



heart of illinois

Down Syndrome Association

Newsletter

March 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

- | | |
|-------------------------|--|
| Mon. April 6th | Board Meeting - 6:00pm
Bethel Lutheran Church, Morton |
| Fri. April 10th | New Parent Breakfast - 9:00am - 10:30am
Bethel Lutheran Church
425 N. Missouri Ave, Morton |
| Fri. April 10th | My Two Cents - 7:00pm
Fox Pub & Café, 7800 N. Sommer St #302, Peoria |
| Sun. April 12th | Young Athletes Practice - 3:00pm
St. Philomena School gymnasium,
3216 N Emery, Peoria |
| Fri. April 24th | Inclusion Series Workshop - Part 1
The "Why" of Inclusion - see page 4 for details
8:00am - 3:00pm
WeaverRidge Gold Club
5100 N. WeaverRidge Blvd, Peoria |
| Tues. April 28th | The Common Core and Students with Disabilities Workshop - see page 7 for details
6:00pm - 8:00pm
Advocates for Access Conference Room
4450 W Prospect Rd (Ste C-8), Peoria Heights |
| Tues. April 28th | Grandparents Group - 6:00pm
Perdue's, 201 S. Sampson St., Tremont |
| Sun. May 3rd | Young Athletes Practice - 3:00pm
St. Philomena School gymnasium,
3216 N Emery, Peoria |

Board meetings are held the first Monday of the month at 6:00 p.m. at Bethel Lutheran Church in Morton unless otherwise noted.

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

March 2015

For many of us, this is IEP season. Some teachers and administrators and parents work together very well to create an Individualized Education Program (IEP) that meets the child's needs, while maintaining high expectations and as much access to the general education curriculum as possible. However, if you are a parent who struggles with IEP meetings and feel like it's you versus the school, HOIDSA can help. We have several experienced parents who have been there and are willing to talk you about your issues with creative problem-solving ideas. Send an email to info@hoida.org or leave a message at (309) 712-4852, and one of our IEP advisors will get back to you.



We would also like to invite parents and your child's teachers and their administrators to attend HOIDSA's Two-Part Inclusion Series featuring Dr. Patrick Schwarz and Dr. Paula Kluth. These renowned experts in the field of education will address WHY inclusive education is essential and HOW to teach a diverse group of learners in an inclusive classroom. Teachers will receive a discount for registering for both sessions, and principals, special education directors, and superintendents attend for FREE!! Give your school a copy of the flier in this newsletter and personally invite them.

HOIDSA parents attend for FREE as well. Parents play a key role in the education planning process and need to be informed decision-makers in order to advocate for the best educational placement for their child. Register through www.hoidsa.org before April 20th.

Carol

BIRTHDAYS NEXT MONTH



April

Benaiah Schoenbein
4/2

Kenedi Boucher
4/6

Garrett Geier
4/12

Derek DeBolt
4/15

Bailey Fifer
4/15

Aries Rush
4/16

Natalie Ballor
4/18

Mackenzie Brunson
4/20

Holly Randall
4/21

Bridget Buscemi
4/23

Kaelie Morgan
4/24

Chris Kezele
4/26

Jazmine German
4/25

Charlie Grahek
4/27

Jeremiah Larson
4/28

Adam Masso
4/28

Jason Phillips
4/30

Jordan Phillips
4/30

Ryan Miller



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.

Memorial/Recognition Donations

- **Memorial donations in honor of Jeanie Palmer.**

- **Bev and Duane Palmer**
- **John and Wilma Hessler**
- **Kellen Ehrenhardt**
- **Kevin and Teri Ehrenhardt**

*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.

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>

Two-Part INCLUSION Series

Featuring

Dr. Patrick Schwarz and Dr. Paula Kluth

WeaverRidge Golf Club

5100 N. WeaverRidge Blvd., Peoria IL, 61615

Friday, April 24, 2015

The "WHY" of Inclusion

Presented by Dr. Patrick Schwarz

Thursday, Sept. 24, 2015

The "HOW" of Inclusion

Presented by Dr. Paula Kluth

Sponsored by:

Heart of Illinois Down Syndrome Association, Inc.

