heart of illinois
Down Syndrome Association
Newsletter

July/August 2016

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.

Contact Us:
c/o Bethel Lutheran Church
325 E. Queenwood Rd.
Morton, IL 61550
309-712-4852
info@hoidsa.org

2016 Board of Directors

Shelli Willoughby, *President*
309-251-7102
shelliwilloughby@gmail.com

Meri Tucker, *Vice President*
309-694-2984
endroad@comcast.net

Milly Howeler, *Treasurer*
309-692-3688
millyhoweler@gmail.com

Anita Hohimer

Anne Hollis

Laurie Mattheessen

Christy Sanchez

Kim Sarff

Editor: Carol Nepolello
309-243-8414
c.nepolello@comcast.net

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

Calendar of Events

Sat. Sept 10th	**Buddy Walk T-Shirt Order Deadline!** Register online by 9/10 to be guaranteed a t-shirt
Sun. Sept 11th	**Young Athletes—3:00-4:00pm** See pages 12-13 St. Philomena School, 3216 N Emery, Peoria
Mon. Sept. 12th	**Board Meeting—6:00pm** Fondulac Library, East Peoria
Tues. Sept. 20th	**Education Conference Registration Ends!**
Fri. Sept. 23rd	**Fall Education Conference** Embassy Suites, East Peoria—See pages 4-5
Sat. Oct. 1st	**BUDDY WALK** - Details on pages 6-9 Your help is needed to solicit sponsors!

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.

Inside this Issue

Content	Page
Calendar of Events	1
Greetings from the President	2
Young Adult Cooking Class	3
Memorial Donations	3
Education Conference	4-5
Buddy Walk	6-11
Young Athletes	12-13
Research Study on Mental Health	14
Chillin' Pictures	15
Family Stipends	Back Cover
Editor's Remarks	Back Cover

Greetings From The President

July/August 2016

Hello! I'm hoping that everyone had an enjoyable and safe summer! School is back in session and Joe is loving being at the high school this year. He is excited to be taking Spanish (all those early years of watching Dora the Explorer are finally going to pay off) but I think he is most excited about all the new food options he has available at the cafeteria!

It is with a heavy heart, though, that I have to announce that I will be stepping down as president of HOIDSA. Todd has accepted a position with his work that will be moving us to Texas in early September. It is definitely a bittersweet move. We have family there (our daughter, my sister and several nieces and a nephew) and it will be nice to be close to them, but it is very difficult to leave the family and the friends we have here.

HOIDSA has been a part of our lives for over 15 years! Joe would not be the great kid he is today without the love, support and kindness that this organization has shown us throughout the years. Many people within this group have helped us raise him through their wisdom and encouragement, and we cannot thank you enough. Todd and I have gained a tremendous amount of knowledge that we will be taking with us from the many educational seminars we have been privileged to attend through HOIDSA.

I encourage you all to continue to be the wonderful group of people that you are! Participate in what HOIDSA has to offer and give back your talents to others. Remember the Keep Calm and Presume Competence conference is coming in September and the Buddy Walk in October. Both promise to be outstanding events!

Even though we are leaving, our hearts will always be with HOIDSA.

Shelli

"Ditto"
-Todd

Birthdays

August

Payton Mills 8/2
Maggie Scherder 8/2
Colin Avril 8/4
Payten Presley 8/6
Robert Bettenhausen 8/10
Morgan Brandstatter 8/10
Mandy Shrader 8/10
Jerry Harlan 8/11
Quincy Hinthal 8/12
Seth Bauersfeld 8/14
Jared Janovetz 8/14
Nicholas Woodin 8/17
Holly Stephenson 8/20
Jacee Lowery 8/22
Max Pepino 8/23
Adam West 8/25
Rachel Rice 8/26
Cody Rieves 8/26
Jared Fossum

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
Kaylee Keefauver 9/11
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

August & September Birthdays

HOIDSA would like to thank Shelli and Todd Willoughby for their many years of service to our organization. Shelli has been our President since January, and Todd served on the board for 15 years. We appreciate their leadership contributions, as well as their contributions to our social events. Todd has been a wonderful host of our holiday socials, Fall socials, and My Two Cents outings. Shelli and Todd always volunteer before, during, and after the Spaghetti dinner. Todd, Shelli, and Joe helped represent HOIDSA in the Morton Pumpkin Parade last year. We will certainly miss your presence at HOIDA's activities. You have been a part of nearly everything we've done since joining our group. We'll also miss your entertaining stories and Joe's lively personality!

