

heart of illinois

Down Syndrome Association

Newsletter

May / June 2015

Contact Us: c/o Bethel Lutheran Church 425 N. Missouri Ave. 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.

Calendar of Events

New Parent Breakfast - 9:00am - 10:30am

Bethel Lutheran Church, 425 N. Missouri Ave, Morton

Wed. June 17th

Fri. June 12th

Young Adults Cooking Class - 7:00pm

Bethel Lutheran Church, 425 N. Missouri Ave, Morton

Fri. June 19th

My Two Cents - 7:00pm

Oliver's Pizza - 1231 E. Samuel Ave, Peoria Heights

Fri. July 10th

New Parent Breakfast - 9:00am - 10:30am

Bethel Lutheran Church, 425 N. Missouri Ave, Morton

Wed. July 22nd

Young Adults Cooking Class - 7:00pm

Bethel Lutheran Church, 425 N. Missouri Ave, Morton

Fri. July 24th

My Two Cents - 7:00pm

Keps Bar & Grill - 313 Mueller Rd, Washington

Sun. Aug 2nd

Family Pool Party - 7:00pm - 9:00pm

Morton Pool - 450 E. Idlewood, Morton

Fri. Aug. 14th

New Parent Breakfast - 9:00am - 10:30am

Bethel Lutheran Church, 425 N. Missouri Ave, Morton

Sat. Oct. 3rd

BUDDY WALK! - Details on page 6

*The newsletter will be bi-monthly through the summer.
The July/August newsletter will arrive in mid-August.

*Board meetings will not be held during June, July, or August.

The next board meeting will be held on

Monday, September 8th at 6:00pm at Bethel Lutheran Church

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

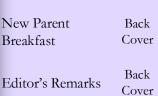
Jamie Czesak Laurie Mattheessen Becky McDaniels Kim Sarff Shelli Willoughby Todd Willoughby

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

May / June 2015

As you visit with family and friends this

summer, start forming your team for the Buddy Walk® which takes place in October, during Down Syndrome Awareness Month. Our event has grown every year, and



it is very exciting to see the vast number of people who turn out to show their support. This is also a major fundraising campaign that raises funds so we can support new parents, provide educational workshops and conferences, coordinate social events for our members, offer programs like the Young Adult Cooking Class, and promote acceptance of people with Down syndrome. Get your teams ready!

Have a great summer! Carol

Help Wanted: Newsletter Editor

Jamie Czesak has been a wonderful newsletter editor for the past 2 years, but she is moving out of the area and would like to pass this on to someone new.

Jamie will share all her files with the new editor. She currently uses Microsoft Publisher to generate the monthly newsletters, however there are other programs that could be used for this task.

If you are interested, please contact us at info@hoidsa.org for more information.

BIRTHDAYS

June Chad Applen 6/2 Jacob Urban 6/4 Hannah Capitelli Jacob Monrad 6/7 Kaden Barnewolt 6/12 Fancis Couri 6/19 Trecker Ralph 6/20 Bridget Bielenberg William Harston-Meagher 6/23 **Anthony West** 6/23 Jesse Hatfill 6/24 Jeremy Quintiliani 6/24 Kellen Ehrenhardt 6/26 Adam Nepolello 6/28 Gregory DeBoer Rory O'Hanlon

July Timmy Wynkoop Stuart Booker 7/7 Kristin Koch 7/7 James Piper Scott Willock 7/7 John Meyer 7/10 Trevor Vincent 7/10 Ian Massey 7/14 Emma Cramer

7/16

Sean Harris

7/17

7/18 Charlotte Nauman

7/28

Janae Sutton

Sam Heim



Payton Mills

Name: Payton Mills
Age: 6 Years Old

School: Steele Elementary School, Kindergarten

Recent milestones: Payton recently learned to ride a tricycle. Payton can now read many sight words, and can read short sentences. Payton can also write and spell his name.

