



heart of illinois

Down Syndrome Association

Newsletter

December 2014

Contact Us:

c/o Bethel Lutheran Church
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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.

HAPPY NEW YEAR!

2014 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

- Fri. Jan. 9th** **My Two Cents** - 7:00pm
Kep's Sports Bar and Grill
313 Muller Rd, Washington
- Sun. Jan. 11th** **Young Athletes Practice** - 3:00pm
St. Philomena School, 3216 N Emery, Peoria
- Sat. Jan. 24th** **HISRA Summer Camp Registration Fair**
9:00am - 3:00pm
HISRA Office
8727 N. Pioneer Road, Peoria
- Mon. Jan. 26th** **Planning for Individuals with Disabilities**
6:00pm - 7:00pm
Advocates for Access
4450 N. Prospect Rd. Ste. C8, Peoria Heights
- Sat. Feb. 7th** **Annual Family Dance Party**
6:00pm - 9:30pm
Morton Knights of Columbus Hall
616 David St, Morton
- Tues. March 17th** **ACCESS March Madness Experience**
FREE Event - see page 7 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 The President

December 2014

As the end of 2014 draws near, I am reflecting on all of our accomplishments this year. Three board members and two self-advocates met with our congressmen in Washington D.C. regarding the ABLE Act, Down Syndrome Research, and the Down Syndrome Caucus. We arranged for Barbara Doyle to come and present her suggestions for creating positive behavioral change, which was well attended by parents and local schools. We helped sponsor educational workshops by Family Matters and Illinois Includes. We started our focused social groups this year that included special activities for New Kids on the Block, Super Fly Kids, Funsters, Teen Titans, and Chillin' young adults. We hosted monthly new parent breakfasts, the dance party, a swim party, a Fall picnic, the Holiday social, and several monthly gatherings for members to share "My Two Cents." We held our 7th annual Buddy Walk® and participated in the Pekin Marigold Parade and Morton Pumpkin Parade to raise awareness of Down syndrome. We contributed \$2500 to support Down Syndrome Research, reimbursed \$2600 to members for conferences or activities, donated \$6800 to other agencies that provide services to our families, and bought holiday gifts for several families and individuals. And each month we print and mail this newsletter.



We could not have done all this without the help of dedicated people. Our organization is blessed with so many wonderful families - you are what make HOIDSA great!

From our family to yours, we wish you and those you love, good health, good fortune, happiness and peace throughout the New Year.

Carol Nepolello

BIRTHDAYS NEXT MONTH



January

Libby Heger
1/4
Christopher Garza
1/6
Adrianna Austin
1/9
Caitlyn Shirley
1/10
Joel Wynkoop
1/11
Terry Cowley
1/15
Dylan Lundy
1/15
Austin Ray
1/15
Joseph Clore
1/16
Bianca Feazel
1/16
Melissa Heiman
1/16
Nathan Parks
1/18
Danny Moreland
1/22
Nick Butler
1/23
Brett Pezold
1/27
Jesslyn Jo Schultz
1/30
Melissa Zuercher
1/30



HAPPY NEW YEAR!

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, 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.**



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, January 11, 2015

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

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/>

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!

8th Annual

HODSA 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!

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 Edna Gold.**
- **Memorial donations in the name of Judy Gill.**

*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.

Planning for Individuals with Disabilities

Presented by

Michael F. Gulo

Mr. Gulo is an attorney who practices in the area of planning for individuals with disabilities with an emphasis on Special Needs Trusts and Guardianship for Disabled Individuals.

Date: January 26th, 2015

Time: 6:00p.m.– 7:00p.m.

Cost: Free

Location: Advocates for Access
4450 N. Prospect Rd, Suite C8
Peoria Heights, IL 61616

Please RSVP to Stephanie
at 309-682-3500 or by email at
smcginnis@advocatesforaccess.com.

A light meal will be provided!





HEART OF ILLINOIS SPECIAL RECREATION ASSOCIATION

Summer Camp Registration Fair

**HISRA's 2015 Summer Camp Registration Fair is on
Saturday, January 24, 2015 from 9:00 am - 3:00 pm.**

HISRA Office: 8727 N. Pioneer Road, Peoria

OPEN CAMP REGISTRATION WILL CONTINUE UNTIL APRIL 1ST!

Registrations will be taken on a first-come, first-served basis.