We're glad HOIDSA was there for you when you were blessed with Joe, and you have shown your love and support for many other families that have come since then.

We wish you the best in this new chapter of your life!

Sincerely,
HOIDSA

Young Adult Cooking Class

For any member **16 years old & older**
Classes will resume in October

Bethel Lutheran Church
Contact Meri at 309-264-4900

To all of our students heading back to school, we wish you a happy & productive school year!

Memorial/Recognition Donations

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

- **Memorial donations in honor of Don Riegler, grandfather of Rachel Lamb and father of Lisa Lamb.**

Thank you!

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.

Fall Conference for Educators, Parents, School Administrators, College Students, anyone who works with people with disabilities!

Friday, September 23rd, 8:30am-3:30pm

Embassy Suites & Conference Center, East Peoria IL

Keep Calm and Presume Competence

featuring
Dr. Cheryl Jorgenson
and Family Matters
presented by
Heart of Illinois
Down Syndrome Association

Join us Friday, Sept. 23
8:30 AM to 3:30 PM

(registration & sign-in from 7:50 to 8:30 AM)

Light breakfast and complete lunch included

at the Embassy Suites & Conference Center in East Peoria, IL

REGISTER at www.hoidsa.org

Administrators and students attend for FREE

(more detail in the brochure)

The Least Dangerous Assumption is to Presume All Students' Competence!

When students with Down syndrome or other disabilities have difficulty communicating they are often assumed to have an intellectual disability.

Dr. Jorgensen will present an argument for presuming all students' competence to learn academics in an inclusive general education classroom, communicate about age-appropriate academic and social topics, make and sustain reciprocal social relationships, and go on to post-secondary education and life in the community.

She'll challenge our assumptions about intelligence, inclusion, and communicative competence and ask us to adopt new assumptions that will promote a high quality educational experience and rich quality of life.

What will our day look like?

7:50 to 8:30 Registration & light breakfast items

8:30 to 10:00 ALL attend

The Least Dangersous Assumption is to Presume All Students' Competence!

- Cheryl Jorgenson

10:00 to 10:15 Break

10:15 to 11:45 Choose one

- Inclusion is more that just being "In"
- Problem Solving 101

11:45 to 12:45 Lunch

12:45 to 1:45 ALL attend

"Trying to Get It Right"

1:45 to 2:00 Break

2:00 to 3:30 Choose one

- How to Effectively Participate in an IEP Meeting
- Instructional Adaptation and Apps that Promote Inclusion

Conference Fee $50

FREE for school administrators, college students, and HOIDSA families!

Extra school benefits:

- ◊ Professional development credit available for teachers who provide IEIN number
- ◊ Substitute reimbursement of $85 per certified teacher, up to 3 per school. Must request at registration table.

Register at www.hoidsa.org by September 20th

Questions? Email info@hoidsa.org

Instructional Adaptations and Apps that Promote Inclusion

Students with Down syndrome and other intensive support needs sometimes need individualized supports that enable them to fully participate in general instruction and learning of general education content. This breakout session will describe resources for adapted informational and literary text, a process for creating adapted books from scratch, and many apps or technology tools in the areas of reading, writing, speaking, organizing, and presenting work. Most are free or low cost and can benefit other students.

Inclusion is More Than Just Being "In:" A Team Planning Process for Full Participation and Learning of General Education Academics in the General Education Classroom

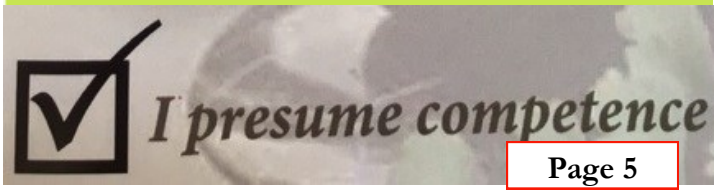
When students with Down syndrom or other disabilities are physically present in a general education classroom but off the side being taught by a paraprofessional, they miss valuable opportunities to learn the essentials of the general education curriculum. This breakout will describe a team planning process that promotes full participation.

Problem Solving 101

Participants in this session will be able to identify the difference between positions and interests when conflicts arise, will learn how to focus on interests to develop new solutions to conflicting viewpoints, how to use data to illustrate their concerns, how to use parent rights as strategies for making requests and otaining justification for decisions, and will learn the procedural safeguards for conflict resolution.