Activities: Payton has been involved in the Young Athletes program and attends programming monthly at St. Philomena Church, in Peoria. Payton's cousins and sisters also take part in this wonderful program. Payton is looking forward to nature camp this summer. Payton attends summer literacy tutoring at GiGi's Playhouse in



Moline. Swim lessons at the YMCA. Payton will also be doing Tee Ball this summer for the first time.

Interests and/or hobbies: Train, Dinosaurs, Books and Animals.

Favorite things to do: Payton loves playing with his family. Payton loves playing outside on his trampoline. We got the kids a trampoline for Christmas this year and Payton runs off the bus after school and immediately starts jumping. He also loves playing in his sandbox. Swimming is probably his favorite thing in the entire world.



When I grow up, I want to... Work with animals.

Siblings: Claire, Grace, and another on the way.

Pet: Urlacher (Cat)

Favorite place to go: The Zoo. Monkey Joes. Water Parks.

Talents: Exceptional swimming skills for his age. Caring and easily

makes new friends.

Something interesting about me: I went to Disney World last summer with my Dad, Uncle Matt, Cousin Bradley, and my Grandma. I loved all the rides, especially the 7 Dwarves Mine Train.

Something I am really good at: Puzzles.

Favorite toy: Train Sets. Matchbox cars. Play Dough.

Electronic devices (iPod/iPad)

Favorite food: Cucumbers, Chicken Fries, Pizza and Popcorn.

Favorite TV shows or movies: Blaze and the Monster Machines. Ice Age.

Special Olympics Illinois

Congratulations to all HOIDSA athletes who competed in the Area 6 Special Olympics regional's on May 3rd!

Athletes pictured:

Chad Applen
Kellen Ehrenhardt
Brad Fornoff
Sam Heim
Trevor Kalke
Logan Serrano
Mercy Thacker
Adam West
Joe Willoughby



























Special Olympics: POWERLIFTING

Austin Ray has been involved with Illinois Special Olympics for numerous years, playing basketball,



softball, track & field, bowling and soccer.
Austin is participating in powerlifting for the first time this year, lifting with Tri-County Independents. Austin



represented Area 6 at the state qualifier April 19th at McKendree College in Lebanon, IL. He earned a 1st place medal for deadlift, 2nd place medal for bench press and a medal for combo. He will compete again, in both dead lift and bench press, at the state competition. The Special Olympic state competition will take place at the summer games in Bloomington/Normal, June 12-14.

Project 111

A group home development project for adults with disabilities.

Trevor is a 25-year-old adult with Down Syndrome, but his disability doesn't prevent him from having the same kinds of experiences the rest of us encounter. What's his next big milestone? Moving out of mom and dad's home.

Trevor's parents own a house in Morton, 111 E. Jefferson St., which the Colby family is working hard to convert into a group home for Trevor and up to four other adults with disabilities, who will be able to live there with intermittent supports. The home, although a sound structure, is being updated and remodeled to provide appropriate access for individuals with disabilities.





Visit Project 111's Go Fund Me page at: http://www.gofundme.com/project111 to see how you can donate or volunteer to help make this dream a reality.

Your donation will not only help Trevor achieve his housing dream, but it will also have a huge impact on the lives of Trevor's living companions. In Illinois, there is a great need for housing for adults with disabilities, and this project strives to address that need.

To learn more about Trevor, the Colby family, and Project 111, visit: http://www.gofundme.com/project111

SAVE THE DATE

HOIDSA'S 8TH ANNUAL BUDDY WALK® Saturday October 3rd, EastSide Centre

Register and Manage Your Fundraising Online

Help raise Down syndrome awareness here in the heart of Illinois by registering online for HOIDSA'S 8th Annual Buddy Walk® and creating your own personalized fundraising page for collecting pledges. These pledges will help HOIDSA's mission of providing information and support for families and friends of individuals with Down syndrome. Visit www.firstgiving.com/hoidsa to get started.