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

Phone: (309) 712-4852

PARENTS • TEACHERS • ADMINISTRATORS
SUPPORT STAFF • FUTURE EDUCATORS

Register online at www.hoidsa.org

Each Session - \$50

Save and Register for Both Now - \$80

College Students, Administrators and

HOIDSA members attend FREE!

*** HOIDSA will reimburse schools substitute pay
for up to three educators at \$85 each.**

For more information, contact HOIDSA at info@hoidsa.org or 309-712-4852

**Who should attend the "WHY"
and "HOW" of Inclusion Series?**

General education teachers, special education teachers, administrators, therapists, parents, and anyone who supports the growth and learning of children.

For Parents

Who knows your child best? You do! Who is your child's biggest and most important advocate? You are!

Parents need to be informed decision-makers in order to advocate for the best educational placement for their child. Find out why research has shown students with disabilities should be educated with their typically developing peers. As members of the IEP team, parents play a key role in the education planning process. Dr. Patrick Schwarz will explain what inclusion is, what it does (and doesn't) look like in a classroom, and how to work with educators to fulfill your vision of your child's future.

For Educators and Service Providers

Who wants all of their students to achieve the most they can? You do! Can teaching a diverse group of learners be challenging and time-consuming? Sometimes!

If you're fortunate enough to have a student with special needs in your classroom, you may be struggling with how to keep them included and engaged in your lessons. Students with disabilities do not need to engage in the curriculum in the same way that students without disabilities do, but no one has time to plan separate lessons! You will love to learn from these renowned speakers about planning processes and teaching strategies that help all students reach their maximum potential, while accessing the same material.



AGENDA

8:00 am – 8:45 am	Registration
8:45 am – 10:00 am	Presentation part 1
10:00 am – 10:15 am	Break
10:15 am – 11:30 am	Presentation part 2
11:30 am – 12:30 pm	Lunch provided
12:30 pm – 1:45 pm	Presentation part 3
1:45 pm – 2:00 pm	Break
2:00 pm – 3:00 pm	Presentation part 4

**5 PD
credits
available**

***Gifts for all
attendees!***



Friday, April 24, 2015
The "WHY" of Inclusion

Presented by Dr. Patrick Schwarz

The "WHY" of Inclusion: Creating Classroom Communities Where All Belong

In this workshop, definitions and rationales for inclusive education will be examined, focusing on the belief that everyone belongs everywhere with everyone else in our schools and community. In addition, components of inclusion will be outlined, and types of classroom supports with many ideas will be discussed. Research studies about why inclusive education is essential will be examined to strengthen its' importance as the best learning and teaching approach. Promising practices in a bag of tricks such as co-planning, co-teaching and creative instructional delivery will be introduced.

Further planning processes will be illustrated with discussions around how we meet IEP goals and curricular learning targets at the same time for all diverse learners. Definitions of instructional strategies such as differentiation, universal design and student accommodations will be outlined and discussed. Applications will assist participants to consider the individuals they represent in order to enhance and improve their educational status. Be prepared for a very meaningful, engaging and fun day that will prepare participants for further quality educational delivery.

About Patrick:

Dr. Patrick Schwarz is a dynamic and engaging professor, author, motivational speaker and leader in Education (Inclusive Education, Special Education, General Education, Educational Leadership) and Human Services. He is a professor at National-Louis University, Chicago. Patrick's company is Creative Culture Consulting LLC. He is the author of *From Disability to Possibility, You're Welcome* (with Paula Kluth), *Just Give Him the Whale* (with Paula Kluth) and *Pedro's Whale* (with Paula Kluth). His new book is *From Possibility to Success*.

The Heart of Illinois Down Syndrome Association, Inc. is a local support group of parent volunteers dedicated 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.



