



**heart of illinois**

**Down Syndrome Association**

**Newsletter**

**October 2020**

*Contact Us:*

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Morton, IL 61550  
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*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.

NATIONAL  
**DOWN SYNDROME**  
AWARENESS MONTH



**THE 2020 FRIENDS OF HOIDSa WALK  
IS GOING VIRTUAL!!  
YOU HAVE THE ENTIRE MONTH OF  
OCTOBER TO GET YOUR WALK DONE**



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

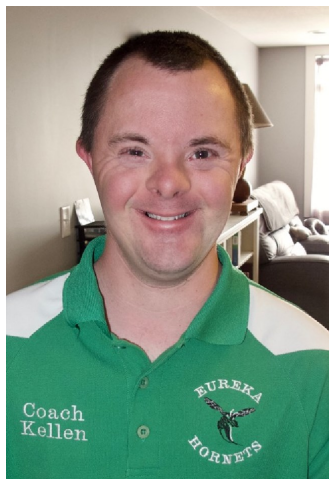
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## Kellen Ehrenhardt

This is our 30<sup>th</sup> personal celebration of Down Syndrome Awareness Month! Kellen was born on June 26, 1990 with a prenatal diagnosis of Down syndrome and duodenal atresia. Our family got wonderful support through Early Intervention and our involvement with HOIDSA. I've been inspired by those who blazed trails ahead of us, and I'm thankful for the learning opportunities and friendships that sustained us over the years.



Kellen and his older sister attended public schools in Eureka. He was fortunate to have an inclusive educational journey with many social and enrichment experiences. He graduated in 2009 and attended ICC part-time with his peers. Kellen fulfilled his dream of being a coach and has continuously assisted various Eureka High School sports teams since graduation. Coach K is currently assisting EHS cross country, and will then help with girls basketball and boys track. In non-pandemic times, he also volunteers at Davenport Grade School as a P.E. teacher assistant.



Kellen has been employed as a Dietary Aide at the Eureka Apostolic Christian Home for 11 years. It is a wonderfully supportive work environment with good wages and benefits! In his spare time, he participates in Special Olympics track, bowling and snow shoeing. He is an altar server at church and a community volunteer. Kellen's cherished roles include Boyfriend, Best Man, Uncle and Godfather!

We still live in Eureka and recently built a new home with a large apartment space for Kellen, allowing him more independence—and the companionship of those he loves! That fulfills a dream of mine!

Wishing you a Happy Down Syndrome Awareness Month—2020! It's been a challenging year, to say the least, but here's to dreams fulfilled!

Written by Teri Ehrenhardt

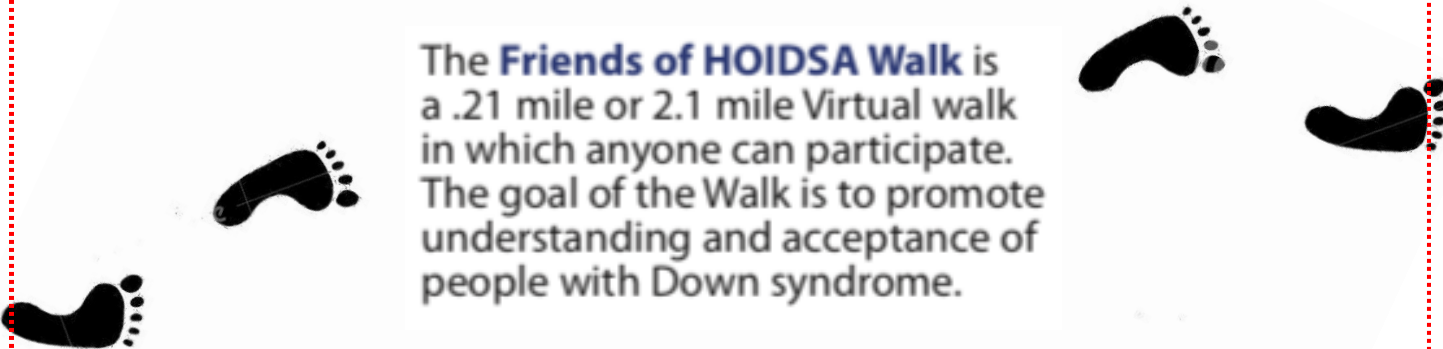
## Birthdays Next Month

### November

Steven Knaack  
11/3  
Courion Williams  
11/10  
Reagan Dunaway  
11/15  
Alex Tucker  
11/15  
Uriah Tierra  
11/16  
Logan Serrano  
11/18  
Quinn Hayes  
11/21  
Blade Glover



Due to the current covid-19 pandemic,  
**HOIDSA's 12th Annual Friends of HOIDSA Walk**  
is going virtual!



The **Friends of HOIDSA Walk** is  
a .21 mile or 2.1 mile Virtual walk  
in which anyone can participate.  
The goal of the Walk is to promote  
understanding and acceptance of  
people with Down syndrome.

For the entire month of October you will be able to sign up  
and participate in our walk.

