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SYNDROME FOUNDATION MARCH 2020 A DIGITAL UTAH DOWN

March is the month where we kick off our shoes and show off our bright-colored, mismatched socks, on March 21st--World Down Syndrome Day (WDSD). What is WDSD? In 2012, the United Nations designated March 21st as WDSD to raise public awareness of Down syndrome (Ds). This date was chosen because March (the third month) and the 21st day signifies the triplication (trisomy) of the 21st chromosome that causes Ds. Why socks? Because they look like chromosomes, the various colors represent the diversity that individuals with Ds offer to the world, and the mismatched socks to encourage conversations about Ds that promote advocacy.

While the date on which WDSD falls is meaningful and the socks add color to our regular black and white lives, WDSD is about advocacy. Support for a world where individuals with Down syndrome experience inclusion, respect, and opportunities. Unfortunately, the world's treatment of individuals with Down syndrome has not always been good. There was a time when parents were expected to institutionalize their child with Down syndrome. Such was the case when Layne K Johnson (age 66) from St. George and Amy Lin Monson (age 46) from Provo were born. Fortunately, their parents chose not to institutionalize them. Instead, they were raised at home, experiencing inclusion in their families and their communities. As a result, they lived meaningful lives as Amy learned to sing, was employed, had many friends, and traveled. Layne learned to play the organ, worked for JCPenny for 30 years, and was married for 27 years. A few weeks ago, both Layne and Amy passed away, leaving behind a legacy of hope for individuals with Ds (click on their pictures below to learn more).



Although the world has improved since Layne and Amy were born, there is still much more advocating that we can do to make this world a better place for individuals with Down syndrome. Advocacy is part of the Utah Down Syndrome Foundation's mission, and the following are some of the ways we are carrying out this mission today:

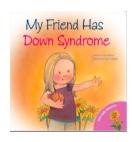
- 1. Working with the Utah Department of Health to publish resources about Ds on their website.
- 2. Collaborating with the University of Utah on a video project that portrays what parents experience when they receive a Ds diagnosis for their child (still in production).
- 3. Supporting Ds healthcare by writing letters for research grants. Currently working with Primary Children's Hospital on a research study about Ds (coming soon).
- 4. Meeting with the Utah Transit Authority to discuss ways to improve transportation for individuals with Down syndrome.
- 5. Providing resources to hospitals and medical professionals about Down syndrome and how to connect new parents to UDSF.

We invite you to join UDSF in its mission of advocacy. This World Down Syndrome Day day you can help advocate for Down syndrome by doing the following:



Wear Your WDSD Socks

Start a conversation about Ds with your friends and co-workers because of your bright, mismatched socks. Don't have WDSD socks? Donate to UDSF and we will send you a free pair. Your donation supports Ds programs and is tax-deductible.



Use a Peer Presentation Tool Kit

Teach others about the importance of inclusion and Down syndrome using a Peer Presensentation Tool Kit.



Enter the Mighty Steps T-shirt Contest UDSF is hosting a T-shirt design contest for its 2020 Mighty Steps

for Down Syndrome Walk. This contest is to inspire individuals with Down syndrome to share their creative and artistic talents with our community. The winner of this contest will be announced

on March 21, 2020--World Down Syndrome Day! The first 20 entries will receive a \$10 Amazon gift card, and the winner will receive a \$50 Amazon gift card plus free Mighty Steps Registrations for up to five immediate family members.



Sign up for Kindergarten Kickoff

Learn how to advocate for your child in the classroom. (New workshops starting in Fall 2020).



Celebrate WDSD with UDSF

Join UDSF on March 21st for celebration events in Cache County, Davis County, Salt Lake County, & St. George.

Share this WDSD Video

UDSF asked members of its community, "How do individuals with Down syndrome make the world a better place?" This is what they said...



Over the years, the advocacy work done by individuals, parents, and Down syndrome associations has been successful and is why the United Nations signed the WDSD resolution. However, its individuals like Layne and Amy, whose lives are the real advocates for others with Down syndrome and make this world a better place!



This month's "Love.Lift.Launch." highlight features Heather Roman, Utah County's Community Group Leader.

Growing up, Heather lived all over the world from Japan to Iceland, and then Spain where she graduated from high school. Her family eventually ended up in Arizona where Heather graduated from Arizona State University.

Heather currently lives in Utah County with her husband and her children.



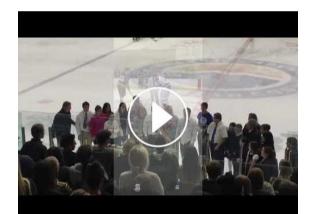
Heather has worked as a reading recovery teacher for first graders in the Alpine School District for over 18 years.