Thursday, Sept. 24, 2015
The "HOW" of Inclusion

Presented by Dr. Paula Kluth

The "HOW" of Inclusion: 7 Ways to Create Better Classrooms for All

You may know the "why" of inclusion, but do you have the tools you need to support all students in the classroom? Do you understand the practices of high-quality inclusive school districts? Do you want to learn more about what steps teachers, administrators and families can take to improve the services and supports received by students with identified needs? If you answered "yes" to any of these questions, come to this daylong workshop focused on the "HOW" of inclusive schools and learn practical strategies related to community, curriculum, instruction, collaboration and more. Specifically, participants will learn how to create an inclusive identity, how to grow inclusive strategies across a building or district and how to explore new collaborative roles.

This day-long workshop will include case studies, video clips of inclusive schools and collaborative activities. In addition, Dr. Kluth will share the newest research in the area of inclusive education and a range of practical resources (e.g., website recommendations).

About Paula:

Dr. Paula Kluth is a consultant, author, advocate, and independent scholar who works with teachers and families to provide inclusive opportunities for students with disabilities and to create more responsive and engaging schooling experiences for all learners. Paula is a former special educator who has served as a classroom teacher and inclusion facilitator. Her professional interests include differentiating instruction and inclusive schooling.

She is the author or co-author of more than ten books including: *"From Text Maps to Memory Caps": 100 Ways to Differentiate Instruction in K-12 Inclusive Classrooms*, *"Don't We Already Do Inclusion?": 100 Ways to Improve Inclusive Schools*, *"You're Going to Love This Kid": Teaching Students with Autism in Inclusive Classrooms*, *Joyful Learning: Active and Collaborative Learning in the Inclusive Classroom*, *A Land We Can Share: Teaching Literacy to Students with Autism*, and *"The Autism Checklist": A Practical Reference for Parents and Teachers*. Paula is also the director of a documentary film titled *"We Thought You'd Never Ask": Voices of People with Autism*.



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. This program is designed to address two specific levels of play.

Level 1 includes physical activities focused on developing fundamental motor tracking and eye-hand coordination. Level 2 concentrates on the application of these physical activities through a sports skills activity program and developing skills consistent with Special Olympics sports play. The activities will consist of foundational skills, walking & running, balance & jumping, trapping & catching, throwing, striking, kicking and advanced skills. Siblings ages 2-7 of the participants are welcome to participate. We are very excited about this program and your family's participation!

A Special Olympics registration form will need to be completed for each participant and volunteer.

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

**Sunday, April 12, 2015
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

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

April 10 - Fox Pub & Café

7800 N. Sommer St, Ste 302, Peoria

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.**



The next **GRANDPARENT'S GROUP** *meeting*

Tuesday April 28th @ 6pm

Perdue's

201 S. Sampson Street
Tremont IL

an informal evening with casual conversation

Contact Anita with any questions
309-241-8195

hohimer_home@comcast.net

**Join Family Matters PTIC, HOIDSA
and Advocates for Access**



**The Common Core and Students
with Disabilities**

At this FREE workshop you will learn how the new Common Core State Standards (CCSS) will promote higher expectations for students with disabilities and will improve access by students with disabilities to grade level learning standards by increasing the use of high quality, evidence based, individualized instruction and support services.

Tuesday, April 28, 2015

6:00pm to 8:00pm

**Heritage Square: Advocates for Access
Conference Room (Ste C-8)
4450 W Prospect Rd
Peoria Heights, IL, 61616**

-A Light meal will be provided.

Registration is required.

<http://www.fmpitic.org/events/trainings>

(866)436-7842 Ext:107

**If accommodations are needed, please call
two weeks prior to training date.**



Family Matters PTIC is 95% funded by the U.S. Department of Education with additional support from ARC Community Support Systems.



**YOU'RE INVITED TO PARTICIPATE IN
AN ONLINE SURVEY:**

**ANALYZING REASONS FOR INCLUSION OF
CHILDREN WITH DOWN SYNDROME IN
CHROMOSOMAL THERAPY STUDIES**

You are eligible to participate in this study if you are a relative, parent, or guardian to someone with Down syndrome, whether they are an adult or a child.