If you are unable to come in to register your camper during the Registration Fair, please come into HISRA during office hours beginning January 26 to register. If you are unable to come into HISRA during office hours, please contact Jennifer at (309)691-1929 to set up an appointment.

THE FOLLOWING PAPERWORK MUST BE COMPLETED IN ORDER FOR A REGISTRATION TO BE ACCEPTED AND PROCESSED (All forms are available on HISRA's website www.hisra.org):

1. Registration Form
2. 2015 Annual Information Form
3. Personal Care Request
4. Payment Arrangements with deposit

* Additional paperwork will be mailed to all registered participants and will be due back to HISRA by 5/1/15

Due to camp staffing and program supply costs, no changes to 2015 Summer Camp registrations will be allowed after May 1, 2015. If you registered for camp, extended care, member district transportation and/or inclusion services - please make all changes by 5/1/15. Any changes or cancellations made after 5/1/15 will not be eligible for a refund.

ACCESS Steam

Access Steam is an all-inclusive exercise and fitness program that is designed to meet the needs of individuals of ALL ages who have been diagnosed with cognitive, developmental or physical disabilities. The additional beauty of this unique program is that it is designed for not only the individual, but the families and loved ones of these individuals are encouraged to participate with them! Steamboat training programs have been heralded for their ability to create a healthy and nurturing environment that successfully fuses Fitness, Friendship, and Fun to help individuals prepare for the Steamboat Classic 4-mile or 4K race held on June 13, 2015.

Please contact HISRA at [\(309\) 691-1929](tel:3096911929) for times, locations, and registration accommodations.



**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!

Access the March Madness Experience Field Trip Day

Tuesday, March 17, 2015

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.

Access the March Madness Experience Family Night and Special Needs Information Fair

Tuesday, March 17, 2015

5:00 pm - 8:00 pm • Peoria Civic Center, Peoria, IL

Calling all families with children and adults 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.

Contact Jennifer at HISRA for your FREE TICKETS to one or both of these special events!
Please include your name, phone number, e-mail address and the number of tickets you need.

Call in your request! (309)691-1929

Fax in your request! (309)691-4383

E-mail your request! jwahl@peoriaparks.org

Interested in Volunteering? Contact Jennifer at jwahl@peoriaparks.org

Obama Signs ABLE Act

With his signature, the president has paved the way for people with disabilities to open tax-free savings accounts where they can amass more than \$2,000 without losing government benefits.

President Barack Obama signed the Achieving a Better Life Experience, or ABLE, Act Friday before leaving Washington for the holidays.

The new law will allow people with disabilities to open special accounts where they can save up to \$100,000 without risking eligibility for Social Security and other government programs. What's more, individuals can keep their Medicaid coverage no matter how much money is accrued in an ABLE account.

Modeled after 529 college savings plans, interest earned on savings will be tax-free. Funds accrued in the accounts can be used to pay for education, health care, transportation, housing and other expenses.

To be eligible, individuals must have a condition that occurred before age 26 and each person may only open one ABLE account. Under current gift-tax limitations, as much as \$14,000 could be deposited annually.

People with disabilities may be able to start opening ABLE accounts as soon as 2015. However, some hurdles remain. While the new law alters federal rules to allow for ABLE accounts, each state must now put regulations in place — much as they have done for other types of 529 plans — so that financial institutions can make the new offering available.

“We can't mandate that a state will create a 529, but given the lobby that we've seen, I think by the end of next year, I think we'll see this in every state,” Sen. Richard Burr, R-N.C., one of the measure's chief sponsors, said on a recent call with reporters.

The law's name was amended in recent weeks to honor Stephen Beck, Jr., a longtime proponent of the bill who died unexpectedly in early December.

Read more at:

<http://www.disabilitycoop.com/2014/12/22/obama-signs-able-act/19935/>

Feds Inch Closer To Disability Hiring Goal

The federal government added people with disabilities to its payroll at a higher rate last year than at any other time in the last three decades.

More than 16,000 people with disabilities were hired by the U.S. government during fiscal year 2013, according to a new [report](#) from the Office of Personnel Management. That brought the total number of federal workers with disabilities to 234,395.

This success has led to more people with disabilities in federal service, both in real terms and by percentage than at any time in the past 33 years.

By September 2013, people with disabilities accounted for 12.8 percent of federal employees, an increase of nearly 1 percent over the prior year.

The increased hiring comes after Obama issued an executive order in 2010 calling on the federal government, as the nation's largest employer, to hire 100,000 people with disabilities within five years.

