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SPRING 2021

DOWN SYNDROME NETWORK OF WV



DSNWV SPRING 2021
NEWSLETTER

PAINTING PARTY!

VIRTUAL CELEBRATION

While we weren't able to get together for a WDSO celebration in person, Karen Wolfe of Art by Karen Wolfe hosted a virtual painting party! Participants were able to join in from all across the state to paint a Down syndrome-themed gnome, complete with a blue and yellow striped hat and mismatched socks! If you are in the Fairplain, WV area, stop by and see Karen in Fairhaven Square, or check out her upcoming events at <https://www.facebook.com/ArtbyKarenWolfe>.

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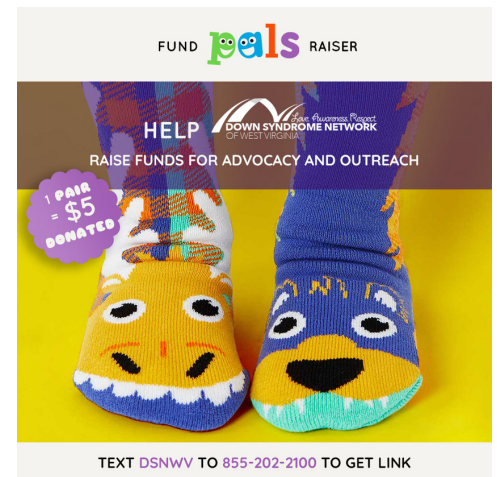
SANDWICHES, SOCKS, AND STORYBOOKS!

What a busy year for fundraising so far! We have been fortunate enough to participate in THREE fundraisers for WSDS this year: Penn Station, Pals Socks, and Usborne Books.

Penn Station began a preliminary Round-Up for Down Syndrome campaign in 2019, partnering with the Down Syndrome Association of Greater Cincinnati. Last year, the restaurant expanded the campaign to include ALL franchises, with donations benefiting the local Down syndrome associations. We are proud to report your efforts raised over \$5,700 in 2020!! We will share the 2021 results in our next newsletter.

This was our first partnership with Pals Socks, which is also a fairly new fundraiser. Partnering with Down Syndrome Diagnosis Network, Pals helps local Down syndrome organizations raise money through their sock fundraiser. The campaign ran from February 19 to March 8, 2021, and our supporters helped raise \$525! For more information: www.palssocks.com

We were so humbled that Jennifer Criner reached out wanting to partner with us for an Usborne Books & More party! Jennifer worked for 10 years as a pediatric physical therapist and was looking for a way to give back to families who welcomed her into their homes for so many years. For every purchase, Jennifer receives a 25% commission, and she donated all of her commission to the DSNWV! We are thankful for her continued dedication to our families. For more information: <https://k11102.myubam.com/>



DSNWV WELCOMES EXECUTIVE DIRECTOR

ASHLEY ORNDORFF

Ashley Orndorff has been involved with the DSNWV since late 2014 after her daughter, Hannah, was born. She has served as a member of the Board of Directors since 2015 and, for the past three years, as Board President before being hired as the organization's Executive Director in January. She is a graduate of West Virginia University's Masters of Occupational Therapy program, and practiced for 11 years prior to pursuing the non-profit domain. Originally from Cross Lanes, she and her husband, Chris, live in South Charleston with their children, Hannah and Daniel.



Meet the Board:

Amy Loftis
Jessica Luikart
Mason Olszewski
Judy Paul
Sara Raynes
Jessica Wooten

MEET THE OFFICERS

Jessica Wooten, President

Jessica is a mother of three from Ravenswood, West Virginia. The birth of her third child and his Down syndrome diagnosis prompted her interest in disability and inclusion advocacy. An alumni of West Virginia University, Jessica completed a Doctorate of Nursing Practice in 2011 and currently works as a family nurse practitioner where her passions are public and women's health. She currently serves as the Secretary of the Board of Directors for Wood County Society and in 2019 was appointed to the West Virginia Early Intervention Interagency Coordinating Council by Governor Jim Justice.

Sara Raynes, Vice President

Sara lives in Cross Lanes, is a wife and mom of 3 boys: Jordan, Justice, and Jonah (her "homie with an extra chromie"). Sara joined the board in 2017. Her family is always on the move with soccer games and exploring the outdoors. After Jonah was born, Sara has gained great strength from all of the families she has met along the way. She has said that while having a child with a disability isn't always easy, "the rewards are worth it as we continues to grow and promote inclusion within the community."

Mason Olszewski, Secretary

Originally from Columbus, Ohio, Mason moved to West Virginia to attend the University of Charleston, where he earned his Bachelor and Master Degrees. He is the Director of Telemedicine for Charleston Area Medical Center and has been working tirelessly throughout the pandemic to get residents registered for COVID-19 tests and vaccines. His role led him to managing the COVID Monoclonal Antibody Infusion Site and CAMC Mobile Clinic. He has a 3-year-old nephew with Down syndrome, and he is eager to expand his work with the DSNWV.

Amy Loftis, Treasurer

Amy is a graduate of West Virginia State University and works as a teacher in Kanawha County Schools. She became involved with the Down Syndrome Network of WV in 2007, after her youngest son, Adam was born with Down syndrome (prenatally undiagnosed). Adam was quite the surprise and learning curve, and his family was thankful to find the support of the DSNWV! Amy began her volunteer work on the Buddy Walk committee. She has served several roles on the board of directors, including board member, president, and currently treasurer. Amy and her husband, Jeff, have 3 sons (Matthew, Nick, and Adam) and 2 dogs. They live in St. Albans.

