



heart of illinois

Down Syndrome Association

Newsletter

September 2014

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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

- Fri. Sept. 26th** **My Two Cents** - 7:00pm
Burger Barge, 1401 N. Main St., East Peoria
- Wed. Oct 1st** **Buddy Walk Pre-Registration Deadline**
Must register by October 1st to get a ticket for a free hot dog lunch!
- Thurs. Oct. 2nd** **Last Buddy Walk Meeting—Sort T-Shirts**
6:00pm, Bethel Lutheran Church, Morton
- Fri. Oct. 3rd** **Buddy Walk Set Up**
6:00pm, EastSide Centre, East Peoria, IL
- Sat. Oct. 4th** **BUDDY WALK!!!**
Registration and Pre-Walk activities begin at 8:00am
EastSide Centre, 1 EastSide Drive, East Peoria
- Mon. Oct. 6th** **Board Meeting** - 6:00pm
Bethel Lutheran Church, 425 N. Missouri, Morton
- Fri. Oct. 10th** **New Parent Open House**
9:00am, EP!C 1913 W. Townline Road, Peoria
- Fri. Oct. 10th** **My Two Cents** - 7:00pm
Oliver's Pizza and Pub, 1231 E. Samuel Ave, Peoria
- Sun. Oct. 12th** **Young Athletes Practice** - 3:00pm
St. Philomena School, 3216 N Emery, Peoria
- Oct. 16th & 17th** **Helping Children and Adults with Disabilities Succeed Workshop**
See pages 10 - 11 for more 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 The President

September 2014

Thank you to Angie Reuter for her service on our Board of Directors. She was previously a board member in 2004/2005/2006 and then returned to the Board in January this year. Unfortunately for us, her family relocated to the St. Louis area this summer. We are grateful for her leadership contributions and wish her and her family well!



Thank you to everyone who has registered for the Buddy Walk® and started fundraising for us. A very special thank you goes out to our donors and corporate sponsors, including Valerin Group, Maurer-Stutz, G&M Distributors, Canton Veterinary Clinic, Anytime Towing, ARV AutoGlass, Ed Pollitt Concrete Construction, RBR Performance, Spoon River Heating & Cooling, Jukebox Saturday Night, Pepsi, Pekin Prescription Lab, Pekin Paintball Park, Brewer Law Office, and many more. We are very appreciative of all the support we've received from our families and friends and from the community. If you haven't registered yet, there is still time! Participants who pre-register by October 1st will receive a ticket for a free hot dog lunch. Visit our website at www.hoidsa.org to sign up today!

Carol

UPCOMING BIRTHDAYS

September

- Devin Detra 9/1
- Jameela Williams 9/2
- Kinlie Kearney 9/3
- Karen Kinley 9/7
- Dakota Peak 9/8
- Hannah Gerkin 9/9
- Tristen Sanchez 9/11
- Kurt Kinley 9/17
- Brian Howeler 9/19
- Zakary Capponi 9/21
- Rachel Lamb 9/22
- Tamara Thorpe 9/25
- Laura Walters 9/27
- Hayden Mattheessen 9/28
- Jonathan Jester 9/29



October

- Matthew Schultz 10/3
- Daniel Van Buskirk 10/3
- Jonah Johnson 10/5
- Zoey Melton 10/5
- Allie Cowden 10/9
- Juan Quintero-Vargas 10/13
- Katie Swenson 10/15
- Autumn Botkin 10/24
- Joseph Willoughby 10/25

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.

Board of Directors Vacancies!

The Heart of Illinois Down Syndrome Association has at least two vacancies on our Board of Directors. 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, and provide input to direct the Board's efforts.

HOIDSA is specifically looking for candidates in the following areas:

- families with young children
- school districts/educational needs
- relationship with the medical community
- represents adults with disabilities

We will accept nominations through December 1, at which time vacancies will be filled by voting at the December Annual Meeting/Social. 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.