How to Effectively Participate in an IEP Meeting

Gain an understanding of parent rights during the processof developing an Individual Education Program for their children, develop some strategies for addressing the barriers to effective parental participation in the IEP meeting, learn how to share their knowledge and expertise about their children's abilities, identify the appropriate IEP team members, and how to work collaboratively to develop the program.



BUDDY WALK® NEWS

8:00 am - T-shirt pickup, Same day registration, RAFFLE sale and all activities begin
9:30 am - Walk starts
RAFFLE drawing immediately following the walk

This year's walk is off to a great start! Multiple businesses have shown their support with their donations and sponsorships. If you have the opportunity, please express your thanks to the following: Children's Hospital of Central IL at OSF, Maui Jim, Peoria Rivermen, OtterBox, Plough Publishing and Magnabilities.

WHAT'S NEW?

"Virtual Walker" option is new this year. If you know you cannot attend the walk, but would still like to fundraise for this great cause, you can choose to register as a Virtual Walker at no cost.

New to this year's entertainment will be two inflatables along with the face painters and balloon artists.

Also new this year is the opportunity for individuals to earn incentives for specific levels of fundraising. The incentives will be a variety of Buddy Walk® branded items that can be viewed from the registration home page, *http://hoidsa.donordrive.com/event/2016*. When registering you are strongly urged to use a valid email address to receive your specific fundraising incentive info and the certificate you earn for your prize.

REGISTRATION and FUNDRAISING

T-shirt deadline is fast approaching. Be sure to register by September 10th to be guaranteed a T-shirt!
Thank you to those who have already registered, created their teams and made donations!

There is still time to set up a personal page at *http://hoidsa.donordrive.com/event/2016.* You will be increasing awareness about Down syndrome and raising necessary funding, which will continue to provide the programs and services to support the mission of the Heart of Illinois Down Syndrome Association, Inc. Under the "How Do I?" tab are complete instructions for registering, creating or joining a team, making a donation and great fundraising tips. Once your personal fundraising page has been set up, you can send emails to your friends and family through your Fundraising Portal. The emails will provide a direct link to your personal page where your friends and family can make a donation on your behalf. There are even written samples to help get you started! You can also connect to social media by selecting "Settings" midway down on your page.

Pledge money you have collected can be mailed to HOIDSA's 9th Annual Buddy Walk® c/o Bethel Lutheran Church, 325 E Queenwood Rd., Morton IL 61550. Be sure to include the name of the person with Down syndrome who is being recognized. If you prefer to turn in money in person, call 309-415-0540 and arrangements will be made for pick up. If possible, we would like any fundraising money to be turned in before the walk, but will gladly accept them the day of walk.

SPONSORS and DONATIONS

The Buddy Walk's main focus has always been to raise awareness about individuals with Down syndrome within their communities, but fundraising is an important part to ensure HOIDSA can continue to promote the value, acceptance and inclusion of those individuals. We are asking once again for our HOIDSA members to invite their families, friends and neighbors to take the opportunity to fundraise and contact potential sponsors to support our event. Remember a potential sponsor can be anyone in the community. The Buddy Walk® Sponsor letter and form are both attached in this newsletter and can also be found online at *www.http://hoidsa.org/get-involved*. Please copy both and sign your name with a contact phone number on the sponsor letter before mailing or handing out in person. In

previous years I have found that most small businesses are very receptive to walking in during the manager's shift and asking for their support in person.

Sponsors donating at the $500 level and above, are requested to email their logo to *buddywalk@hoidsa.org*. We make every effort to recognize all levels of sponsorship by listing their name on our t-shirts, the appreciation board displayed the day of the walk, in our newsletter and on our Facebook page.

The deadline to submit sponsor logos and/or names for print on the back of our t-shirts is September 10th.

RAFFLE

We will be selling raffle tickets the day of the walk. The cost will be $1 each or 6/$5.

VOLUNTEERS

Laurie Mattheessen is organizing volunteers for this year's walk. There will be spots for setup on Friday evening, September 30th and Saturday morning, October 1st. If you are interested in being involved in this rewarding event, please contact her at laurie.mattheessen@gmail.com or 309-645-8370 .

