own vision!

Nancy Brown, Family Engagement Partner for the Illinois Autism Partnership (Easter Seals), has facilitated Microboards through IAMC and was an educational inclusion consultant for ISBE (Project CHOICES) for many years. She and her daughter are inclusion educators through Butterflies for Change. Nancy specializes in inclusive education; person-centered planning, adaptations & accommodations, parent issues, inclusive social emotional models of support, organizational development, transition, as well as access and equity. She is co-author of Models of Support and Kid Konnections.

Bridget Brown, a young woman with Down syndrome, encourages people to “dwell in the possibilities.” She is a strong advocate of inclusive education and community living; a national public speaker; an actress; a person-centered planning coach; and the second vice president of the National Association for Down Syndrome where she spearheaded a public speakers training program and a self-advocacy board. She is the recipient of many state and national awards and co-founder of Butterflies for Change.

Tyson Bedford, is a talented, smart, handsome, gentle, funny, courageous young man who also has Autism. In high school, he enjoyed academics, plays, musicals, community experiences, and choir (numerous awards). Currently, Tyson is in the UI-REACH program at the University of Iowa and is enjoying being a Hawkeye—attending classes, sharing a dorm room, attending clubs/groups, and going out with friends.

WHO SHOULD ATTEND

The Conference is for adult family members and caregivers of children (birth-22) who have developmental delays or disabilities. This year we are welcoming self advocates age 14 and over to register as well. Service providers and educators are also welcome.

CONFERENCE COLLABORATORS

Early CHOICES • Family Matters Parent Training Information Center • **Heart of Illinois Down Syndrome Association, Inc.** • Project Reach: Illinois Deaf Blind Services • STARnet Region I & III • STARnet Region IV • The Arc of Illinois Family to Family Health Information Center / Family Voices

REGISTRATION

There is a \$10 per person (nonrefundable) registration fee for self-advocates and family members and a \$20 (non-refundable) registration fee for professionals. Breakfast and lunch are included.

HOIDSA members will be reimbursed for their registration fee at the conference.

Register by March 18, 2016. Registration is limited. Registration form available at <http://hosted.verticalresponse.com/1719035/40ae89cb5c/573252183/561d06e0bf/>

Advocacy News

Governmental Affairs Newsline



Advocacy Toolkit

The National Down Syndrome Congress, together with other disability and aging advocacy groups, have issued a toolkit to help advocates push for strong implementation of the new Home and Community Based Services (HCBS) Settings Rules in their states. The new HCBS Settings Rules require all settings funded by Medicaid HCBS programs to, among other things, provide opportunities for participants to be integrated in and engage in community life, have access to the community, control their personal resources, and seek employment and work in competitive settings. States have until March 2019 to transition their HCBS programs into full compliance with the new settings requirements.

"Most adults with Down syndrome need support services to live and work in the community. The HCBS rules, part of the state/federal Medicaid program, are the manner in which these services are funded. Parents and self-advocates need to be aware of and advocate for strong enforcement of these new rules to ensure life choices based on the individual's needs and desires," said Susan Goodman, NDSC's Director of Governmental Affairs. All states have already submitted to the Center for Medicare and Medicaid Services (CMS) their initial transition plans, and CMS has provided feedback to states about needed improvements and next steps for amending and implementing their plans. "The next several months are a critical time for advocacy because that is when states will be making important decisions about their transition plans," she said.

This new toolkit provides advocates with detailed information about the HCBS Settings Rule and provides action steps for advocates to impact implementation of the new rules in their states. The toolkit contains three documents: (1) The Medicaid Home and Community-Based Services Settings Rules: What You Should Know; (2) Home and Community-Based Services Regulations Q&A: Settings Presumed to be Institutional & the Heightened Scrutiny Process, and (3) The Home and Community-Based Settings Rules: How to Advocate for Truly Integrated Community Settings (unabridged and abridged) .

The HCBS Advocacy Coalition includes the Bazelon Center, the American Network of Community Options and Resources (ANCOR), Association of People Supporting Employment First (APSE), Association of University Centers on Disabilities (AUCD), Autistic Self Advocacy Network (ASAN), Coalition to Promote Self-Determination (CPSD), Justice in Aging (formerly National Senior Citizens Law Center), Human Services Research Institute (HSRI), National Association of Councils on Developmental Disabilities (NACDD), National Consumer Voice for Quality Long Term Care, National Council on Independent Living (NCIL), National Disability Rights Network (NDRN), National Down Syndrome Congress (NDSC), National Health Law Program (NHLP), TASH, and The Arc of the United States.

The Toolkit is available at <http://hcbadvocacy.org/national-resources/>

To view this full article, visit:

<http://www.ndsccenter.org/news-and-blog/>



ILLINOIS INCLUDES

Annual Conference

When: May 5-6, 2016

**Where: DoubleTree by Hilton Chicago—Oak Brook
1909 Spring Rd, Oak Brook, Illinois 60543**

A wide range of topics will be featured:

- the role of the principal in inclusive schools
- supporting students with significant disabilities
- collaborating with students in instruction & advocacy
- the inclusive IEP
- early childhood for all
- cooperative learning
- including students on the autism spectrum
- understanding the role of families in the inclusive school
- differentiating instruction
- co-teaching and collaboration
- supporting friendships and building classroom community

Registration is NOW Open!! Only 310 spots are available each day, so register NOW!

Register online at <http://www.illinoisincludes.org>

CONGRATULATIONS

Winners of FREE 2-day registration
to Illinois Includes Conference
Courtesy of HOIDSA

Professional Winners

Dan Eckert, Dunlap Grade School

Jill Napier, Clark Pleasant School Corp.

Parent Winners

Mary Brown

Sarah Pepino



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.

There are a couple conferences coming up with great speakers. I encourage you to attend the Family Leaders Annual Conference in March, which is free for HOIDSA members, or the Illinois Includes Conference in May.

Carol Nepolello c.nepolello@comcast.net

NEW PARENT OPEN HOUSE

*The monthly
"New Parent
Open House"
will not take
place in
March
2016*