**Helping Children and Adults
with Disabilities to Succeed:
Creating Positive Behavioral Change**

**TWO OPPORTUNITIES to learn
from a leader in the field**

3 CPDU's offered

BARBARA T. DOYLE, MS

www.barbaradoyle.com

Thursday, October 16, 2014

5:30 pm - 8:45 pm

or

Friday, October 17, 2014

12:30 pm - 3:45 pm

**Best Western Ashland House
Morton, IL**

Sponsored by

The Heart of Illinois Down Syndrome Association, Inc.

www.hoidsa.org

See More Details on pages 10 and 11

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/>

SPOTLIGHT ON...

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

If you would like your family member with Down syndrome to be featured, please e-mail Jamie at jamieczesak@gmail.com to sign up for a month!

BUDDY WALK® NEWS



HOIDSA's 7th Annual Buddy Walk® is right around the corner. I am looking forward to a fun filled morning to honor our loved ones and seeing the outcome of everyone's hard work and the great community support we have been shown.

The walk will take place on Saturday October 4th at EastSide Centre in E Peoria. T-shirt pickup, same day registration, raffle sales, carnival games and activities all begin at 8am. The walk starts at 9:30am. Raffle drawings will take place after the walk. A hot dog lunch will be served from 11am-12:30pm (pre-registration is required to receive your lunch ticket). The walk will take place rain or shine and is ADA accessible.

REGISTRATION/FUNDRAISING

Online registration for the walk is available through October 1st at <http://www.firstgiving.com/hoidsa>. If registering offline mail your form and money due to HOIDSA, Attn: Buddy Walk, c/o Bethel Lutheran Church, 425 N. Missouri Ave, Morton IL 61550 and must be received by October 1st. Be sure to list the name of the person with Down syndrome who is being recognized. Registration will also be available the morning of the walk beginning at 8am.

SPONSORS/DONATIONS

Please continue fundraising and securing sponsors for the walk. We are in need of lunch items such as hot dogs, buns, individual pre-packaged desserts. For anyone wanting to make arrangements for pick up of a food donation or collected monetary donations, please contact Anita at 309-241-8195 or at buddywalk@hoidsa.org. If mailing send to HOIDSA, Attn: Buddy Walk, c/o Bethel Lutheran Church, 425 N. Missouri Ave, Morton IL 61550 and be sure to include the name of the person with Down syndrome who is being recognized. Donations will gladly be accepted the day of the walk. We will make every effort to show recognition of all sponsors for their support. We will have an Appreciation Board displayed at the walk, names listed on Facebook and in our October Newsletter.

RAFFLE

Raffle tickets will be available the morning of the walk. Ticket cost is only \$1 each or 6 for \$5 so be sure to stop by the raffle table and purchase yours! You could become the winner of a Strider Balance Bike, a gift certificate for husband and wife will package or one of the many other prizes that will be available.

OCTOBER IS DOWN SYNDROME AWARENESS MONTH

As in previous years you are encouraged to display a poster with photos and other interesting facts about your loved one at EastSide the day of the walk and leave on display the following week to promote Down syndrome awareness.

If you have any questions about registration, fundraising, sponsors or the walk in general, please contact me. Thank you to everyone for promoting and supporting the Buddy Walk®!

Anita Hohimer
309-241-8195 or buddywalk@hoidsa.org

BUDDY WALK® MEETING

The final Buddy Walk meeting will be to sort and bag t-shirts. We will meet at 6pm on Thursday October 2nd in Room #101 at Bethel Lutheran Church, 425 N. Missouri Ave. in Morton.

Sign Up To Be A Buddy Walk® Volunteer!

We're using VolunteerSpot (the leading online signup and reminder tool) to organize our volunteers for the Buddy Walk. Volunteers can sign up for specific times and duties on VolunteerSpot.

Please sign up to help out at our Buddy Walk!

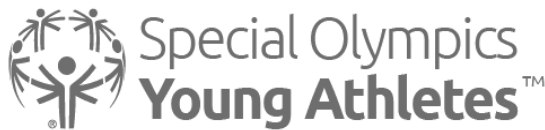
Here's how it works in 3 easy steps:

1. Follow this link to go to our invitation page on VolunteerSpot: <http://vols.pt/mstjTe>
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.

