
WINTER 2023

EPDSC News

Eastern Pennsylvania Down Syndrome Center Member Newsletter



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Mom's Coffee Meet Up

The New & Expecting Parents Program kicked off 2023 with a Mom's Coffee Meet Up on January 22nd at Bitty & Beau's in Bethlehem.

BOARD OF DIRECTORS

Kelly Nelson, President
Brian Paugh, Vice President
Greg Meyer, Treasurer
Danielle Horn, Secretary
Carrie Gross
Peter Iorio
Bryan Meltzer
Joseph Roller
Dr. Teresa Romano
Dr. Donald Levick, at large

OFFICE AND SUPPORT STAFF

Kerri DiDario
Executive Director

Claire Dainese
Office Administrator

Patti Mertz
Family Support Specialist

Anne Marie Dolinish-Meltzer
Family Support Specialist

Laura McKelvey
Family Support Specialist and
Educational Advocate

Letter

FROM THE EXECUTIVE DIRECTOR

Happy New Year Friends and Family!

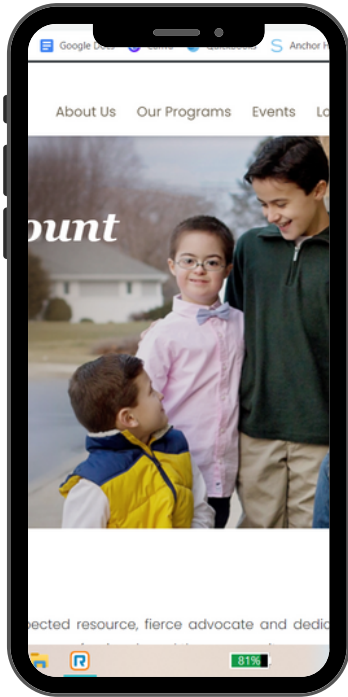
I am bursting with excitement for what is to come in 2023! If you joined us for the Annual Membership Meeting in January, you know our calendar is as full as our hearts!

From the transition of medical services to the LVPG Down Syndrome Medical Clinic to the new Club 21, Parent to Parent Mentor Program, and School Aged Programs; the EPDSC continues to impact the Down syndrome community in positive and meaningful ways. I genuinely believe this is only the beginning of new growth for us all!

Thank you so much for all you do for us so we can do more for you! As always, if you have any thoughts, questions, concerns or ideas for our organization or if you'd like to get involved, never hesitate to reach out to me at epdsckerri@gmail.com.

Sincerely,
Kerri DiDario

Exciting News!



We've got a new number!

484-224-5288

If you wish to make or change a current appointment, you may still call 610.402.0184.

Thank you!

In September, we hosted a blood drive in honor of Blood Cancer Awareness Month. Thank you to our 5 special donors who contributed during our campaign and helped saved lives!

 [About Us](#) [Our Programs](#)

EPDSC Blood Drive

09/30/2022



AWARENESS MONTH
BLOOD CANCER
SEPTEMBER

**BLOOD DONOR
SAVE LIVES**

September 1st - September 30th

Easter PA Down Syndrome Center is hosting a special blood drive to save lives in Honor of Blood Cancer Awareness month. Our only source of blood is from blood donors like you.

September 1st - September 30th

A Message from the Board of Directors

The Board of Directors of the Eastern Pennsylvania Down Syndrome Center is pleased to announce the selection of Brian Paugh as its new President. Brian has served on the Board of Directors for nearly 4 years, and as Vice President of the Board since 2022.

