



heart of illinois

Down Syndrome Association

Newsletter

April 2015

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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

- Sun. May 3rd** **Young Athletes Practice - 3:00pm**
St. Philomena School gymnasium,
3216 N Emery, Peoria
- Fri. May 8th** **New Parent Breakfast - 9:00am - 10:30am**
Bethel Lutheran Church, 425 N. Missouri Ave, Morton
- Fri. May 15th** **Dr. Kyle Haynes Informational Evening**
6:00pm - 7:30pm
Bethel Lutheran Church,
425 N. Missouri Ave, Morton
- Wed. May 20th** **Young Adults Cooking Class - 7:00pm**
Bethel Lutheran Church, 425 N. Missouri Ave, Morton
- Fri. May 22nd** **My Two Cents - 7:00pm**
Firehouse Pizza - 240 S. Main St., East Peoria
- Fri. June 12th** **New Parent Breakfast - 9:00am - 10:30am**
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

***The newsletter will be bi-monthly through the summer.
The May/June newsletter will arrive in mid-June and 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**

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

April 2015

We just returned from a family vacation over Spring break. We took grandparents with us to help keep extra eyes on Adam because he certainly has a mind of his own sometimes. I used to blame his extra chromosome for his challenging behavior, but now when I see him interacting with strangers and handling new situations, I think he just has a really strong personality. His actions seem to be more a product of heredity, our parenting styles, his observation of the world, and immaturity, than from Down syndrome. Most of the time he is friendly, outgoing, and helpful, but he can also be quite loud, opinionated, and stubborn. There's a wide range of elements to his personality! And there are a few people who were in the O'Hare airport on March 27th who now know that kids with Down syndrome aren't sweet and loving all the time, and that's OK.



As you prepare your summer plans, keep in mind that HOIDSA offers family reimbursement stipends of up to \$100 for summer activities. We'd like to see our kids continue to be involved in community activities with their peers. Don't forget to utilize special recreation associations like HISRA and IRVSRA, who provide support to children with special needs, free of charge, so they can be included in typical activities and programs.

Carol

BIRTHDAYS NEXT MONTH



May

- Stephanie Brant
5/3
- Elizabeth Rice
5/7
- Addy Duensing
5/9
- Shea Gale
5/11
- Madison Haynes
5/12
- Claire Schwarting
5/13
- Rebecca Nickerson
5/14
- Brad Fornoff
5/20
- Oliver Smith
5/22
- Wyatt Lauber
5/28
- Tom Weiss
5/30
- Nicholas Mueller
- Triston Walbright



Join us for an informational evening with
Dr. Kyle Haynes to learn about:



- Atlantoaxial Instability in people with Down syndrome
- Benefits of Chiropractic Care
- Relief of pain and other symptoms when they can't tell you what's wrong
- Blair Upper Cervical adjustments of the spine (without "cracking" your neck)

Friday, May 15, 2015

6:00 p.m. – 7:30 p.m.

Bethel Lutheran Church

425 N. Missouri Ave, Morton IL

Light supper will be provided. RSVP at www.hoidsa.org by May 13.

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 www.hoidsa.org, under the "About Us" tab click on "Newsletters". On this page you should see "HOIDSA wants you to be featured in the "Spotlight On..." section of the newsletter! Click [here](#) to find out how!".

When you click this link it will open a word document.

Fill out this document and e-mail it to jamieczesak@gmail.com with 1 or 2 pictures.

Spotlights will be published on a first come first served basis.

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

April Showers bring May Flowers



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.

Previous cooking experience not necessary.

Class participants will learn how to recognize and plan healthy meals, how to handle food safely, proper measuring, and cutting safety.

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

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.

The cost of ingredients will be paid by HOIDSA and the individuals will supply their own utensils, aprons and cook book. I will send a waiver and utensil list to all who register.

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).

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

May 22 - Firehouse Pizza

240 S. Main St., East Peoria

June 19 - Oliver's Pizza

1231 E. Samuel Ave, Peoria Heights

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.**



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.



Family Matters Webinar:

**Everyday Math:
Being Your Child's Math Coach**

Would you like information on how to help your child learn foundational math skills?

This webinar will provide the following:

- information on basic math skills vital for children to build on
- fun activities to do with your child to enhance math skills
- ideas on how to overcome your own math phobias

This webinar is being presented on two different dates/times.

DATE: Tuesday, May 5, 2015

TIME: 7:00pm to 8:15pm

To Register for this webinar go to:

<https://attendee.gotowebinar.com/register/5692276516429893121>

DATE: Tuesday, May 12, 2015

TIME: Noon to 1:15pm

To Register for this webinar go to:

<https://attendee.gotowebinar.com/register/1388581297130006018>



Special Olympics
Young Athletes™

Come be a part of this exciting program through Special Olympics Illinois. 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. This program will prove enormously beneficial on multiple levels for your child including helping the children improve physically, cognitively and socially. Siblings ages 2-7 of the participants are welcome to participate. We are very excited about this program and your family's participation!