Feel free to share this information with any friends or family who may be interested in volunteering!

Volunteers who do not have internet access can call Jamie at (309)303-8475 to sign up for a spot.

Note: VolunteerSpot does not share your email address with anyone. If you prefer not to use your email address, please contact us at buddywalk@hoidsa.org and we can sign you up manually.



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**

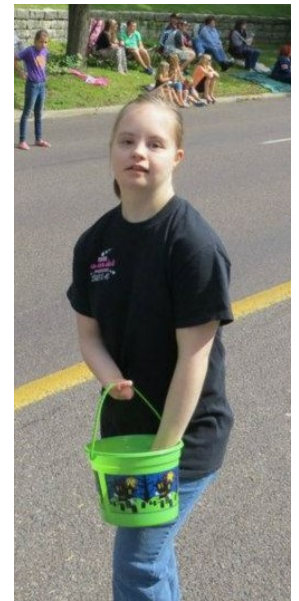
**Sunday, October 12, 2013
Sunday, November 2, 2013
Sunday, December 14, 2013
Sunday, January 11, 2014
Sunday, February 8, 2014
Sunday, March 8, 2014
Sunday, April 12, 2014
Sunday, May 10, 2014**

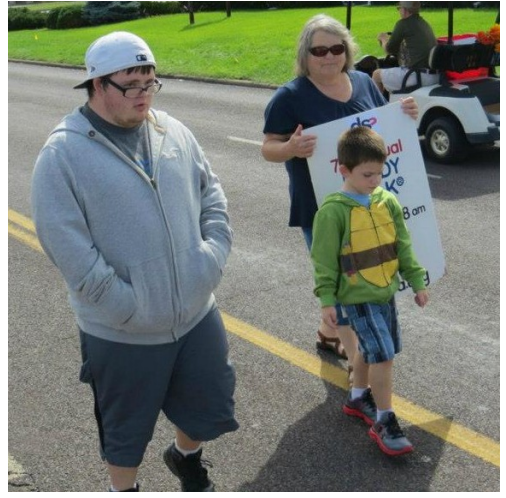
**If interested in participating or volunteering,
e-mail: youngathletespeoria@yahoo.com**

OCTOBER IS NATIONAL DOWN SYNDROME AWARENESS MONTH!

On September 28, 1984, President Ronald Reagan signed a resolution proclaiming October as National Down Syndrome Month. Down Syndrome Awareness Month is a chance to spread awareness, advocacy and inclusion throughout the community. During the month of October, we celebrate individuals with Down syndrome and make people aware of their abilities and accomplishments.

THANK YOU TO EVERYONE WHO CAME OUT TO MARCH WITH HOIDSA IN THE PEKIN MARIGOLD AND MORTON PUMPKIN PARADES!





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 Sept. 26 - Burger Barge (the new one)

123 Meadows Ave, East Peoria

Friday, October 10 - Oliver's Pizza and Pub

1231 E. Samuel Avenue, Peoria Heights

Friday, November 14 - Ludy's Kickapoo Creek Saloon

9828 W. US Highway 150, Edwards, IL

Friday, December 12 - Kelleher's Irish Pub & Eatery

619 SW Water St, Peoria

Friday, January 9 - Kep's Sports Bar and Grill

313 Muller Rd, Washington

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.



University of South Carolina School of Medicine USC Genetic Counseling Program

A graduate student in the genetic counseling program at the University of South Carolina School of Medicine, is researching parent's perspectives on the support given to their family through their child's pediatric health care. The research involves taking a survey that is online. Each survey is meant to be filled out individually by either parent.

The survey contains a series of questions about your child with Down syndrome and the types of medical providers he/she sees on a regular basis. The survey also asks about your opinions and perspectives on the level of psychosocial/emotional support that is offered by your child's pediatric health care providers.

All responses from the surveys will be kept anonymous and confidential. The results of this study might be published or presented at scientific meetings; however, your answers will not be identified in any way. The survey should take about 10-15 minutes to complete.

