



heart of illinois Down Syndrome Association Newsletter

August 2017

Contact Us:

c/o Bethel Lutheran Church
325 E. Queenwood Rd.
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.



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

Calendar of Events

- | | |
|-------------------------|---|
| Thurs. Aug. 31st | Walk T-Shirt Order Deadline!
Register online by 8/31 to be guaranteed a t-shirt
See page 4 for details |
| Mon. Sept. 11th | Board Meeting—6:00pm
Fondulac Library, East Peoria |
| Tues. Sept. 12th | Texas Roadhouse Fundraiser—3:00-10:00pm
East Peoria— Must bring flyer on page 8 |
| Fri. Sept. 22nd | Walk Online Registration Ends
See page 4 for details |
| Sun. Sept. 24th | FRIENDS of HOIDSA
Walk for Down Syndrome
Dozer Park in Downtown Peoria
See page 5 for details |
| Oct. 28-29th | Down Syndrome Innovations Conference
Houston, TX—See page 11 for details |

This newsletter publishes items of interest relating to Down syndrome and other disability issues. The Heart of Illinois Down Syndrome Association, Inc. (HOIDSA) does not promote or recommend any therapy, treatment, institution, professional system, etc. Individuals or organizations referred to are not necessarily endorsed by this publication or its editor. We hope to bring together those interested in Down syndrome and attempt to create an optimistic future and attitude. The editor reserves the right to make corrections as are appropriate and in accord with established editorial practice in material submitted for publication.

Greetings From The President

Birthdays
Next
Month



Inside this Issue

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August is here which means soon those of us with school aged students will be caught up in the daily tasks of sorting through backpacks, admiring "art work," and trying to keep with school schedules and routines. A new year means a new opportunity to advocate for your child and grow your relationship with your district, teachers, and service providers. To help get the year started in the right direction, I sought some "tips" that I thought others might find useful as well.



1. Get a new 3 ring binder to file the IEP, latest Parental Rights guide, notices, emails, official reports and all communication with your school and service providers. Include a section in the binder where you can document incidents concerning your child at home and at school, and conversations with the school and professionals. Include how your child did over the summer, which is important if you plan to ask for Extended School Year.
2. Get a new very large folder in which you can place ALL school work and notes that your child brings home for the year. I know it is helpful to have one place (besides my kitchen counter!) to store all school things and is a great resource to evaluate, monitor and document your child's progress during that year and from year to year.
3. Relieve back-to-school jitters by talking to your child about exciting new classes, activities, and events that they can participate in during the new school year. If attending a new school, try to schedule a visit before the first day. Discuss and plan the changes in your daily routine before they occur or begin implementing them well in advance of the first day of school.
4. Attend school events. I know after a busy day that often includes work, doctors/therapists and home responsibilities, I am tired and just want to be relaxing in my yoga pants! However, being involved in school activities helps me to build relationships and better partner with my school team including teachers, other staff, students and families.
5. Stay up to date on special education news! Be knowledgeable about your child's IEP and new special education legislation, news and events. The more you know, the more prepared you will be to navigate the world of special education and successfully advocate for your child!

We have many exciting events happening with HOISDA in the next 2 months. I look forward to hopefully crossing paths with each of you soon.

Anne Hollis

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
9/29



Register Now at www.hoidsa.org!!

\$5/person \$10/t-shirt (must order by Aug 31st)

Friends with Down syndrome get:

- ♦ Free registration
- ♦ Free t-shirt (if ordered by Aug 31st)

FRIENDS of HOIDSA **Walk for Down Syndrome**

10th Anniversary Walk

September 24th @ Dozer Park

Purchase Raffle tickets to WIN:

- * Overnight stay at Eastland Suites in Bloomington
- * Overnight stay at Par-A-Dice Hotel
- * Otterbox
- * Movie passes
- * And more!!!!



Free entertainment for the kids!