DOWN SYNDROME AWARENESS MONTH

October is Down Syndrome Awareness Month and everyone is encouraged to take the opportunity to show the public what you would like them to know about your loved one with Down syndrome. Please consider bringing a poster with information and pictures showing their personality, what they like doing, their accomplishments or something that might surprise others. The posters will be displayed the day of the walk and left through the following week to share our message with many who many not have had the opportunity to know someone with Down syndrome.

Call or email with any questions you may have or to request additional information about fundraising or soliciting sponsors. We are looking forward to another fantastic event. Thank you to everyone for promoting and supporting this important event and for your efforts to raise necessary funding to support our mission! We couldn't have a successful event without you!

Marcy Ray
309-415-0540
buddywalk@hoidsa.org

HOIDSA's 9th Annual Buddy Walk Events

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

- ⇒ **8:00 am** T-shirt pickup, same day registration, RAFFLE sales and entertainment all begin
- ⇒ A continental style breakfast, fruit and water will be available for all participants
- ⇒ **9:30 am** - Walk begins
- ⇒ **RAFFLE** drawing immediately following the walk
- ⇒ **Entertainment** - face painters, craft activities, balloon artists, bouncy houses

VOLUNTEERS NEEDED
for Friday night (9/30) and
Saturday morning (10/1)
SET-UP

If you are interested in being a volunteer, contact Laurie Mattheessen.

laurie.mattheessen@gmail.com
309.645.8370

Great opportunity to earn service hours for high school community service volunteers

Free entertainment for the kids!

Face Painters

Craft Activities

Balloon Artists

NEW THIS YEAR:
Bouncy Houses

Last year's Buddy Walk sponsors:

Pepsi Beverages Co.
Casey's General Stores, Inc.
Haddad's Market
Avanti's Italian Restaurant
Prairieland Band
Hy-Vee
Woodbine House
Taco Bell

HOIDSA's 9th ANNUAL BUDDY WALK®

Saturday October 1st

EastSide Centre, East Peoria

Register and fundraise online at

http://hoidsa.donordrive.com/event/2016

Register by September 10th to be guaranteed a T-shirt

8:00 am

T-shirt Pickup, Same Day Registration, Raffle, Face Painting and all other activities begin

9:30 am

Walk starts

Questions? Call 309-415-0540 or email buddywalk@hoidsa.org

dsa heart of illinois Down Syndrome Association

www.hoidsa.org

NATIONAL DOWN SYNDROME SOCIETY BUDDY WALK® TOGETHER FOR DOWN SYNDROME

heart of Illinois Down Syndrome Association
c/o Bethel Lutheran Church
325 E Queenwood Rd Morton IL 61550

BUDDY WALK® TOGETHER FOR DOWN SYNDROME

Dear Friend:

The Heart of Illinois Down Syndrome Association will be sponsoring HOIDSA's 9th Annual Buddy Walk® on Saturday, October 1, 2016 at EastSide Centre in East Peoria, IL. Families and friends whose lives have been touched by Down syndrome will join others from our communities to celebrate the many abilities and accomplishments of people with Down syndrome in our communities.

We are asking for your support to help us make this year's Buddy Walk® the best yet. We would like to invite you to consider sponsoring our 9th Annual Buddy Walk®. As a local business within our community, we are hopeful you want to offer us your support and invest in this worthy cause. 93% of the funds raised will be used locally to support families and the professionals who work with them. Your investment in this event will help support our Resource Library, conference stipends, recreational scholarships, collaboration with service agencies, Young Adult Cooking Class, New Parent Breakfast, Grandparents Group and many other opportunities for networking and to advocate and educate throughout the year.

History: The Buddy Walk® was developed 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 2016 worldwide. In 2015, nearly $14 million was raised nationwide to benefit local programs and services, as well as the national advocacy and public awareness initiatives of NDSS that benefit all individuals with Down syndrome.

Please feel free to call 309-415-0540 or email *buddywalk@hoidsa.org* if you have any questions or need any further information. Your support is greatly appreciated.