Your answers may help health care professionals provide the best care for children with genetic conditions and their families.

To participate in this research study, you can take the survey by following this link:

<https://www.surveymonkey.com/s/psdsparentperspective>

Check out HOIDSA's updated website!!!

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/>



Sexuality, Education and Support for People with Intellectual and Developmental Disabilities

There has been significant progress in the last 40 years toward inclusiveness for people with Intellectual Disability (ID). But enjoying a mature intimate relationship with another adult, simply doesn't exist for many people with ID.

Join TASH on October 2 to kick off this 5-part webinar series with Dr. David Westling - Western Carolina University. Dr. Westling's 60 minute webinar will focus on life curriculum; what to teach and when to teach it.

To register for this webinar, visit: <http://tash.org/product/sexuality-i-about-life-curriculum/>

Values-Based Leadership in Supported Living: Stepping Up to the Promise and the Spirit of the Home and Community Based Waiver

The 2014 Home and Community Based Waiver regulations hold enormous potential for the way support services are provided to people with intellectual and developmental disabilities. These new regulations mark one step closer to the promise of the Olmstead Decision — upholding the “most integrated setting possible” standard of Title II of the Americans with Disabilities Act!

This 7-part webinar series offers state agency leaders, adult service providers, family members, and service beneficiaries meaning behind the new Waiver regulations and a comprehensive review of *WHY* and how to implement them.

Join Alison Barkoff, Bazelon Center for Mental Health Law and Rachel Patterson, Association of University Centers on Disabilities as they kick off this series on September 30th with "The Promise and Intent of HCBS Regulations and Settings Requirements."

To register for this webinar, visit: <http://tash.org/product/hcbs-waiver-i-promise-intent-hcbs/>



**Helping Children and Adults
with Disabilities to Succeed:
Creating Positive Behavioral Change**

**THURSDAY, OCTOBER 16, 2014
OR
FRIDAY, OCTOBER 17, 2014**

**Best Western Ashland House
201 E Ashland St, Morton, IL 61550**

**Fee - \$30 per person
(Walk-in Registration Fee will be \$40)**

Register online at www.hoidsa.org

ONLINE REGISTRATION ENDS ON OCTOBER 15.

HOIDSA families attend free

*Scholarships available for others unable to pay.
Email request to: info@hoidsa.org.*



Please let us know if we can accommodate your special concerns or accessibility. Two weeks notice is required.

For conference or scholarship information, contact:
Heart of Illinois Down Syndrome Association, Inc.
Phone: 309-712-4852 Email : info@hoidsa.org

Agenda

Thursday, Oct. 16

- 5:00 pm Registration
- 5:30 pm-7:00 pm Workshop
- 7:00-7:15 pm Break (refreshments provided)
- 7:15-8:45 pm Workshop Continues

Friday, Oct. 17

- 12:00 pm Registration
- 12:30 pm-2:00 pm Workshop
- 2:00-2:15 pm Break (refreshments provided)
- 2:15-3:45 pm Workshop Continues

3 CPDU's are available for this workshop.

(Participants must stay for the entire workshop to receive these credits. Certificates of attendance will also be provided.)

**HOIDSA will reimburse
schools substitute pay for
up to three
educators at
\$50 each.**



Information on Sponsor:

Heart of Illinois Down Syndrome Association, Inc. is a volunteer driven support group 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.

BARBARA T. DOYLE, MS

www.barbaradoyle.com

About the Speaker:

Barbara T. Doyle is a nationally known teacher, consultant, trainer, presenter and author. She is known for her passionate approach to presenting practical and realistic solutions for everyday issues at home, school, work and social situations. She is an interesting and engaging presenter who keeps her audiences thinking and moving. Her "ready to apply" information is delivered with humor and humanity. Her more than 43 years of professional experience add to her life experiences as a family member of seven people with disabilities. Barbara's mission is to make the world a more inclusive place for everyone by increasing understanding, creating a truly accessible service delivery system and promoting effective teaching, adaptations and accommodations.