This study is voluntary and involves completion of an anonymous, web-based questionnaire. The questions will gather information about your experience to improve the medical profession's understanding of your unique circumstances and the current services provided to people with Down syndrome.

This study was developed by Marissa Lewis under the mentorship of bioethicist Dr. Arthur Caplan and was approved by the New York University (NYU) Institutional Review Board.

If you have questions about this study you may contact Marissa Lewis at dsurvey@optonline.net

WHY IS THIS STUDY BEING DONE?

The purpose of this study is to better understand peoples' experiences with respect to background and services. Your participation will improve our understanding of patients' circumstances and help us to provide appropriate information and support to individuals in similar situations.

WHAT IS INVOLVED IN THE STUDY?

Your participation in this study involves completing an anonymous, web-based questionnaire. "Anonymous" means that we will not collect any personal information that identifies you. The questionnaire will take approximately 15 minutes to complete. The questions will ask you about your background and experiences, your relative's circumstances and medical background, the kind of schooling and environment in which your relative has grown up, and your family's income level.

TO PARTICIPATE IN THIS STUDY, VISIT:

**[http://www.sogosurvey.com/survey.aspx?
k=SsSTVWUsRsPsPsP&lang=0&data=](http://www.sogosurvey.com/survey.aspx?k=SsSTVWUsRsPsPsP&lang=0&data=)**

Graduation Rates Inch Up For Students With Disabilities

New figures from the U.S. Department of Education suggest that more students — including those with disabilities — are graduating from high school.

An increasing number of students with disabilities are graduating high school, federal officials say, though they still receive diplomas at far lower rates than other students.

The graduation rate for students with disabilities reached nearly 62 percent during the 2012-2013 school year, representing a rise of almost 3 percent compared to two years earlier.

The figures released Monday from the U.S. Department of Education's National Center for Education Statistics come a month after federal officials said the nation's overall high school graduation rate reached a record-high of 81 percent in 2012-2013.

Despite the gains, however, graduation rates for students with disabilities varied tremendously from one state to the next. Mississippi reported a low of 22.5 percent while Arkansas topped the list with over 80 percent of students with disabilities receiving diplomas.

The data accounts for the number of students nationwide who obtained a high school diploma within four years. Students who completed an individualized education program but did not earn a traditional diploma and those who were held back a grade were not included.

In addition to students with disabilities, the Education Department data also pointed to lower graduation rates among blacks and Hispanics, those from low-income households and students with limited English proficiency.

"While these gains are promising, we know that we have a long way to go in improving educational opportunities for every student — no matter their zip code — for the sake of our young people and our nation's economic strength," U.S. Secretary of Education Arne Duncan said.

To view this full article, visit:

<http://www.disabilityscoop.com/2015/03/17/graduation-rates-inch-up/20141/>

People With Down Syndrome May Actually Age Faster

New research suggests that blood and brain tissue in those with the chromosomal disorder ages at an accelerated pace. (Shawn Raecke/Idaho Statesman/TNS).

The inner workings of people with Down syndrome age much faster than typically-developing individuals, a new study suggests.

Various parts of the body age at an accelerated pace in those with Down syndrome, researchers say, possibly explaining the heightened risk for various medical issues among this population.

Brain tissue from people with Down syndrome appears to be about 11 years older than their chronological age, according to [findings](#) published online this month in the journal *Aging Cell*.

Meanwhile, blood tissue sampled from those with the chromosomal disorder looks to be about four years older, the study found.

Researchers used a molecular marker of aging known as an epigenetic clock to assess samples from people with and without Down syndrome in four areas of the body — the brain, blood, white blood cells and the inner lining of the cheeks and lips known as buccal mucosa.

Gaining a better understanding of aging in people with Down syndrome is significant, researchers say, since these individuals are six times more likely to develop Alzheimer's disease and currently have an average life span of just 60 years.

"As it is well known that (Down syndrome) is associated with clinical manifestations of premature aging in brain and to a lesser extent in blood tissue, it is reassuring that we observe significant age acceleration effects in brain (11 years) and blood (4 years) tissue," wrote Steve Horvath of the University of California, Los Angeles and his colleagues in their findings.