Advanced online registration is encouraged, however you may print a registration form at www.hoidsa.org/get-involved and mail it along with payment to: HOIDSA Buddy Walk® c/o Bethel Lutheran Church, 425 N. Missouri Ave., Morton IL 61550.

Sponsor and Donation Forms

To view complete details about the walk, download and print the sponsor letter, donation letter and sponsor form to solicit potential sponsors visit www.hoidsa.org and click on Get Involved.

Questions? Call 309-712-4852 or email buddywalk@hoidsa.org

Registration Costs

\$5 - per participant with Down syndrome, includes FREE t-shirt \$5 - per participant without T-shirt \$15 - per participant with T-shirt

Registration Deadlines

September 10th - registration with a T-shirt ends
September 30th - online registration ends
Registration must be received by September 10th to be
quaranteed a t-shirt.

Walk Details

8:00 arm—T-shirt pickup, On-Site registration, continental breakfast, face painting, games & activities all begin

9:30 am - Walk kicks off



Come and enjoy a morning of fun and a one mile walk to raise Down syndrome awareness and support families and friends of individuals with Down syndrome.

Walk will take place rain or shine | Site is ADA accessible

The Buddy Walk® was created by the National Down Syndrome Society in 1995 to celebrate Down Syndrome Awareness Month in October and to promote acceptance and inclusion of people with Down syndrome. The Buddy Walk® has grown from 17 walks in 1995 to nearly 300 walks planned for 2015 worldwide. In 2014, more than \$13 million was raised nationwide to benefit local programs and services, as well as the national advocacy initiatives of NDSS that benefit all individuals with Down syndrome.

Memorial/Recognition Donations

Our sincerest appreciation to all the family and friends who contributed to the following memorial donations:

- Memorial donations in honor of James Moehlenhof, uncle of Katie Swenson.
- Memorial donations in honor of Maureen Addis, grandmother of Charlie Otten.
- Memorial donations in honor of Warren Martin, grandfather of Heather Gill.

Our sincere appreciation.

Also thank you to the Knights of Columbus Father John Raho Council in Morton for their donation.

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.





Sunday, August 2nd ■ 7 - 9 pm

Cost: \$1.00/person
Concession stand will be open



FAMILY FUN • WATER SLIDES • DIVING BOARDS • ZERO DEPTH SPLASH
POOL • INTERESTING PEOPLE • GOOD CONVERSATION
(So come on out even if you're not a swimmer!)
For questions or more info, call Julie at 231-3713



SPOTLIGHT ON...

If you would like to have your family member with Down syndrome featured in our newsletter, you can download the interview sheet on our website.

Go to the "Newsletters" page on www.hoidsa.org to download the interview sheet. Fill out this document and e-mail it to jamieczesak@gmail.com with 1 or 2 pictures.

Contact Jamie Czesak (309)303-8475 or jamieczesak@gmail.com with any questions. I

Cousin Uses 3D Printer To Create Prosthetic Hand For Pekin Girl

For Kaelie Morgan, 26, of Pekin, not having any fingers on her right hand has meant that she has had to adapt physically for many activities. Born with Down Syndrome, Kaelie enjoyed an active childhood and attended Pekin Community High School.

At home, she mastered many routine tasks, such as buttoning shirts and tying shoes. During free time, she'd spend days like the rest of the neighborhood kids, running and playing with her sisters and friends.

"She did so well compensating," says her mom. "It didn't slow her down."





Philip Hopping, 37, is married to one of Kaelie's cousins. Like Kaelie, he graduated from Pekin High. He is a design engineer for Excel, specializing in the hydraulic systems of mining crushers. Excel, located just south of Pekin, drafts, makes and sells replacement parts for mining machinery.

Recently, Excel spent about \$2,500 for a 3D printer. About the size of a large microwave oven, the device takes computer-inputted coding and creates objects, often mining parts or models.