Thank you for your time and consideration in this matter.

heart of illinois Down Syndrome Association
c/o Bethel Lutheran Church
325 E Queenwood Rd. Morton IL 61550

NATIONAL DOWN SYNDROME SOCIETY
BUDDY WALK®
TOGETHER FOR DOWN SYNDROME

Contact Name: _____

Company: _____

Address: _____

Phone: _____

Option #1: We are pleased to sponsor the BUDDY WALK® at the following level:

- ☐ *ALLY SPONSOR* ..... *$100 - $249*
- ☐ *PAL SPONSOR*..... *$250 - $499*
- ☐ *BUDDY SPONSOR*..... *$500 - $999*
- ☐ *BEST FRIEND SPONSOR*..... *$1,000 - $2,499*
- ☐ *FRIEND FOR LIFE SPONSOR*..... *$2,500 - $4,999*
- ☐ *BEST FRIEND FOR LIFE SPONSOR*..... *$5,000 OR MORE*

Option #2: We are pleased to donate the following item(s) for the continental breakfast portion of the event: _____

_____

Option #3: We are pleased to donate the following item(s) for the raffle: _____

_____

Estimated fair market value of each donated item: _____

_____

All sponsors please list your company name above as you wish it to appear in print. For sponsors at the $500 level and above, please email your company logo to *buddywalk@hoidsa.org* by September 10, 2016. Please return this form with check enclosed for sponsorship, or any gift certificates and brochures, etc. to the address listed above. Call 309-415-0540 or email *buddywalk@hoidsa.org* if you prefer to have the donation picked up at your convenience.

September 10, 2016 is the deadline for submitting your sponsor information to be included in print on the back of the t-shirts.

We make every effort to include all of the above levels of sponsorship in our newsletter, on Facebook and on the appreciation board at the walk.

The Heart of Illinois Down Syndrome Association, Inc. is incorporated in the state of Illinois as a non-profit corporation operating under the Internal Revenue Code 501 (c) (3). No goods or services were exchanged for this.

Our mission is to improve the quality of life of persons with Down syndrome by providing support, advocacy, and educational opportunities to those individuals, their families, and community advocates.

Special Olympics
Young Athletes™

Come join us for the 11th year of Special Olympics Young Athletes Program at St. Philomena School gymnasium - 3216 N Emery, Peoria - 3:00 pm – 4:00 pm
September 11 - October 9 - November 6 - December 11, 2016
January 8 - February 12 - March 12 - April 9 - May 7, 2017

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.

Email youngathletespeoria@yahoo.com if interested in participating or volunteering.

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

Special Olympics Young Athletes™

Young Athletes™ Registration Form

Special Olympics Illinois
605 E. Willow St. Normal, IL 61761-2682
309-888-2551

SO ILL Rev 8-1-2014

Athlete's Name _____ **Parent/Guardian Name:** _____
(Last/Family) (First/Given) (Last/Family) (First/Given)

Address:_____ **City:**_____

State:_____ **Zip Code**_____ **Birth Date:** Month_____ Day_____ Year_____ **Gender:** ❒Male ❒Female

Home Phone: _____ **Cell Phone:** _____ **Email:** _____

Secondary Contact Name: _____ **Phone:** _____

Athlete T- Shirt Size: ❒ Child Small ❒ Child Medium ❒ Child Large ❒ Adult Small ❒ Adult Medium

Basic Health Information:

Heart Problems	❒ Yes	❒ No	Blind	❒ Yes	❒ No
Diabetic	❒ Yes	❒ No	Deaf	❒ Yes	❒ No
Epileptic / Seizure	❒ Yes	❒ No	Hepatitis	❒ Yes	❒ No
Down Syndrome	❒ Yes	❒ No If Yes ---------→	Clear AAI	❒ Yes	❒ No

Other: _____ Allergies: _____

Ethnicity: ❒ White ❒ Black/African American ❒ Asian ❒ Hispanic/Latino ❒ Other_____

Young Athlete is being registered as a: ❒ Traditional Young Athlete (with Intellectual Disability)
❒ Peer Partner (without Intellectual Disability)

Young Athletes Release Form

I am the parent/guardian of the minor participant, on whose behalf I have submitted the attached application for participation in Special Olympics. The participant has my permission to participate in Special Olympics activities. I further represent and warrant that to the best of my knowledge and belief, the participant is physically and mentally able to participate in Special Olympics.

In permitting the participant to participate, I am specifically granting my permission to Special Olympics to use the participant's likeness, voice and words in television, radio, film, newspapers, magazines and other media, and in any form, for the purpose of publicizing, promoting or communicating the purposes and activities of Special Olympics and/or applying for funds to support those purposes and activities. I also understand that group data collected from the Young Athletes Program will be used to plan, evaluate, and improve the program.