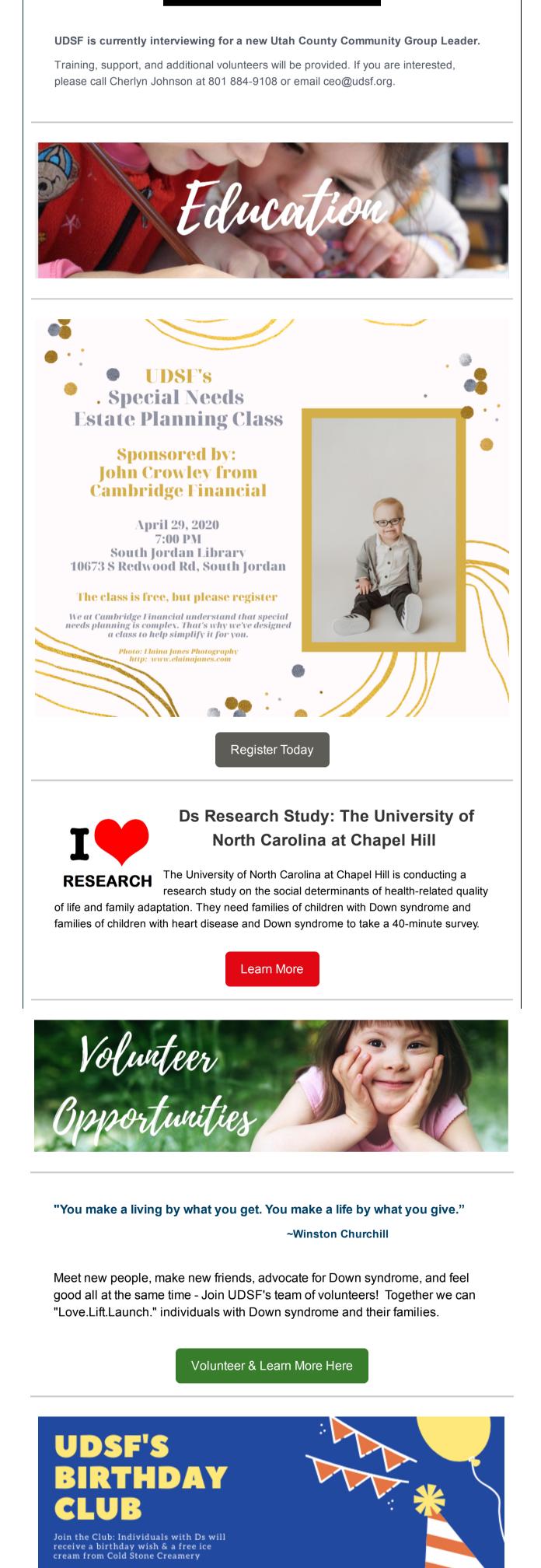
Twelve years ago, Heather received a new parent care package and a personal visit from UDSF parents when her youngest of five, Leora was born with Down syndrome. This experience created a connection with Heather and the rest of the UDSF community, which she found invaluable as she was raising her daughter. Soon Heather found herself giving back to the UDSF community as she became UDSF's Community Group Leader in Utah County. As the group leader for the past five years, Heather has planned a myriad of animal shows, movies, and holiday parties, all with the purpose of helping other families of children with Down syndrome connect with one another.

Heather's ability to connect UDSF families will be greatly missed as she is stepping down as the community group leader. There are no words that can adequately express our profound gratitude for the many years of selfless service that Heather has given to UDSF families.

When asked what advice she would give to new parents of a child with Down syndrome Heather stated, "It's important to connect with other families, a lot of times you are experiencing the same things. Also, don't forget to enjoy the ride, because it is a ride!"

The following video is from one of Heather's last Utah County activities, which she planned with the purpose of helping individuals with Down syndrome experience the joys of music and to feel important.

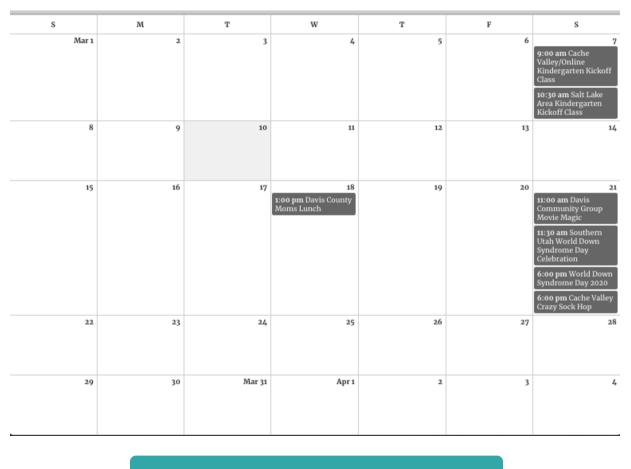




Join the Club







TO VIEW CALENDAR DETAILS CLICK HERE

CORONAVIRUS

Coronavirus

UDSF is monitoring the news and developments surrounding the Coronavirus. The foundation has determined for the time being to continue as usual with scheduled community activities. UDSF views the health and safety of our community members as paramount. As a result, we

will continually assess the situation and adapt and modify our activities as necessary. If UDSF cancels an event, registration fees will be refunded. For any questions, please contact us at info@udsf.org.



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