Face Painters

Games

Craft Activities

Bouncy Houses

Memorial/Recognition Donations

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

- **Memorial donations in honor of Betty Durst, Levi Miller's grandmother**
- **Memorial donation for Cheryl Chavez from Laborers' Local 165**
- **Donation from Virginia Schindler in honor of son Alan's 40th birthday**
- **Donation from State Farm Companies Good Neighbor Grant Program**

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.

FRIENDS² of HOIDSA

Walk for Down Syndrome

Sunday - September 24th
Activities begin at 1:00 pm
Walk begins at 2:30 pm

NEWS

HOIDSA is planning a fun family afternoon to celebrate our 10th Anniversary walk. Some of the activities include the face painters along with a craft table, bouncy houses and games.

Lil Caesar's Pizza will be provided to registered participants.

SPONSORS

We are excited to announce our newest sponsor, WestPoint Financial Group. Kroger is also a returning sponsor for the 10th year along with Children's Hospital of Central IL at OSF St. Francis Medical Center. Other sponsors include New Vision Theater, OtterBox, Uftring Automall, Par-A-Dice Hotel & Casino, Tanners Orchard, Accenture, Inc., Haul-Pak Employees Community Service Assn, Eastland Suites, Clark Management/McDonalds, John & Christy Getz and Laurie Mattheessen.

A heartfelt thank you to each and everyone for your support of our walk!

RAFFLE

There will be a variety of items for the raffle, such as tickets to Tanners Orchard, NewVision Theatre movie passes, OtterBox certificate, overnight stay at Eastland Suites in Bloomington and an overnight hotel stay at Par-A-Dice Hotel. Tickets will be available the day of the walk. \$1 each or 6/\$5

FUNDRAISING

Texas Roadhouse Invitation - Once again the E Peoria Texas Roadhouse is hosting a Dine to Donate event. The event will take place on Tuesday September 12th from 3pm-10pm. All you need to do is present the included invitation or an electronic copy found on www.hoidsa.org or www.facebook.com/hoidsa to your server and 10% of your total purchase will be donated to HOIDSA.

firstgiving.com/hoidsa - Setup a fundraising page and you can use the **Share** links on your fundraising page to post to social media sites to share with family and friends.

REGISTRATION

Registration is available online at www.firstgiving.com/hoidsa or www.hoidsa.org/home. If you registered in a previous year for one of the walks through FirstGiving, then your login information is still valid. It will prompt you if you are using the same email address as before.

You can also register offline by filling out the form in the brochure and mailing it and your check to FRIENDS of HOIDSA Walk for Down Syndrome c/o Bethel Lutheran Church, 325 E Queenwood Rd., Morton IL 61550.

Registration and T-shirts are FREE for Down syndrome individuals this year. Registration is \$5 for all other participants and T-shirts are \$10 per participant. Online registration will end September 22nd; however registration will be available the day of the walk. **The deadline to be guaranteed a T-shirt is August 31st.**

SOLICITING SPONSORS

Our walk wouldn't be a success without the help of our families, friends and co-workers soliciting potential sponsors. Feel free to copy the sponsor letter and form that is included. Be sure to sign your name on the sponsor letter before mailing. You can also download and print both forms at www.hoidsa.org/get-involved.

Sponsors at the \$500 and above level must submit their logo information by August 31st to fundraising@hoidsa.org to be included on the back of the T-shirts.

GET INVOLVED

Please consider getting involved in this inspiring and rewarding opportunity to make a difference in the lives of individuals with Down syndrome. Full details about the walk are available online at www.firstgiving.com/hoidsa.

Thank you in advance for your support to celebrate our loved ones and ensuring our 10th Anniversary Walk will be a success!

Co-chairs:

Anita Hohimer/Jamie Czesak

309-241-8195/309-303-8475 or fundraising@hoidsa.org



FRIENDS² of HOIDSA **Walk for Down Syndrome**

Heart of Illinois Down Syndrome Association

10th Anniversary Walk

Sunday, September 24th

Dozer Park, Peoria IL

1:00pm

T-Shirt pick up, same day registration, raffle,
face painting, and all other activities

2:30pm

One Mile Walk Starts

Walk will take place rain or shine!