Upload photos to your social media to share with us  
using the hashtag **#HOIDSAFriendship2020**

Register and donate at <https://www.firstgiving.com/event/hoidsa/HOIDSA-2020>

We are also selling Walk apparel through A Cheep Tee in East Peoria, IL  
<https://acheept.com/product-category/down-syndrome/>

For more information, contact Mary Kelly at 309-258-8023  
or [fundraising@hoidsa.org](mailto:fundraising@hoidsa.org)

### Adaptive Jiu-Jitsu is back!!

The Peoria Athletic Club is happy to offer an Adaptive Jiu-Jitsu program. Classes are shorter and modified to keep everyone safe. Students do wear masks for a majority of class and need to bring their own bottled water. This program is designed to teach Brazilian Jiu-Jitsu to both children and adults with physical or intellectual disabilities. The techniques taught in class will be adapted to accommodate each student's abilities.

**Classes are every Saturday and FREE to all students with a disability**

- ♦ The teen/adult class for students 16 and older is at 9:30 am
- ♦ The children's class for students 15 and under is at 10:00 am



Classes are held at the Peoria Athletic Club,  
704 E War Memorial Drive, Peoria Heights, IL

For any questions, please contact Nick DeTrempe at  
309-868-5810 or [ndetrempe@gmail.com](mailto:ndetrempe@gmail.com)

Have you ever wanted  
to join a book club?



HOIDSA is looking for tweens, teens,  
and young adults who would like  
to be in a book club

The group would choose a novel  
that has audio as well as a book,  
so anyone can participate.

The group will meet virtually each month to  
discuss, and then get together at the end to  
watch the movie.

If you are interested, please contact  
Becky DeTrempe by November 7th.

309.231.3002  
[rmcdaniels78@gmail.com](mailto:rmcdaniels78@gmail.com)



## Romero Family Personal Statement for Adoption

Meet our new daughter Livia Diana Romero! Livia is an adorable 2-year-old that was born in Ukraine and lived her first two years of life in an orphanage. She was left at the hospital after being born because she had Down Syndrome and a heart defect. Unfortunately, her mother didn't feel that she would be able to take care of her given her special needs.

In August of 2018 as Livia was being born, I was preparing to attend a Retreat for Moms of Children with Down Syndrome in Phoenix, Arizona. The retreat is an annual event hosted by an organization called Down Syndrome Diagnosis Network (DSDN), and the purpose of the retreat is to connect moms and provide opportunities for education, relaxation and some fun. I was hesitant to sign up because I had just recently become a mom to a child with Down Syndrome. My son Cruz was just 4 months old and although we had received his diagnosis very early in the pregnancy, I was both nervous and excited about attending this event. My husband and Cruz came along, and I had a wonderful time at the retreat. There were lots of breakout sessions that the moms could attend, and for some reason the session on Adopting a Child with Down Syndrome was calling to me. I had never thought about adopting previously but I followed this pull and attended the session. During the session, I learned all about the need for adoption of children with Down Syndrome globally, a bit about the process and even met some amazing mothers that had already adopted children with Down Syndrome. From that day on, I knew that someday when the time was right that we would adopt a child with Down Syndrome and provide them with a family, a home and LOVE! Over the next year, I would periodically look at the waiting children listed on Reece's Rainbow which is a non-profit organization that advocates and finds families for orphans internationally with Down Syndrome



and other special needs by raising funds for adoption grants and promoting awareness through an online community and media communications. The cost to adopt a child internationally is approximately \$35,000, which is a barrier for many families, so Reece's Rainbow plays a big role in helping many families to cover some of these costs. I saw so many beautiful children that were so worthy of having a family. I would show them to my husband and daydream about adopting them and adding them to our family. I shared their pictures and started learning about the different countries that had special needs adoption programs in place. I followed other families' adoption journeys and continued to gather information. Finally I got my husband on board and we were ready for our child.

In early November of 2019, I came across a little brown-haired baby girl with dark hair and big brown eyes. She looked like our sons and I showed her to my husband, and I said "I want to commit to her." He responded with "Do It," so we started our adoption journey. We completed our home study in early January, got approval from the US government in February, and finally we got our completed dossier submitted to the Ukraine Adoption Authority in March of 2020. Unfortunately, COVID-19 evolved into a pandemic and everything was halted including our adoption. Ukraine closed its borders and our time to travel to finally meet Livia came and went. Finally, in mid-July we received our travel invitation and were officially invited to travel to Ukraine to be matched with Livia. We met her on July 28<sup>th</sup> and accepted her referral. Due to ongoing COVID-19 post-travel quarantine requirements in both the US and Ukraine and the chance of borders closing again, we opted to stay in country until after court when we would be able to take her out of the orphanage. We visited her orphanage almost every day and were able to bond with her a lot prior to bringing her home.



Finally on August 25<sup>th</sup>, we officially became her parents in a little tiny courtroom in Kharkiv, Ukraine. The next day which was the day before her 2<sup>nd</sup> birthday, we took her out of the orphanage forever and traveled by train back to Kyiv, the capital of Ukraine.

