



Down Syndrome Network of West Virginia Executive Director Ashley Orndorff, of South Charleston, and her daughter, Hannah.

Courtesy photos

## A day of inclusion, awareness

World Down Syndrome Day highlights need for support, occupational therapy

By CLINT THOMAS  
Daily Mail WV

This Sunday, March 21, will be observed as World Down Syndrome Day 2021, a time of awareness, attention to and appreciation of abilities.

The date of the 21st day of the 3rd month was selected to signify the distinctive triplication of the 21st chromosome which causes Down syndrome.



Culicerto



McCombie

It's a day with added professional and personal meaning for Down Syndrome Network of West Virginia Executive Director Ashley Orndorff; the South Charleston resident is also the parent of a Down syndrome child, daughter Hannah, 7.

Orndorff graduated from the West Virginia University occupational therapy program in 2009 and practiced occupational therapy for 11 years. She stepped away from the field last year to pursue her self-described passion in the Down syndrome advocacy domain.

The DSNWV is composed of a volunteer board that meets monthly, virtually over the past year due to the COVID-19 pandemic. "Most of our board members are moms of children with Down syndrome. One gentleman who lives out of state is also on the board; he has a nephew with Down syndrome. He reached out to our organization because he wanted to get more involved in our state," Orndorff said.

"We just consider it a large support network," she said. "I got a call from a dad in Morgantown this morning. He had questions about schooling, and I put him in contact with a family I know in that area who could provide some guidance. We're here when people need us, and we try to get the families involved as much as possible."

The DSNWV hosts a variety of family-oriented events for fun — and funding — annually, Orndorff said, albeit with modifications impelled by social distancing caveats in recent months.

"In 2019, we had World Down Syndrome Day Bowling. We hosted bowling events all across the state, in Nitro, Bluefield, the Eastern Panhandle and north-central West Virginia," she said. "We all had our crazy, mismatched socks on and celebrated across the state. But last year, we didn't, because ... COVID."

The pandemic also precluded gathering for the group's fall 2020 Buddy Walk fundraiser, but Orndorff said the 2021 event is already being planned for an in-person return in September.

"Every fall, the National Down Syndrome Society has a national Buddy Walk program," she explained. "We host it locally and always have it in Charleston at the Capitol. We invite legislators, because we want them to be aware of who they're making decisions for. Usually, it's the last Saturday in September; October is Down Syndrome Awareness Month, so we kick that off with the Buddy Walk."



Kassie Frohnafel (left), of Proctor, enrolled in West Virginia University's master of occupational therapy program because of the impact occupational therapy has had on the life of her cousin with Down syndrome, Nathaniel Frohnafel, also of Proctor.

## Facts about Down syndrome

Down syndrome, or Trisomy 21, is a naturally occurring chromosomal arrangement affecting approximately 3% of all children born in the United States each year.

Since 2012, March 21 has been designated specifically as World Down Syndrome Day each year because those with the condition possess a 21st (extra) chromosome.

Down syndrome is a genetic disorder often characterized

by distinctive physical features such as a flattened face, short neck, almond-shaped eyes, poor muscle tone and small ears, hands and feet, among others, according to the Centers for Disease Control and Prevention. The CDC also states people with Down syndrome generally have an IQ in the mildly to moderately low range.

Also, according to the Down Syndrome Network of West

Virginia reports, children with Down syndrome face a high rate of congenital heart defects. Approximately half of infants with Down syndrome have some form of heart condition, compared with approximately 1% of other infants.

The condition was named Down syndrome after Dr. John Langdon Down, a British physician who first reported it in 1866 and classified it in 1862.

Walk prizes, she said, and she, Hannah and others took part in a smaller-scale awareness walk from Jefferson Road along Corridor G in South Charleston.

### Roles and goals of occupational therapy

While marking a Sunday in March and the month of October to raise awareness is helpful, Orndorff and others agree that children with Down Syndrome need attention every day of the year.

To fulfill that need, occupational therapy is key.

According to Randy McCombie, Ph.D., of the WVU School of

Medicine's Division of Occupational Therapy in Morgantown, West Virginia has two occupational therapy educational programs: a master of occupational therapy program at WVU (soon to include an occupational therapy doctoral program) and an occupational therapy assistant program that culminates in an associate degree at the University of Charleston-Beckley (soon to launch a master of occupational therapy program on the Charleston campus).

"Because Down syndrome is a lifespan syndrome, occupational

SEE **DAY, 7A**

## Down Syndrome Network of W.Va. offers outreach and resources

By ASHLEY ORNDORFF  
For Daily Mail WV

Based on birth rates nationally, approximately 24 babies are born with Down syndrome in West Virginia each year (the most recent vital statistics from Centers for Disease Control 2017).

The Down Syndrome Network of West Virginia is a 501(c)(3) nonprofit serving the entire state. One of our largest outreach projects is our New Parent Packet, which provides new and expectant families with general information about Down syndrome, resources available such as WV Birth to Three, and a gift for the new baby.

We provide information and resources across the lifespan, including navigating programs available to people with Down syndrome and their families such as CDCSP (a medical card for people with disabilities who are over the income limit) and Title XIX/IDD Waiver (a Medicaid Waiver program for individuals with intellectual and developmental disabilities that, again, waives the income limit).

World Down Syndrome Day is celebrated annually on March 21 (3/21) to signify the three copies of the 21st chromosome. We often show our support on this day by wearing fun, mismatched socks — because chromosomes kind of look like socks, and even though the socks may look different, they both serve a purpose!

We also work with other statewide organizations such as the West Virginia Developmental Disabilities Council to share resources and education opportunities. We affiliate with national Down syndrome organizations, including the National Down Syndrome Congress and National Down Syndrome Society.

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Ashley Orndorff of South Charleston is the executive director of the Down Syndrome Network of West Virginia. She can be contacted at [dsnwvinfo@gmail.com](mailto:dsnwvinfo@gmail.com).

### Charley West says ...



A day to wear mismatched socks on purpose? Count me in for celebrating World Down Syndrome Day!