Register and fundraise online at

www.firstgiving.com/hoidsa

Register by August 31st to be guaranteed a t-shirt.

Questions? Call (309)241-8195 or

email fundraising@hoidsa.org

Site is ADA Accessible.



c/o Bethel Lutheran Church
325 E Queenwood Rd. Morton IL 61550

FRIENDS^o of HOIDSA Walk for Down Syndrome

Dear Friend:

The Heart of Illinois Down Syndrome Association is proud to announce the 10th Anniversary FRIENDS of HOIDSA Walk for Down Syndrome will be held on Sunday, September 24, 2017 at Dozer Park in 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.

We would like to invite you to consider sponsoring our 10th Anniversary FRIENDS of HOIDSA Walk for Down Syndrome. As a local business within our community, we are hopeful you want to offer us your support and invest in this worthy cause. 100% 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 conferences which feature renowned speakers on disability issues, recreational scholarships, conference stipends, collaboration with service agencies, young adult cooking class, new parent breakfast, grandparent's group, young athletes program and many other opportunities for networking and to advocate and educate throughout the year.

Please feel free to call 309-241-8195 or email fundraising@hoidsa.org if you have any questions or need any further information. Your support is greatly appreciated.

Thank you for your time and consideration.

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 are exchanged for donations.

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.



c/o Bethel Lutheran Church
325 E Queenwood Rd. Morton IL 61550

FRIENDS[®] of HOIDSA

Walk for Down Syndrome

Sponsorship & Donation Form

Contact Name: _____

Company: _____

Address: _____

Phone: _____

E-mail: _____

Option #1: We are pleased to sponsor the Walk for Down Syndrome at the following level:

Sponsor Level		Incentive
		Each level includes incentives from all previous levels unless otherwise noted.
<input type="checkbox"/> Ally	\$100	Thank you Facebook post which will include your name AND name on appreciation board at the walk AND name printed in HOIDSA's newsletter
<input type="checkbox"/> Buddy	\$250	Name printed on t-shirts AND you may set up a table at the walk (you may hand out promotional material at your table)
<input type="checkbox"/> Friend	\$500	Logo printed on t-shirts (instead of name printed on shirts from "Buddy" level) AND logo will be displayed on the jumbotron at the walk
<input type="checkbox"/> Best Friend	\$1,000	Verbal thank you over the loud speaker before the walk AND you will receive a framed thank you certificate
<input type="checkbox"/> Best Friend Forever	\$2,500	HOIDSA self advocates will bring cookies or donuts to your business and present you with a thank you plaque. A photo of the plaque presentation will be posted on our Facebook page along with a second thank you post.

Option #2: We are pleased to donate the following snack items/drinks:

Please list total fair market value of items donated. _____

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

Please list fair market value of each donated item. _____

August 31, 2017 is the deadline for submitting your sponsor information to be included in print on the back of the t-shirts. 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 fundraising@hoidsa.org.

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 donation.

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.



Fundraising

Heart of Illinois Down Syndrome Assn.

Tuesday, September 12th

3pm til 10pm

10% Donation Night

Support Heart of Illinois Down Syndrome Assn. by presenting this invitation to your server the night of the event at the East Peoria, IL Texas Roadhouse and Texas Roadhouse® will donate 10% of your total food purchases to the fundraiser!