**All sessions held at
St. Philomena School gymnasium
3216 N Emery, Peoria
3:00 pm – 4:00 pm**

Sunday, May 3, 2015

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

John & Christy Getz
Curt & Amanda Nauman
Coordinators, Peoria Independent Families

**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>



Ruby's Rainbow Scholarship Application Deadline: Friday, May 15, 6 PM Central

Eligibility Requirements for Ruby's Rainbow Scholarship

Scholarship applicants must:

- be 18 years of age or older and have Down syndrome
- have the desire and intent to enroll or continue enrollment in a class or program that will enhance your life through employment, independent living or life skills, or interests in any other areas
- provide high school transcripts or equivalent (e.g., certificate of completion)

Our goal at Ruby's Rainbow is to help individuals with Down syndrome achieve their dreams of higher education, and **our mission** is to spread awareness of their many capabilities. After our lil' daughter Ruby's birth, we were inspired to help people who are ***Rockin' that Extra Chromosome*** gain confidence and independence, and ***reach their highest potential.***

Ruby's Rainbow grants scholarships to adults with Down syndrome for post-secondary education, vocational or enrichment classes.

To apply for this scholarship, visit this link:

[https://www.rubysrainbow.org/apply-now/?utm_source=DSAs&utm_campaign=aa430346fd-Ruby's Rainbow Scholarship Deadline 4 7 2015&utm_medium=email&utm_term=0_149d560d5f-aa430346fd-30376725&ct=t%28Ruby's Rainbow Scholarship Deadline 4 7 2015%29&mc_cid=aa430346fd](https://www.rubysrainbow.org/apply-now/?utm_source=DSAs&utm_campaign=aa430346fd-Ruby's+Rainbow+Scholarship+Deadline+4+7+2015&utm_medium=email&utm_term=0_149d560d5f-aa430346fd-30376725&ct=t%28Ruby's+Rainbow+Scholarship+Deadline+4+7+2015%29&mc_cid=aa430346fd)



Down Syndrome Association of Greater St. Louis

iCan Shine Bike Camp

Liberty Middle School

1 District Drive, Edwardsville, IL 62025

Monday, June 8 – Friday, June 12, 2015

To learn more or register for this bike camp, visit:

<http://dsagsl.org/programs/educational-programming/>

Volunteers Wanted for a Research Study

Family-Based Sexuality Education Training For Parents of Adolescents with Down Syndrome

The purpose of this study is to investigate the effectiveness of a family-based sexuality curriculum for parents of teens with DS on improving the self-efficacy and attitudes around sexuality and healthy relationships for adolescents with DS as well as increase the parent-child communication on sexuality topics.

Who's Eligible?

The University of Illinois at Chicago is offering a **free** training for parents of adolescents (ages 12-19) with Down syndrome. Interested participants must be able to communicate in English.

What's Involved?

Participants must be able to meet three (3) times over a two (2) month time frame for two and a half (2½) hours each visit. Trainings will be held in April and May 2015. Participants will be asked to complete a pre- and post-training evaluation.

You may choose to attend trainings offered and three convenient locations:

- University of Illinois at Chicago, 1640 W. Roosevelt Rd, Chicago, IL 60608
- Adult Down Syndrome Center, 1610 Luther Lane, Park Ridge, IL 60068
- Community Alternatives Unlimited, 8765 W. Higgins Rd, Chicago, IL 60631

For more information, please contact the primary investigator, Katie Frank, at (312) 413-1116, or kfrank7@uic.edu.

STARTS APPROVAL EXPIRES

MAR 16 2015

MAR 15 2016

UNIVERSITY OF ILLINOIS AT CHICAGO
INSTITUTIONAL REVIEW BOARD



Home-Based Adolescent Sexuality Education
for Developmental Disabilities

UIC Department of Disability and
Human Development
UNIVERSITY OF ILLINOIS
AT CHICAGO
COLLEGE OF APPLIED HEALTH SCIENCES

Flyer for training, version 2, 2/16/15

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Program Looks To Turn People With Disabilities Into Entrepreneurs

With an eye toward increasing employment opportunities, a new effort is looking to provide people with intellectual and developmental disabilities the tools to work for themselves.

Researchers at the University of Illinois at Chicago are developing a new program designed to help people with disabilities become entrepreneurs.

Organizers say the effort will bring together people with disabilities, service providers as well as members of the business community to establish a model that can be replicated across the country.

“Some people are just at the idea phase, and are often told ‘no’ before they can even begin because they have an intellectual or developmental disability,” said Sarah Parker Harris, associate professor of disability and human development who’s helping lead the project. “A lot of building success is connecting the right people.”

