



heart of illinois

Down Syndrome Association

Newsletter

March 2021

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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. March 1st | Board Meeting - 6:00pm
Virtual meeting via Zoom |
| March 1st-21st | Penn Station East Coast Subs Fundraiser
4620 N. University St., Metro Centre, Peoria
See page 3 for details |
| Thurs. March 18th | Portillo's Fundraiser - 11:00am-8:00pm
4412 N. Rockwood Dr., Peoria
See page 5 for details |
| Sun. March 21st | World Down Syndrome Day |

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

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March 2021

2020 brought lots of changes. First, Meri Tucker and Milly Howeler retired from the HOIDSA Board. Fortunately, they're both a call or email away, and they're always willing to answer our questions.

Then, after a very successful 2020 Spaghetti Dinner, the COVID lockdown completely changed everything. Gone were all in-person events including the Grandparents' Group, Christmas Party, and Dance Party. However, we were able to have a Virtual Friendship Walk in October.

Sadly, as many of you already know, COVID has also claimed the 2021 Spaghetti Dinner. With the COVID vaccine and infections dropping, here's hoping that we can soon have in-person events and, of course, we're already looking forward to the 2022 return of the Spaghetti Dinner.

Until that time, please help us by going to our 2021 fundraisers at the Metro Centre's Penn Station between March 1st and March 21st, and at Portillo's on March 18th.

At the end of 2020, the board of director terms ended for Laurie Matheesseen and Renee Hayes. We thank them for their service, and they will be missed. Trisha Romero is our new board secretary. Thanks, Trisha. We are continuing to look for a couple of new board members, so please email me at mwking@rocketmail.com if you are interested.

Finally, 2020 has been difficult on everyone. Despite the hardships, HOIDSA continues to function thanks to the army of volunteers that perform roles because they believe in our kids. I thank you all.

Stay healthy and safe,

Mike



Board of Director Vacancies

HOIDSA would like to add at least 2 people to our Board of Directors. We are seeking candidates that are passionate about helping people with Down syndrome reach their full potential.

Board members will

- *serve a three-year term*
- *attend monthly board meetings*
- *participate on at least one committee*
- *help develop and oversee the operating budget*
- *provide input to direct the Board's efforts*

Contact Mike King at mwking@rocketmail.com for more information.

March

Janelle Begner
3/1

Chris Bigelow
3/1

Maggie Getz
3/6

Jax Gander
3/11

Dakota Herold
3/11

Gia DeTrempe
3/12

Benit Roth
3/13

Jared Hicks
3/14

Jessica Pribble
3/15

Willis Leighty
3/17

Nicholas Stuber
3/18

Jack Robison
3/20

Joe Zimmerman
3/21

Zak Durdle
3/21

Jamie Martin
3/23

Mercy Thacker
3/24

Ashley Wertz
3/26

Trevor Colby
3/27

Lisa Pattelli
3/30





World Down Syndrome Day is annually observed on March 21 to raise public awareness and understanding of Down syndrome. Down Syndrome International encourages our friends all over the world to choose your own activities and events to help raise awareness of what Down syndrome is, what it means to have Down syndrome, and how people with Down syndrome play a vital role in our lives and communities.



Round Up for Down Syndrome at Penn Station East Coast Subs

For the first 21 days of March (March 1 - 21), all Penn Station locations will host a **Round Up for Down Syndrome campaign**. Customers at our local Penn Station in the Metro Centre in Peoria will be able to round up their purchase to donate to the Heart of Illinois Down Syndrome Association. If you donate \$2 or more, get a free sub on your next visit!



4620 N. University St., Peoria

We need your help to make this as successful as possible. Here is how you can help:



Eat at Penn Station - Grab a bite to eat with family or friends at your local Penn Station one or more times between March 1-21. Do your coworkers like to eat out? Consider doing a large group order for carry out.

Get the Word Out - Share Facebook posts from HOIDSA and Penn Station on your Facebook wall encouraging others to participate in the campaign!



We hope that you will join us and participate in the **Round Up for Down Syndrome campaign** as we lead up to World Down Syndrome Day (3/21)!

After discussions with the Spaghetti Dinner committee and the HOIDSA board, we regret to announce that the 2021 HOIDSA Spaghetti Dinner has been cancelled due to concerns surrounding COVID-19. As always, our top priority is the safety of our families.

We have high hopes that the virus will soon be gone, and we can safely resume having in-person events. As always, HOIDSA appreciates your support, and we look forward to bringing back the Spaghetti Dinner in 2022.

Meet Alex Tucker

Our family just celebrated a milestone. Alex turned 30 years old in November!



Little did we know about Down syndrome that November day in 1990. With the help and support of HOIDSA, Early Intervention programs, and a crack team of pediatric physicians, Alex grew stronger and healthier after a very rocky start. He had open heart surgery at 16 months to correct a life-threatening defect and valve graft.