Barbara is the president and CEO of Barbara T. Doyle, MS, Inc. which she incorporated almost 15 years ago. In her private practice, Barbara educates and supports schools, families, child welfare systems, adult services agencies, employment training programs, mental health programs, employers, and others who are interested in improving the lives of people with autism spectrum disorders and others disabilities. She has a deep understanding of sensory impairments and autism at both a personal and professional level. Barbara is fluent in sign language and highly skilled in non-verbal communication methods.

Barbara has focused her attention on special populations and topics:

- Developmental disabilities
- Positive methods for improving behavior
- Teaching effective communication strategies
- Autism spectrum disorders (ASD) across the spectrum and across the lifespan
- Asperger Syndrome
- Down Syndrome
- Down Syndrome with autism and/or hearing impairment
- Deafness and hearing loss
- Autism with hearing impairment or deafness
- Autism with vision impairment or blindness
- Autism with cognitive impairment or severe learning issues
- Autism with mental health disorders
- Deafblindness
- Children and young adults with developmental disabilities in child welfare systems
- Assistive technology, both low-tech and high-tech that enables people to do more things, more successfully in life
- Sign language training and non-verbal communication

Barbara works with school districts of all sizes to help them become more truly inclusive. Her definition of real inclusion is success for everyone in the classroom: teachers, general education students and students with special needs. She has developed a repertoire of strategies that are likely to benefit most students and school staff and are designed to create a future society that values and empowers everyone. She trains teams to work more effectively together, prioritize what is most important, and understand and respond to family issues. She is skilled in successfully addressing sensory integration issues in people of all ages.

Barbara has worked extensively in adult services for over 35 years. Her experiences have led her to develop her "lifetime" approach to working with people with autism and other developmental disabilities. She focuses on what is most important to learn and on skills that will have the greatest positive impact on individuals across their entire lifetimes. Her approach is realistic and practical.

Who Should Attend and Why?

Parents, family members and friends, regular education teachers, special education teachers, paraprofessionals, staff providing adult services for people with disabilities (residential, vocational, respite, day programming, in-home support), and other team professionals such as social workers, psychologists, speech and language therapists, occupational therapists, behavioral specialists, psychiatrists, nurses, etc.

Using positive and powerful strategies to change behavior is an integral part of services to people with developmental disabilities and others. This presentation teaches educators, adult services staff and care givers, parents and families, managers, therapists, and administrators to become better able to define, discuss and change problematic behavior in a positive, effective manner focusing on practical environmental manipulations and effective communication-based strategies. Participants will be able to make positive changes in behavior without more time or more money!

Participants will learn:

- To apply unifying assumptions that will make behavioral interventions more effective.
- Accurate, working definitions of behavior, behavior management and behavioral programming.
- The rationale for an emphasis on an environmental/communication approach.
- Objective vs. subjective observation and behavioral descriptions.
- The importance of the "can't vs. won't" dilemma.
- Simple, effective ways to collect and analyze data.
- How to communicate more effectively with others regarding behavior in order to have better team decision-making.
- Why typical behavior modification approaches may not always be effective.
- How environmental adaptations can reduce problematic behavior for a learner.



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

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EDITOR'S REMARKS



Hello Everyone!

The Buddy Walk committee is busy getting ready for the big day - Saturday, October 4th! We can't wait to see all of our families and community members coming out to support HOIDSA. It should be a fun day for everyone!

If you would like to get a ticket for a free hot dog lunch after the walk, make sure you pre-register by the **October 1st** deadline. For more details about the Buddy Walk, see pages 4 and 5 of this newsletter.

Parents of school-aged children and all educators are encouraged to attend our workshop by Barbara Doyle on October 16th and 17th. You can see more details about this workshop on pages 10 and 11 of this newsletter.

See you at the Buddy Walk!!!

Jamie Czesak

jamieczesak@gmail.com

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, and there will be take home gifts for all of the kids.

Next Open House Date:
Friday, October 10th
9:00am - 10:30am



Location:

EPIC (formerly PARC)
1913 W. Townline Road, Peoria

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

*Sponsored by HOIDSA and
EPIC Early Intervention*