The effort will expand on a pilot project Parker Harris conducted in 2010 with Maija Renko, an associate professor of managerial studies. Ultimately, the researchers indicated that they plan to develop a training program that disability service providers can use to assess readiness for entrepreneurship and teach individuals everything from writing a business plan to networking and marketing.

By incorporating insights from those with disabilities and business leaders, the researchers said they hope to bridge both cultural and language gaps while also working to increase job prospects for a traditionally underemployed population.

“We’re trying push through not just the policy barriers and the systemic barriers, but some of the attitudinal barriers,” Parker Harris said.

To view this article, visit:

<http://www.disabilityscoop.com/2015/04/21/program-entrepreneurs/20233/>

Senate Plan Retains Testing Cap For Students With Disabilities

A bipartisan plan to reshape the nation’s primary education law would maintain strict limits on the number of students with disabilities taking less rigorous tests.

After months of negotiation, the top Republican and Democrat on the U.S. Senate education committee released a joint proposal this week to update the Elementary and Secondary Education Act, known as No Child Left Behind. The Senate education panel is slated to consider the bill next week.

Currently, students with severe cognitive disabilities are allowed to take alternate assessments in lieu of the general, grade-level tests mandated for most children. However, only 1 percent of all students — or about 10 percent of those with disabilities — may be counted as proficient by schools for taking alternate exams.

The proposal from U.S. Sens. Lamar Alexander, R-Tenn., and Patty Murray, D-Wash., would retain that rule. The plan would also continue a requirement that annual data collection to track student progress include figures specific to students with disabilities.

“Our agreement continues important measurements of the academic progress of students but restores to states, local school districts, teachers and parents the responsibility for deciding what to do about improving student achievement,” Alexander said of the plan which would scale back the federal role in defining academic standards, how teachers should be evaluated and what to do about failing schools.

Disability advocates were concerned by an earlier proposal from Alexander that would have done away with the cap on the number of students who could take less-rigorous tests, potentially leading to lower expectations.

Lindsay Jones, director of public policy and advocacy at the National Center for Learning Disabilities, said that an initial read of the new proposal suggests that it’s a “step in the right direction,” particularly with regard to testing.

“The overwhelming majority of students with disabilities can — and do — take the general assessment with or without accommodations. We believe the bill mirrors this reality and includes important protections that provide access to the general education curriculum for all students — those taking the general or the alternate assessment,” Jones said.

To view this full article, visit:

<http://www.disabilityscoop.com/2015/04/08/senate-retains-testing-cap/20200/>

Photographer Dad Makes His Son With Down Syndrome Fly In Adorable Photo Series

1-year-old William (Wil) Lawrence, the youngest in his family, was born a little bit different from the rest of his brothers and sisters, but that won't hold him back. Wil has Down syndrome, but thanks to a bit of Photoshop magic from his photographer dad Alan, he also has a very special gift – Wil can fly!



Alan, who lives in Utah with his wife and 5 kids (with 1 more on the way), takes the pictures with the hope that they will inspire Wil; “These photos of Wil flying have taken on a special meaning for me as I think about the unique challenges Wil is going to face growing up. I hope to teach him that even with his disabilities he can do anything he puts his mind to.” He takes them by holding up Wil and then editing himself out.

Alan is also preparing a project called “Bringing The Light,” the goal of which will be to inspire and support other families living with Down syndrome.

Hansel & Gretel: A Fairy Tale with a Down Syndrome Twist

Jewel Kats, Author

Claudia Marie Lenart, Illustrator

Loving Healing Press

Suitable for Ages: 3-7

A storm sweeps through a village and a fisherman and his two children, Hansel and Gretel, are the only survivors. Their food runs out and Hansel and Gretel are sent to search for food in the forest. Their mother protests that Hansel is sick and too young for such an adventure. But, Hansel's father disagrees and says he has Down syndrome and that they can't always protect him forever. Hansel takes the lead and bravely runs into the forest and stumbles upon the witch's candy house. Will Hansel be able to outwit and negotiate with the witch?



To learn more about this book, visit: <http://childrensbooksheal.com/2015/03/16/hansel-and-gretel-a-fairy-tale-with-a-down-syndrome-twist/#comment-20242>





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EDITOR'S REMARKS



Hello Everyone!

I want to take this time to remind everyone that the newsletter is bi-monthly during the summer months. The May/June newsletter will come out in mid-June and the July/August newsletter will come out in mid-August. To make sure you stay as up-to-date as possible on all of HOIDSA's news and events, make sure to visit our website at www.hoidsa.org and our facebook page at <https://www.facebook.com/HOIDSA>.

As Carol stated in her greetings, keep in mind that HOIDSA offers a \$100 stipend for recreational activities. Many local organizations offer recreational activities during the summer months. Take some time to visit the websites listed on page 5 to see if any of their activities interest you.

Have a great start to 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, May 8th

Friday, June 12th

9:00am - 10:30am



Location:

Bethel Lutheran Church

425 N. Missouri Ave., Morton

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