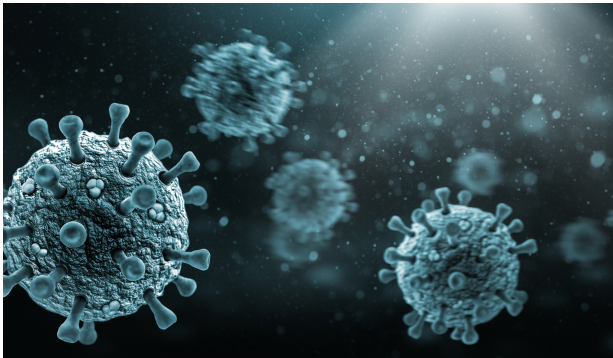
Brian will be stepping into the role previously filled by Kelly Nelson. Kelly will be retiring from the Board of Directors after 9 years as a member, 4 in which she served as President. Kelly has been instrumental in leading the EPDSC through many successes and challenges including hiring the first Executive Director, navigating a pandemic, and the transition of the medical clinic to LVPG. Kelly looks forward to continuing to work with families at the LVPG Down Syndrome Medical Clinic and volunteering at various EPDSC events.

Brian is a Senior Account Executive at Capital Blue Cross and is father to 3 children, Sarah, Cora and Jacob. Jacob has Down syndrome. Brian's wife, Jennifer, is a Volunteer Coordinator for the New & Expecting Parents Program. He serves on the Revolutions for Inclusion Bike Committee, Investment Committee and can be seen actively participating at most EPDSC events.

We are thrilled that someone with so much passion for our mission will lead the Eastern Pennsylvania Down Syndrome Community into the next chapter. Please join us in welcoming Brian as our new Board President.

Spotlight on Health

Study reveals why viral infections are less frequent but more severe in individuals with Down syndrome



Individuals with Down syndrome have less-frequent viral infections, but when present, these infections lead to more severe disease.

New findings publishing on October 14 in the journal *Immunity* show that this is caused by increased expression of an antiviral cytokine type I interferon (IFN-I), which is partially coded for by chromosome 21. Elevated IFN-I levels lead to hyperactivity of the immune response initially, but the body overcorrects for this to reduce inflammation, leading to increased vulnerability later in the viral attack.

"Usually too much inflammation means autoimmune disease, and immune suppression usually means susceptibility to infections. What is unusual is that individuals with Down syndrome are both inflamed and immunosuppressed, a paradox of sorts. Here, we discovered how this is possible."

Dusan Bogunovic, Senior Study Author, Icahn School of Medicine at Mount Sinai

Down syndrome is typically caused by triplication of chromosome 21. This syndrome affects multiple organ systems, causing a mixed clinical presentation that includes intellectual disability, developmental delays, congenital heart and gastrointestinal abnormalities, and Alzheimer's disease in older individuals.

Recently, it has become clear that atypical antiviral responses are another important feature of Down syndrome. Increased rates of hospitalization of people with Down syndrome have been documented for influenza A virus, respiratory syncytial virus, and severe acute respiratory syndrome due to coronavirus (SARS-CoV-2) infections.

Spotlight on Health (continued)

While people with Down syndrome show clear signs of immune disturbance, it has yet to be elucidated how a supernumerary chromosome 21 leads to dysregulation of viral defenses. To address this knowledge gap, the researchers compared fibroblasts and white blood cells derived from individuals with and without Down syndrome, at both the mRNA and protein levels. They focused on the potent antiviral cytokine IFN- α receptor subunits IFNAR1 and IFNAR2, which are located on chromosome 21.

The researchers found that increased IFNAR2 expression was sufficient for the hypersensitivity to IFN- α observed in Down syndrome, independent of trisomy 21. But subsequently, the hyper-active IFN- α signaling cascade triggered excessive negative feedback via a protein called USP18, which is a potent IFNAR negative regulator. This process, in turn, suppressed further responses to IFN- α and antiviral responses. Taken together, the findings unveil oscillations of hyper- and hypo-responses to IFN- α in Down syndrome, predisposing to both lower incidence of viral disease and increased infection-related morbidity and mortality.

"We have a lot more to do to completely understand the complexities of the immune system in Down syndrome," says first author Louise Malle of the Icahn School of Medicine at Mount Sinai. "We have here, in part, explained the susceptibility to severe viral disease, but this is only the tip of the iceberg."