He started public school with an Early Childhood program, moved to our parish parochial school in Kindergarten, and stayed there through 3rd grade. His school was open to us bringing in aides. We had an arrangement with Illinois Central College education students who volunteered as Alex's aides for a few classes in exchange for using Alex as their case study. In grade 4, he moved to our public school system. There he was in regular classes that had co-teachers. In junior high, he had transitional classes that were set up for students with or without IEPs who needed extra help. High school classes were a combination of Gen Ed and Special Ed classes.

His high school days were filled with as many activities as possible. He ran track, was freshman football manager, was a member of Key Club and Snowball. He was part of a Special Olympics swim team and soccer for years. Alex went to all the dances at his school and a few at his girlfriend's school. After he graduated from high school, he attended ICC for about 4 years earning credits.

He has been fortunate with finding work. Our community high school was a great help. Alex has been employed by Mission Mart in Morton for over 8 years working 4 days a week. When he isn't working, prior to Covid-19, he volunteers at TCRC Highland Center. At church, he runs the lights for service, is an usher, and scripture reader.

He has been an advocate for Down syndrome issues, even travelling to Washington D.C., to engage our lawmakers' support on various bills.

Alex is most proud of living in his own apartment with support. He also loves being an uncle!



When we received Alex's diagnosis of Down syndrome, among others, we were afraid of what his future could hold. Without the educational and emotional support we received from HOIDSA, we wouldn't be in a such a comfortable place in Alex's life. Connect and communicate with the members of HOIDSA.

You will be amazed!

Submitted by Meri Tucker



Portillo's **for GOOD**

FUNDRAISERS

Show this flyer to our drive-thru order taker prior to ordering and 20% of the proceeds will benefit

**FOR THE BENEFIT OF THE HEART OF ILLINOIS
DOWN SYNDROME ASSOCIATION (HOIDSA)**

March 18, 2021

11:00am - 8:00pm

at the Portillo's located at:

**4412 N. Rockwood Dr.
Peoria, IL 61615**

We look forward to seeing you there!

For the health and safety of our guests and team members, fundraisers are currently being conducted exclusively in our drive-thru. To learn more about how you can partner with us to serve up a better tomorrow, visit portillos.com/good



Do you spend a lot of time Googling and bookmarking Down syndrome topics and resources?

Then check out how joining myDSC.org (my Down Syndrome Community), a new and free online community hosted by LuMind IDSC, can change that!



When you become a member and set up a profile, you get a personalized dashboard with content tailored to the age of your loved one with Down syndrome and the topics you selected. You can easily search the entire library at any time.

All content and valuable tools are from trusted resources for people with Down syndrome and their families and caregivers.

Next

Other membership benefits include



Exclusive access to the annual **LuMind IDSC Family Weekend** in September at all 19 Great Wolf Lodge resorts.



An additional savings of **up to 30% off at any Great Wolf Lodge** resort the rest of the year.



A \$12 savings on an upgrade to **myDSC plus DSC2U** (Down Syndrome Clinic to You) created by Dr. Brian Skotko and other experts from Massachusetts General Hospital and Harvard Medical School.



Live **podcasts and webinars** plus on-demand recordings.



Post questions and get answers from **Dr. Brian Chicoine, the Medical Director of the Advocate Health Group Adult Down Syndrome Center.**

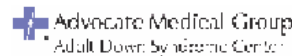


Opportunities to participate in **research from home.**



A list of Down syndrome **events and clinical trials** near you.

Collaborators



Signing up is free and only takes a few minutes.
Join myDSC to take advantage of this one-stop-shop of resources!



JB Pritzker, Governor

Illinois Department of Human Services

Grace B. Hou, Secretary

100 South Grand Avenue, East • Springfield, Illinois 62762
401 South Clinton Street • Chicago, Illinois 60607

January 21, 2021

To Whom It May Concern:

Illinois has a large population of people with disabilities. Recent COVID-19 studies have identified several groups within this population as being at high risk of COVID-19 complications and related fatalities. The purpose of this letter is to clarify that family members of certain people are "health care workers" pursuant to the State of Illinois' [Vaccine Administration Plan](#) (VAP) and thus are prioritized for COVID-19 vaccination within Phase 1a.

Those providing "Home Health" or serving as a "Home Aide/Caregiver" for a relative with a disability are included on pages 13-14 of the VAP. These family members include those who care for people with any of the following conditions. This list is not necessarily exhaustive:

- Cerebral Palsy
- Down Syndrome
- Epilepsy
- Specialized health care needs, including dependence upon ventilators, oxygen, and other technology

The eligibility of these family members can be ascertained by presenting medical documentation of the qualifying condition of the member of their household who has a disability.

We hope this letter clarifies the eligibility of certain family members as "health care workers" for the COVID-19 vaccine pursuant to the VAP, and thereby assists in protecting the health of Illinoisans most at risk from COVID-19 impacts.

Sincerely,

Rahnee Patrick, Director
IDHS Division of Rehabilitation Services

Allison Stark, Director
IDHS Division of Developmental Disabilities

The GLOBAL Guideline was published in the October 2020 issue of the Journal of the American Medical Association.