2020 BUDDY WALK-YOUR-WAY-WEEKEND

RECAP

Our annual Buddy Walk celebration at the State Capitol Complex is our largest event and fundraiser of the year. With rising concerns relating to the COVID-19 pandemic, we hosted our first “Walk Your Way” event on October 3-4, 2020. What a unique experience to share! Teams formed all over the state to celebrate Down syndrome safely by hosting picnics and walks in their own communities with the help of our “Buddy Boxes.” The WV ABLE program donated bags of goodies and information on ABLE Accounts for registered buddies.

For the second year in a row, Four Season Athletics of Spencer, WV (owned and operated by DSNWV’s own Cummings family), designed our shirts with a simple “Peace, Love, Buddy Walk” message. Families across the state chose their own times to walk during the weekend and shared celebrations across social media. We are also grateful for Ten-Up Ministries, which sponsored the t-shirts that were available with registration. With Ten-Up’s contribution, we were able to focus our efforts on fundraising, as Buddy Walk brings in the bulk of our annual donations.



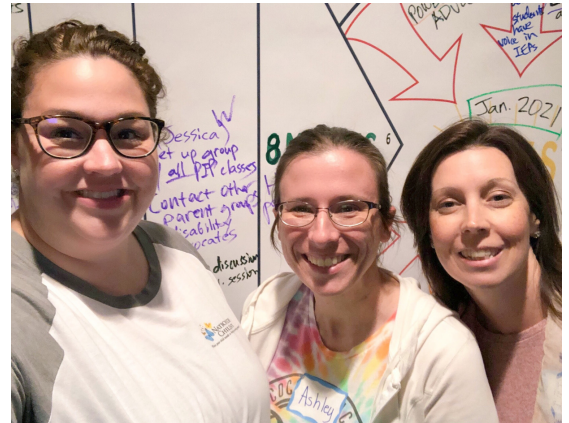
2021 - SAVE THE DATE

We are looking forward to returning to the Capitol Grounds for this year’s Buddy Walk, and have saved the date of September 25, 2021. More information will be released as we continue to follow recommended pandemic guidelines and consider the safety of our families above all else. Be sure to follow our social media (facebook.com/dsnwv) for more information in the coming months!



DSNWV BOARD MEMBERS PARTICIPATE IN POLICY TRAINING

Every two years, the WV Developmental Disabilities Council hosts “Partners in Policymaking” (PIP). The most recent class included three DSNWV board members—Ashley Orndorff, Sara Raynes, and Jessica Wooten. Trainings were held monthly from September 2019 to April 2020 in South Charleston with a remote learning option for those living further away, which allowed a greater attendance radius, including the eastern panhandle!



Classes covered a range of topics, including historical treatment of those with disabilities, the disabilities rights movement, how a bill becomes a law, and even an outing to the West Virginia State Capitol Complex with a mock session in the House of Delegates! Since graduation, Ashley, Sara, and Jessica have been using the knowledge they have gained to delve further into advocacy and policymaking such as counseling other families with questions about IEPs, to educating our legislators on the rights of people with Down syndrome.

For more information on PIP, visit the WVDDC website at <https://ddc.wv.gov/Training/PartnersinPolicymaking>

I/DD Waiver Income and Taxes

For those who are currently benefiting from income through the I/DD Waiver program, please note that the rules changed (for the better!) with the Feigh court case 2 years ago. Such wages can now optionally be included for tax credits like EITC or CTC. This means your refund could be considerably larger. It also means a substantial "refund" is possible even if you have no taxes withheld. Most tax preparers do not know about this and many online tax software programs will not do this automatically. For more free information, email Bill Scharf, IRS Enrolled Agent and dad of Jacob with DS, at ScharfFamilyNC@gmail.com.

Medical Outreach Grant

The DSNWV is participating in a Medical Outreach Grant through the University of Kentucky and Down Syndrome Diagnosis Network (DSDN). Beginning in early 2020, we started compiling data on projected yearly births in WV, contact information for Genetic Counselors and Maternal-Fetal Medicine Specialists, and working with newly diagnosed families to distribute surveys to track more specific data through the University.

As we enter the next phase of the grant program, we will be working with even more medical providers across the state to deliver materials on prenatal testing, diagnosis delivery, and increasing referrals to our network for support. One way we will be doing this is hosting Lunch & Learns. DSDN partners with Lettercase to offer trainings and materials at no cost to us during the grant cycle. We are hopeful that by working with providers across the state, families facing a new diagnosis will be delivered the most accurate information in a compassionate manner and be pointed in the right direction to obtain the support they need.

Welcome to the Family!

This is Grayson and he turned 2 months old on February 1.

He has t21 and a CHD (congenital heart defect).

He is the sweetest, most loving baby and has definitely been our little miracle baby!

He has a long road ahead of him, but he is our little warrior and with God, we can get through anything! "This too shall pass."

-Kayla Harvey



Want to be featured in a future newsletter?

Examples of articles we're looking for:

Sibling Stories

Parent Perspectives

Community News

Recent Accomplishments

Birthdays

New Family

DSNWV

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