Source:

Cell Press

Journal reference:

Malle, L., et al. (2022) Excessive Negative Regulation of Type I Interferon Disrupts Viral Control in Individuals with Down Syndrome. *Immunity*.
doi.org/10.1016/j.immuni.2022.09.007.

Original article link <https://www.news-medical.net/news/20221014/Study-reveals-why-viral-infections-are-less-frequent-but-more-severe-in-individuals-with-Down-syndrome.aspx>

23rd Annual Lehigh Valley Buddy Walk

The 23rd Lehigh Valley Buddy Walk took place on Saturday, October 8th. Thank you to everyone who supported the event helping us raise almost \$60,000 for the EPDSC!



23rd Annual Lehigh Valley Buddy Walk



Cathy's Corner

Welcome to Cathy's Corner!



This Is one of my favorite paintings.

It inspires me to follow my dreams and reach for the stars.

This was challenging for me to paint but I kept trying and correcting my mistakes and before I knew it, it was done and I was proud of myself.

I started painting In 2020 and I absolutely love doing this. I hope you like my painting and maybe It will encourage you to try painting yourself.

Membership Matters

A few reminders about your membership

- Don't forget to send in a membership form with your payment. This helps us keep track of your membership.
- Membership renewals are due yearly in the month in which you last renewed or the month in which you signed up. Lifetime memberships never expire and are a great option so you don't have to worry about yearly dues!
- Membership provides you access to the Brian J. Wittig Enrichment Memorial Fund. Click [HERE](#) to find out more.
- Membership is open to anyone in the community with many options to join. Tell someone you know about why you became a member and invite them to read more at <https://www.epdsc.net/become-a-member>.
- Membership is for you! If you have an idea for a membership event, let us know! We love hearing from you!

World Down
Syndrome Day



PHOTO CONTEST

The EPDSC Self-Advocate Advisory Committee is excited to see how you celebrate #WorldDownSyndromeDay with your crazy socks. Share a picture with us and one winner will be picked by our Self-Advocate Committee to receive a HUGE gift box of John's Crazy Socks and a handwritten note from our committee.

Photos must be received anytime on Tuesday March 21st to be counted. One winner will be chosen and notified by March 23rd.

By submitting your photo, you agree to allow the EPDSC to use your photo in our marketing and social media promotions.

Looking for some cool socks to rock on 3/21? Check out <http://palssocks.com/> and use code EPDSC321 for a 5% discount. A 25% donation will also be made to the EPDSC!



Submit your photos anytime on 3/21 via email to theepdsc@gmail.com. You'll get a confirmation email upon submission.

Looking for more ideas to celebrate World Down Syndrome Day? Visit <https://www.epdsc.net/about/events/wdsd2023/>.

Holiday Party Memories

On December 3rd, we celebrate the holidays together with Breakfast & Santa!





March 3rd

Teens & Young Adults – Pizza with Pals

March 7th

Club 21 – Board Game Party

March 7th

School Aged Parents Support & Social Group

March 21st

World Down Syndrome Day

March 27th

Workshop: Funding a Special Needs Trust & ABLE
Accounts

April 8th

10th Annual 3.21 Run for Down Syndrome

Stay up to date on all our events and find
information on how to register at:

<https://www.epdsc.net/about/events>



AMAZON SMILE ENDS

Effective Feb 20th, Amazon has discontinued their AmazonSmile donation program. In 2022, Amazon Smile donations to the EPDSC totaled \$375.

Thank you for supporting the EPDSC when you shopped Amazon. While cash donations may no longer be provided, you can still help by purchasing an item off our Amazon Wish List.

Our list can be found at the link below or by scanning the QR code. Our list includes items we typically need for programs and event and have to pay out of pocket for.

<https://a.co/6yYbPGC>

Thank you!