Adults with Down syndrome and their caregivers should review the GLOBAL Guidelines with their doctors to ensure they are receiving care meeting best-practice standards.

GLOBAL DOWN SYNDROME FOUNDATION MEDICAL CARE GUIDELINES for ADULTS WITH DOWN SYNDROME

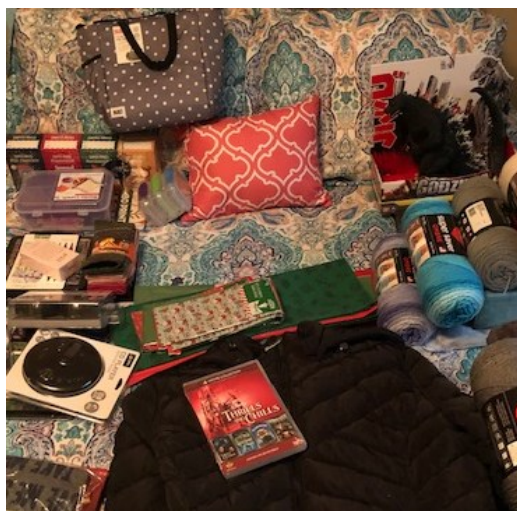
Guideline Narratives

1. Behavior
2. Dementia
3. Diabetes
4. Cardiovascular Disease
5. Obesity
6. Atlantoaxial Instability
7. Osteoporosis
8. Thyroid
9. Celiac Disease

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*This is an excerpt
from the table of
contents*

[Click here to download the complete 92-page document](#)
or visit the Medical Professionals page at www.hoidsa.org



Each year HOIDSA spreads some holiday cheer by buying gifts for individuals in need within our community. We reach out to local organizations (EPIC, ADDWC, TCRC, and AC LifePoints) that work with individuals with Down syndrome and they provide us with wish lists for these individuals. Next our "elves" go out shopping from the lists which include many necessities like winter coats, pajamas and socks but also some fun items like movies, craft items, toys and snacks. Once all of the shopping is done, the elves wrap the holiday gifts and deliver them to the organizations. In December 2020, HOIDSA purchased gifts for a total of 31 individuals plus one family with 4 children. Thanks to all of the elves that volunteered to help make this happen....Anne Hollis, Laurie Mattheessen, Deb Fornoff, Teri Ehrenhardt, and Trisha Romero.



Purchase of Assistive Technology Consumer Stipend Program

The Arc of Illinois, through a grant from the Illinois Council on Developmental Disabilities, administers the Consumer Stipend Program and distributes consumer stipend funds to enable people with developmental disabilities and their family members to attend conferences of their choice that are directly related to developmental disability issues.

Due to the pandemic, there is a need for trainings, important meetings and conferences to be virtual. This program will now allow stipends to pay for the assistive technology needed to attend virtual events.

The attached application is for individuals with developmental disabilities and families to apply for technology needed to stay connected in these difficult and unprecedented times.

Who can apply?

- Illinois resident
- A person with a developmental disability
- Family members of a person with a developmental disability
- A guardian/foster parent of a person with a developmental disability

What Can I Apply For?

- iPads and other tablets
- Laptops
- Apps for tablets
- Software
- Other assistive technology that will help you stay connected

How much can I apply for?

- Determined on a case by case basis depending on the technology needs.

Limitations:

- You may only apply one time for a purchase of technology per individual/family

Click this link to download the complete 4-page application:

How do I apply? <https://www.thearcofil.org/wp-content/uploads/2021/01/Consumer-Stipend-Brochure-for-AT-2021.pdf>

- The application form must be completed and returned to The Arc of Illinois.
- The application must be filled out by the person needing the technology or the family.
- The need for the equipment must specifically relate to having a developmental disability.
- Stipends are not approved retroactively for previously purchased equipment.
- Once your application is approved, you order your device, send The Arc of Illinois the receipts and we will send a check for the amount approved and on receipts. If you cannot pre-pay please let us know. Email Karin@thearcofil.org or call 815-464-1832.



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

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EDITOR'S REMARKS

Hello Everyone!

Who knew that after the spaghetti dinner last year we would be facing a pandemic and our world would be flipped upside down for over a year?!? Many businesses and non-profit organizations were not able to survive the COVID restrictions, but HOIDSA is still here doing what we can to support families.

For the first time in 32 years, there will not be a spaghetti dinner. I sure will miss visiting with everyone and seeing how much the kids have changed in the last year. If you can, we would appreciate your support of our 2 fundraisers in March, or consider making a donation directly to HOIDSA on our website at www.hoidsa.org.

Until we are able to socialize in-person again, I wish you good health and happy togetherness!

Carol Nepolello

THINGS TO DO

Special Recreation Activities:
Check Out the Upcoming Activities

HISRA • IRVSRA

Contact HISRA at 309-691-1929
or visit hisra.org/programs/

Contact IRVSRA at 309-201-4005 or visit
<http://www.irvsra.org/>