If a medical emergency should arise during the participant's participation in any Special Olympics activities, at a time when I am not personally present so as to be consulted regarding the participant's care, I hereby authorize Special Olympics, on my behalf, to take whatever measures are necessary to ensure that the participant is provided with any emergency medical treatment, including hospitalization, which Special Olympics deems advisable in order to protect the participant's health and well-being. **(IF YOU HAVE RELIGIOUS OBJECTIONS TO RECEIVING SUCH MEDICAL TREATMENT, PLEASE CONTACT SPECIAL OLYMPICS ILLINOIS - MANAGER OF YOUNG ATHLETES)**

I am the parent (guardian) of the participant named in this application. I have read and fully understand the provisions of the above release, and have explained these provisions to the participant. Through my signature on this release form, I am agreeing to the above provisions on my own behalf and on the behalf of the participant named above. I hereby give my permission for the participant named above to participate in Special Olympics games, recreation programs, and physical activity programs.

_____ _____
Signature of Parent/Guardian **Print Name** **Date**

Original parent/guardian signature is required by the office of Special Olympics Illinois.
FORM VALID UNTIL INDIVIDUALS NINETH BIRTHDAY WITH CONTINUED PARTICIPATION

Program Information (To Be Completed By Site Coordinator)

A program may have multiple sites. Site is defined as the specific location of the Young Athletes Activities. The Young Athlete site this child will attend is (Select one of the following.)

❒ A group site - Special Olympics Illinois Agency ❒ At home (implemented by you or a family member at home)

Agency Name _____

School Name_____ Teacher Name_____

Class Time: ❒AM ❒PM ❒ALL DAY Agency SOAD/Site Coordinator _____

JOHNS HOPKINS
MEDICINE

Approved January 20, 2016

A Research Study on Mental Health in Persons with Down Syndrome

Who: If you/your child are between 18-35 years, **with** Down syndrome.

We are recruiting DS subjects **with** mental health concerns such as loss of functional skills, low motivation, depressed mood, social withdrawal and motor slowing

We are also recruiting DS subjects **without** mental health concerns or functional decline

We **cannot** accept DS subjects with aggressive, disruptive or non-compliant behaviors

What: All subjects will receive a comprehensive evaluation assessing general level of function, behavior and mental health, sleep quality, as well as body shape/proportion and dietary/nutritional status. This will include; a sleep study, collecting urine, saliva, and a morning blood sample for biochemical testing.

The goal of the study is to improve our understanding of the relationship between sleep, stress, metabolism and mental health in persons with Down syndrome.

Where: At the Kennedy Krieger Institute and Johns Hopkins Clinical Research Center.

When: The study requires one extended visit over a 2-3 day period, including 1 overnight visits at the Johns Hopkins Clinical Research Center. We will try our best to accommodate your schedule!

Why: To characterize the cognitive, behavior and mental health conditions that appear to be associated with sleep disturbance in adolescents/adults with Down syndrome.

Risks and Benefits: There are minimal risks and no direct medical benefits for participating. You will receive medical test results that may be of interest to you or your physician. A cash incentive is offered for your participation.

How: **Join today!** If you are interested in participating, please contact us!

George T. Capone, M.D.
Principal Investigator
Director, Down Syndrome Clinic
Kennedy Krieger Institute
Protocol # NA_00018279

Crystal Thomas
Research Coordinator
443-923-9140
ThomasCr@kennedykrieger.org

Project Sponsor:
The Johns Hopkins Hospital Institute for Clinical and Translational Research-Clinical Research Unit (JHH ICTR-CRU)

Back row: Adam, Kathy, Katie, Chad
Front row: Daniel, Kaelie, David, Jacob, Sam, Trevor

These young adults had a spectacular time celebrating the Olympics!

heart of illinois Down Syndrome Association
c/o Bethel Lutheran Church
325 E Queenwood Rd Morton IL 61550

NONPROFIT
U.S. POSTAGE
PAID
PEORIA, IL
PERMIT NO. 455

_____

EDITOR'S REMARKS

Hello Everyone!
Get your teams registered 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, such as the Keep Calm and Presume Competence conference in September, coordinate social events for our members, offer programs like the Young Adult Cooking Class, and promote acceptance of people with Down syndrome.

Carol Nepolello
c.nepolello@comcast.net

FAMILY STIPENDS

This is a reminder that HOIDSA offers family reimbursement stipends of up to $100 for summer activities.

You can request a reimbursement by sending a copy of your receipt to:
Milly Howeler
5624 N. Graceland Dr.
Peoria IL 61614

Don't forget to utilize special recreation associations like HISRA and IRVSRA all year around:

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