Going forward, the researchers plan to look at tissue samples from teens with Down syndrome to identify when the aging process begins to speed up.

To view this full article, visit:

<http://www.disabilityscoop.com/2015/02/26/people-down-age-faster/20093/>

To read more about these studies, visit:

<http://onlinelibrary.wiley.com/doi/10.1111/accel.12325/full>

Movie Featuring Actor With Down Syndrome Set For Wide Release



“Where Hope Grows” is expected to appear on about 300 screens across the country when it is released May 15th.

Central to the story is a grocery-store worker named Produce, played by David DeSanctis who has Down syndrome.

In the film, Produce strikes up an unlikely friendship with a professional baseball player who was sent into early retirement after having panic attacks at the plate.

The movie marks DeSanctis’ acting debut and makes the Louisville, KY. resident among the first with Down syndrome to have a lead role in a feature film.

“I want people to see me for my abilities, not my disabilities,” DeSanctis told The Hollywood Reporter.

Ahead of the movie’s release, a trailer for “Where Hope Grows” began screening at movie theaters nationwide on March 21st coinciding with World Down Syndrome Day.

To read the full article, visit:

<http://www.disabilitycoop.com/2015/03/24/movie-down-syndrome-release/20156/>

To view the trailer for “Where Hope Grows”, visit:

<https://www.youtube.com/watch?v=tN7TlwduYsM&feature=youtu.be>

Disability Advocate Wins Acclaimed International Prize

An award that’s previously gone to the likes of the Dalai Lama and Mother Teresa will this year honor a man who’s focused on making life better for people with developmental disabilities. Jean Vanier will receive the 2015 Templeton Prize. Vanier, 86, founded L’Arche, a network of communities where people with and without intellectual disabilities live and work together. Today, there are 147 such communities in 35 countries, including 18 in the United States.

Valued at about \$1.7 million, the Templeton Prize is one of the largest awards in the world handed out each year to an individual. It is given to a living person who has “made exceptional contributions to affirming life’s spiritual dimension, whether through insight, discovery or practical works,” according to the John Templeton Foundation.

“By recognizing the importance of every individual, regardless of their station in life, Jean Vanier underscores how each of us has the ability not only to lift up others, but also ourselves,” said Jennifer Simpson, the granddaughter of Sir John Templeton who established the prize in 1972. “His powerful message and practice of love has the potential to change the world for the better, just as it has already changed the lives of countless individuals who have been touched by this extraordinary man.”

The idea for L’Arche began in 1964 when Vanier invited two men with intellectual disabilities who were living at an institution to move in with him in a small home in Trosly-Breuil, France.

“They have brought me so much over the past 50 years, and have taught me more than all those teachers and professors in schools and universities that I have attended,” Vanier said at the ceremony Wednesday of people with intellectual disabilities. “They have taught me about what it means to be human and about how our societies can be transformed to become more peaceful and unified.”

The Templeton Prize will be formally presented to Vanier at an event in London on May 18.

To view this full article, visit:

<http://www.disabilitycoop.com/2015/03/11/disability-advocate-prize/20125/>



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

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EDITOR'S REMARKS



Hello Everyone!

Thank you to everyone who helped make our 26th annual spaghetti dinner fundraiser another successful event. We could not have done this without our generous donors, volunteers, friends, and family members. Thank you so much to all who bought dinners, after-dinner treats, raffle tickets, and auction items; donated gifts and baked goods; and volunteered their time. Thank you to the various entertainment acts for their engaging performances. We also extend a special thank you to Tony and Mary Beth Couri of La Gondola in Decatur, who have been providing the spaghetti for 26 years.

Please take some time to read about the two part Inclusion Series that HOIDSA is organizing. This workshop is free for HOIDSA families. We hope you invite your student's teachers and administrators. You can see more details about this great series on pages 4 and 5 of this newsletter.

Enjoy the beautiful spring weather!

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 Date:

Friday, April 10th

9:00am - 10:30am



Location:

**Bethel Lutheran Church
425 N. Missouri Ave., Morton**

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