309-698-6000

600 Riverside Dr. — East Peoria, IL 61611

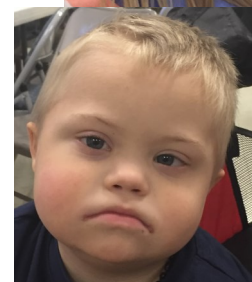
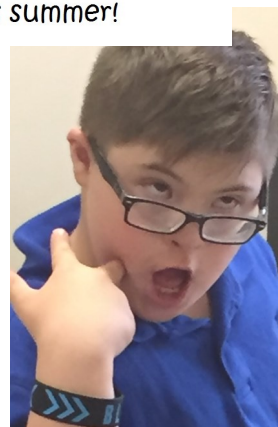


Good Times

at the

ICE Cream Social

Thank you to everyone who came out to make ice cream sundaes. The kids had a blast playing together, and the adults enjoyed "getting the scoop" on what's been going on this summer!



Down Syndrome

Measuring Cognitive Development in Intellectual Disabilities



Are you or your son/daughter between the ages of 6 and 25 years old? Do you like playing computer games? Your participation in this study could help us learn more about thinking and reasoning in individuals with intellectual disability.

The purpose of this research is to evaluate specialized tests for tracking cognitive changes.

Who can participate?

- Individuals with a confirmed diagnosis of intellectual disability caused by Down syndrome, fragile X syndrome, or unknown cause
- Males and females, between 6 – 25 years old

What does the study involve?

- The first visit and third visit will be scheduled over a two day period. The second visit is scheduled 4-weeks after the first visit. The third visit is similar to the first visit and will take place approximately two years later. All visits will involve cognition and behavioral testing.

What are the benefits?

- The study will provide \$50 compensation for your time and effort for the 1st study visit and 2nd study visit, and \$50 for the 3rd study visit
- One of our research psychologists will provide feedback on cognitive assessment results
- We can offer reimbursement for lodging and travel to Rush University from your home.

Sign up for research

To learn more about participating in research, call our research group at 312-563-9307 or email: claire_michalak@rush.edu.



Additional information

Rush University is a collaborative international research center, committed to the awareness, understanding, prevention and care of neurodevelopmental disorders.

All studies take place at the Rush University Medical Center, which is located at 1725 W Harrison St., Chicago, IL 60612.

 **RUSH UNIVERSITY
MEDICAL CENTER**
www.rush.edu



Rush is a not-for-profit health care, education and research enterprise comprising Rush University Medical Center, Rush University, Rush Oak Park Hospital and Rush Health.



Oct. 28-29th Down Syndrome Innovations Conference

Registration is Open!

What?

Seize this opportunity to have translational medical and innovative developmental work explained in a way that you can use to truly benefit your loved one, clients or patients.

A one-of-a-kind experience to hear dynamic researchers, physicians and therapists present cutting edge translational medical research and interventions to improve the health, cognition, behavior and development of individuals with Down syndrome.

Make new friends and connections! Network with other attendees who share a common goal. Speak face to face with expert vendors, check out quality service providers and try innovative products for yourself.



Thank you sponsors:



ICAN

International Christian Association
of Neurodevelopmentalists



Where?

Norris Conference Center/CityCentre
816 Town and Country Blvd #210
Houston, TX 77024



When? October 28-29, 2017

Full 2-day conference - \$170/person

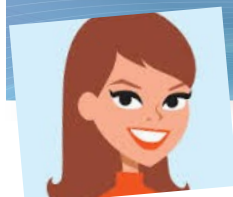
Registration includes **full breakfast**, mid morning beverage service, **plated lunch**, mid afternoon beverage service, access to online conference program and free access to the **2017 conference videos**.

Register at
www.downsyndromeinnovations.com



c/o Bethel Lutheran Church
325 E Queenwood Rd Morton IL 61550

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EDITOR'S REMARKS

Hello Everyone,

Now is the time to get your teams registered for the Friends of HOIDSA Walk for Down Syndrome! This is the 10th Anniversary of our walk, and we have lots of exciting things happening to celebrate. From free pizza and bouncy houses to face painting and raffle prizes, you're not gonna want to miss it this year!

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, organize programs like Young Athletes and the Young Adult Cooking Class, offer family & educator stipends, and promote acceptance of people with Down syndrome.

Carol Nepolello

c.nepolello@comcast.net
www.hoidsa.org

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>