Hopping happened upon Thingiverse (<u>www.thingiverse.com</u>), a website that shares free digital design files for toys, jewelry, watches — whatever lurks inside a designer's imagination.

The Thingiverse designs work by motion in the wrist causing the contraction of simple wires (such as fishing

line), which constrict the plastic hand into a fist. The user can grab a pole or bar, such as a broom.

As Hopping looked over the design, he saw Kaelie using such a hand to grab the handlebars of her bicycle.

Hopping reviewed the hand designs, settling on a model called the Cyborg Beast. Kaelie had input, too. For instance, she wanted the hand to be purple.

"That's my favorite color," she says.

Also, she asked Hopping to dot the hand with stars.

"They're cool," she says.

Hopping brought Kaelie to the Excel lab, where he measured her hand with a 3D scanner. The scanner allowed Hopping to best match her arm with the Cyborg Beast blueprints.

Slowly, the device created purple parts. Almost 70 hours later, the components were finished. In a snap, Hopping attached the wires, bolts and other parts.

"It was awesome," Hopping says. "I was really happy how it turned out."

To read this full article, visit:

http://www.pjstar.com/article/20150530/NEWS/150529120/0/150529120/?Start=1



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

June 19 - Oliver's Pizza

1231 E. Samuel Ave, Peoria Heights *Special Guest*

Dr. Kyle Haynes from Haynes Family Chiropractic

July 24 - Keps Sports Bar & Grill

313 Mueller Rd, Washington

August 28 - Bullpen (at Landmark)

3225 N. Dries, Peoria

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



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 reation.html

Young Adult Cooking Class

Attention Young Adults!!!!

HOIDSA is starting a new cooking class with Bethel Lutheran Church's youth group as mentors.

The class is open to any member 16 years old and older with our mentor's being high school aged.

The class will usually be held the 3rd Wednesday of the month at Bethel Lutheran Church (425 N. Missouri Avenue, Morton, IL).

Class dates:

- June 17
- July 22 (This is the 4th Wednesday of July)
- August 19
- **September 16** (This class may be changed due to the Pumpkin Festival, details TBD)
- October 21
- November 18
- December 16

Start time will be 7:00 PM unless otherwise stated and finish at 8:30 PM.

We will use the "Let's Cook!" cook book ISBN 978-1-1891022-08-5, authors Elizabeth Riesz, Ph.D and Anne Kissack, M.P.H.,R.D. It can be ordered through any book selling outlet.

There is no fee for the class.

We have several participants registered and are accepting more on a first come/ first served basis.

This is a wonderful opportunity for our young adults to make friends and influence their non-disabled peers.

We will have ample supervision but any parent is welcome to stay. Bethel's kitchen is on the first floor with restrooms around the corner.

Meri Tucker is your contact person and will be leading the classes. To register or ask any questions, contact Meri at 309-694-2984 (home) or 309-264-4900 (cell).



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EDITOR'S REMARKS

Hello Everyone! I hope all of you enjoy the summer! If you have some free time this summer, consider taking

some time to solicit local businesses for Buddy Walk sponsorships. Also begin to recruit family and friends for your Buddy Walk team. Buddy Walk registration is now open. You can learn more about the Buddy Walk on page 6 of this newsletter.

You may have noticed on page 2 that there is a "Help Wanted" ad for a new Newsletter Editor. My husband and I will be moving to Springfield later this summer, and I would like to pass the Editor responsibilities on to someone in our group. If you or someone you know are interested in learning more about this position, please do not hesitate to contact me at jamieczesak@gmail.com or (309)303-8475. I would be happy to answer any questions you may have!

Have a great summer!

Jamie Czesak jamieczesak@gmail.com

NEW PARENT OPEN HOUSE

HOIDSA's new parent breakfasts are back!

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.



Next Open House Dates: Friday, July 10th Friday, August 14th 9:00am - 10:30am



Location:

Bethel Lutheran Church 425 N. Missouri Ave., Morton

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