There we worked through the final steps of getting her passport and visa which were required for her to travel back to the United States. We spent the week living in an apartment and getting to know our newest family member. On September 2nd, we all flew home and that is the day that Livia became a citizen of the United States.



Livia has now been home for one month! She has adjusted to her new life in our family surprisingly well. She has been to the pediatrician and the cardiologist so far and has done initial evaluations with Early Intervention so she can get started with all of the necessary developmental therapies. She is eating and drinking well. She sleeps peacefully and is happy and excited to play with toys, take baths and explore our house. We love her and are so happy to have her home!

Adoption is not an easy journey. It is a tough and emotional roller coaster full of ups and downs and many twists and turns. But Livia was worth it and we would do it all over again for her!

Now I'm super excited to announce that the board of HOIDSA has voted to begin offering Adoption Grants to families within the HOIDSA coverage area that have finalized an adoption of a child with Down Syndrome. This adoption grant aligns with our mission statement, and we felt that it could give families the extra financial security that they need to move forward with an adoption of a child with Down Syndrome which can cost more than \$35,000 which is a daunting figure to most families. Additionally this is support that is being offered by other Down Syndrome organizations and we are proud to be able to support our families embarking on the adoption journey. Information on the HOIDSA Adoption Grant can be found on the HOIDSA Website under 'Programs'. (website - <https://hoidsa.org/programs>)

If anyone is interested in learning more about adopting a child with Down Syndrome, please check out the following two organizations:

- ◆ International Adoptions: Reece's Rainbow (website - <https://reecesrainbow.org/>)
- ◆ Domestic Adoptions: National Down Syndrome Adoption Network (website - <https://www.ndsan.org/>)

Also please feel free to reach out to me for any other questions on getting started here locally in terms of home study or to just chat further about our journey. I'm an open book and happy to share more of our story!

Regards,  
Trisha Romero



# SPEAK UP AND SPEAK OUT summit

Funded by the Illinois Council on  
Developmental Disabilities

**November  
16 - 20, 2020  
Summit  
Registration**



Registration  
\$50.00  
for the whole  
week!

★ **This year's SUSO** ★  
**Summit will be held VIRTUALLY,**  
**using Zoom Webinar**

Registration  
is  
Limited!  
Sign Up  
Today!

## \$50 Summit Registration Fee includes:

**Monday, November 16 - Friday, November 20, 2020**  
**All Zoom Speaker Sessions**  
**All Zoom FUN Sessions**

Registration fee is required for all attendees, Financial assistance for registration fee is available. (Please see Form 3.)

## Keynote Speakers

**Scott Palm**

*"Disability Awareness: How to Work Together"*

**Daniel Smrokowski**

*"Special Chronicles: Giving Respect and Voice To  
People with Disabilities Through Digital Media  
Storytelling"*

**Lydia X. Z. Brown**

*"Disability as part of social justice/diversity movements/work"*

**Micah Fialka-Feldman**

*"Through the Same Door: Inclusion Includes College  
and Beyond"*

**Russell Lehman**

*"Finding Success Through Struggle"*

**TJ Gordon and Candace Coleman**

*"Disabled I AM"*

**Link to registration brochure:** <https://www.speakupspeakoutsummit.org/registration-brochure>

**Connect to the VIRTUAL Zoom Webinar using your  
phone, laptop, or tablet, wherever you can access  
the internet.**





## **Board of Directors Vacancies**

*The Heart of Illinois Down Syndrome Association would like to find at least 6 people for our Board of Directors to fill vacancies and expand our leadership. The Nomination Committee seeks 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*

*HOIDSA is specifically looking for candidates in the following areas:*

- representing adults with disabilities*
- families with young children*
- educational expertise/school districts*
- relationship with the medical community*

We will accept nominations through December 6th. Vacancies will be filled at a later board meeting after all candidates have been considered. If you are interested, or know someone who would be a great addition to our Board, please contact us at 309.712.4852 or [info@hoidsa.org](mailto:info@hoidsa.org).

## **Memorial/Recognition Donations**

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

- Memorial donations in honor of Minnie Nepolello, Adam Nepolello's grandmother**
- Memorial donations in memory of George Jason**
- Memorial donation in honor of Decker Marcacci**

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.



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

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## EDITOR'S REMARKS



Hello Everyone!

As you know, October is Down Syndrome Awareness month.

Unfortunately our Friendship Walk will be virtual this year, but I hope everyone can share in the spirit by taking photos and posting messages on social media.

Thank you to the Ehrenhardt and Romero families for sharing your children with Down syndrome with us. Several HOIDSA families have been blessed with adoption, but all of us parents dare to dream of the future for our children, so it's heart-warming to see Kellen living his dream!

If you would like to share pictures of any of your activities for Down Syndrome Awareness month in the next newsletter, please email them to me by November 13th.

*Carol Nepolello*

c.nepolello@comcast.net

## THINGS TO DO

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/programs](http://www.hisra.org/programs)**

**Contact IRVSRA at 309-201-4005 for information or visit**  
**[www.irvsra.org/](http://www.irvsra.org/)**

Follow the Illinois River Valley  
Special Recreation Association on Facebook  
for more information about upcoming events