The nation is on its way toward achieving that threshold, with 57,491 permanent employees with disabilities added during the first three years since the executive order took effect.

However, advocates say that the federal government ought to do more.

“While the last few years have seen some modest increases in the numbers of people with disabilities employed by the federal government, The Arc remains deeply concerned that many people with the most significant disabilities, including jobseekers with intellectual and developmental disabilities, are being left behind,” said Peter V. Berns, CEO of The Arc.

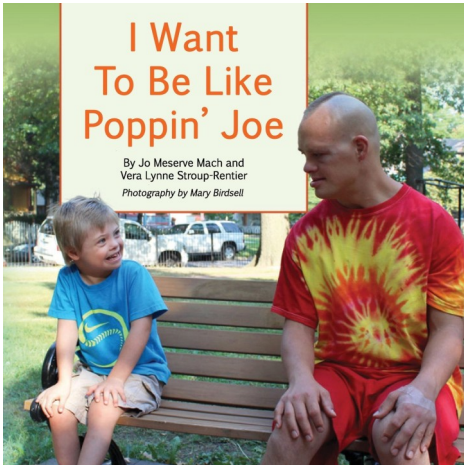
Read more at:

<http://www.disabilitycoop.com/2014/12/15/feds-inch-hiring-goal/19917/>

New series of books: "Finding My Way"

I Want To Be Like Poppin' Joe

'I Want To Be Like Poppin' Joe' is the first book of a new series. Dylan has an awesome friend. His friend, Poppin' Joe, pops and sells popcorn. Poppin' Joe has a very fun job. It's noisy fun! Dylan learns from Joe how to do a job you like.



Kaitlyn Wants to See Ducks

Kaitlyn loves ducks. Her family loves all the animals. Seeing those apes and lions and elephants and goats and giraffes and bears, just isn't what Kaitlyn wants to do. What's a girl to do, when it's family day at the zoo?



'Finding My Way Books' embrace the joy that comes with the development of skills all children need for their self-determination. Each book shares a delightful, true and inclusive story of a child living with a disability or developmental delay. Through fun and bright illuminating photographs, 'Finding My Way Books' show how all children can learn, throughout their daily activities, skills that will promote their self-determination. These opportunities teach them the life skills they need for building a successful, rich, and fulfilling future of their own choosing. 'Finding My Way Books' are fun to read and educational primers for both parents and teachers. Each book includes a specifically written Family Guide describing 'easy to understand' tips for promoting the development of skills needed for self-determination unique to that story.

"Finding My Way Books" can be purchased at [amazon.com](https://www.amazon.com).

Thousands of birthday greetings are mailed to man with Down syndrome

A man with Down syndrome in France got truckloads of cards — some 30,000 from around the world — for his 30th birthday, after his mother put out a call on Facebook that went viral.

By the time Manuel Parisseaux's birthday rolled around on Saturday so many letters had arrived his family in Calais in northern France had to store them in a neighbor's garage.

Jacqueline Parisseaux and her husband posted the following message on her husband's Facebook page, hoping a few people would take notice:

"My son Manuel is going to turn 30 years old on November 22. He has Down syndrome. I'm writing to ask you to take a couple minutes to send him a little card and to pass this information on to your friends so the chain doesn't get broken. I thank you all for your gesture, which will make my Manu so happy."

The cards came by the dozens at first, but then hundreds began to arrive from around the world. Soon the letter carrier couldn't deliver all the cards and they began to come by truck.

The response was global. "We got cards from everywhere: Sri Lanka, Chicago, Hong Kong and sometimes with child's drawings," the mother said, holding back tears.

Read more at [Man with Down syndrome receives 30,000 birthday cards](#).



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

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EDITOR'S REMARKS



Hello Everyone!

I hope everyone had a wonderful holiday! HOIDSA had a great year in 2014 and I think we can expect 2015 to be even better.

The disability community will benefit from years of hard work in 2015 due to the passage of the ABLE Act. You can read more about the ABLE Act on page 8 of this newsletter.

Take some time to examine the recreational activities offered by organizations such as HISRA, IRVSRA, and Special Olympics. Many of these organizations have sign ups for these activities near the beginning of the year.

I hope everyone has a **Happy New Year!**

Jamie Czesak

jamieczesak@gmail.com

NEW PARENT OPEN HOUSE

*The monthly
"New Parent Open House"
will not take place in
2015.*