

The LowDown

A DIGITAL NEWSLETTER FROM THE
UTAH DOWN SYNDROME FOUNDATION
January 2020

Ring Out the Old, Ring in the New

As we say goodbye to the year 2019, the poem, "Ring Out, Wild Bells" by Alfred, Lord Tennyson comes to mind.

*"Ring out, wild bells, to the wild sky,
The flying cloud, the frosty light:
The year is dying in the night;
Ring out, wild bells, and let him die.*

*Ring out the old, ring in the new,
Ring, happy bells, across the snow:
The year is going, let him go;
Ring out the false, ring in the true."*

While this poem eloquently says goodbye to the old year, it happily rings in a new one. Often times, ringing in a new year is filled with feelings of anticipation, hope, and a sense of optimism. A new year can also bring the traditional setting of New Year's resolutions.

In 2019, UDSF kept this tradition by setting the following New Year's resolutions:

UDSF's 2019 New Year's Resolutions

Resolution (1): Create a state walk committee to help unify UDSF - Accomplished in February 2019.

Resolution (2): Train community group leaders - Accomplished on January 26, 2019.

Resolution (3): Launch the new UDSF website - Accomplished on September 1, 2019.

Resolution (4): Design and implement a new education program for parents called Kindergarten Kickoff - Accomplished on October 28, 2019.

Resolution (5): Increase Ds Awareness by doubling the number of Peer Presentation Tool Kits distributed - Accomplished, tripled the number of tool kits in 2019.

Although UDSF is grateful to have had a successful 2019, UDSF is excited about "ringing out the old and ringing in the new." UDSF looks forward to a new year that is filled with more hope, more support, more education, more activities, more outreach, and more advocacy for individuals with Down syndrome, their families, and our community.

UDSF's New Year's resolutions for 2020 are as follows:

UDSF's 2020 New Year's Resolutions

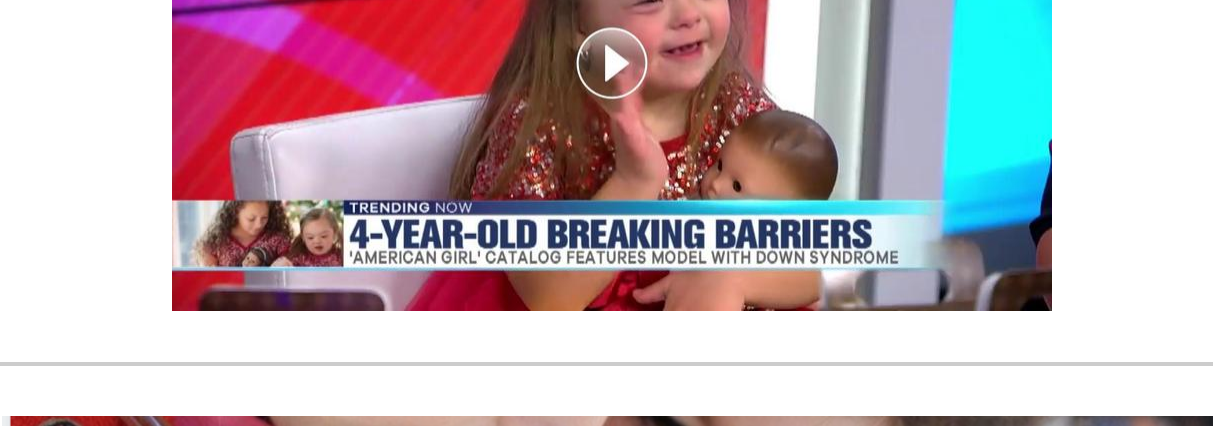
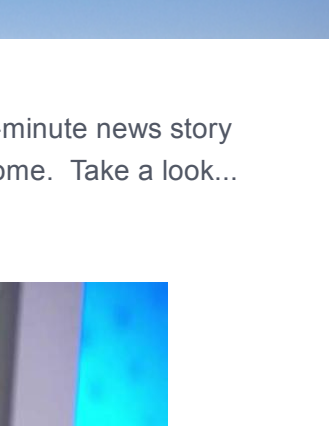
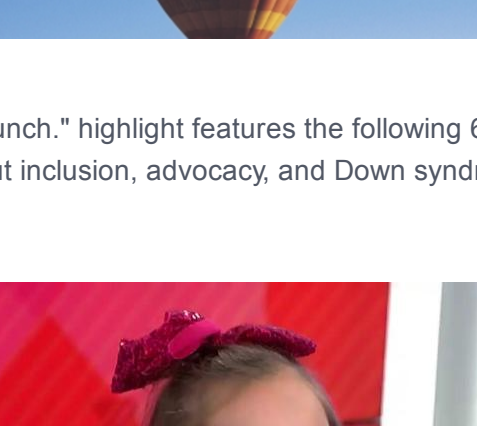
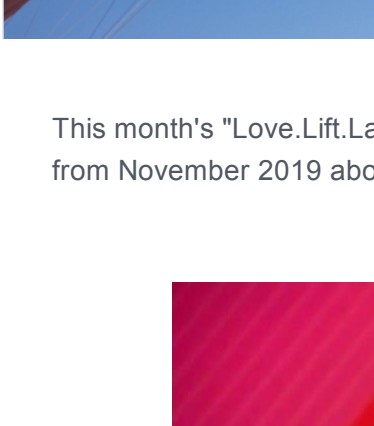
Resolution (1): Establish transparency by publishing UDSF's first annual report.

Resolution (2): Increase outreach by creating a new Weber County Community Group.

Resolution (3): Improve New Parent & Adult Programs.

Resolution (4): Promote community awareness of Ds.

The Utah Down Syndrome Foundation is optimistic about accomplishing these new goals, with your help. As Henry Ford once said, "Coming together is a beginning. Keeping together is progress. Working together is a success." Cheers to a successful New Year with UDSF!



This month's "Love.Lift.Launch." highlight features the following 6-minute news story from November 2019 about inclusion, advocacy, and Down syndrome. Take a look...



Come Share Your Voice!

The Utah Developmental Disabilities Council is hosting meetings across the state to hear what YOU think our community needs. The Council is seeking input as they develop their new state plan that guides advocacy work for the next five years.

These meetings will be held at the following locations:

Salt Lake City—January 9, 2020
SLC Independent Living Center, 4pm

St. George—March 5, 2020
Red Rock Center for Independence, 4pm

Salt Lake City—January 23, 2020
Asian Association Building, 6pm

Logan—April 9, 2020
Options for Independence, 6pm

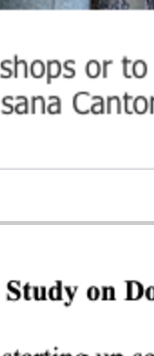
Provo—February 6, 2020
Ability First, 6pm

Price—April 16, 2020
Utah State University Eastern Alumni Room, 6pm

Ogden—February 20, 2020
Roads to Independence, 6pm

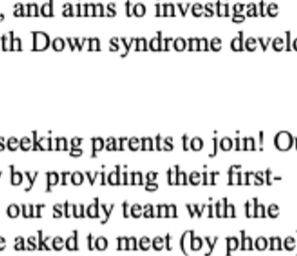
If you are unable to attend, but still wish to share your comments with the Council, please complete the online survey using the link below, or call Council offices to request a paper copy that can be mailed to you.

<https://forms.gle/KWoVKnXYLskhiBBf7>



For more information or to request accommodations and alternative formats, please contact:

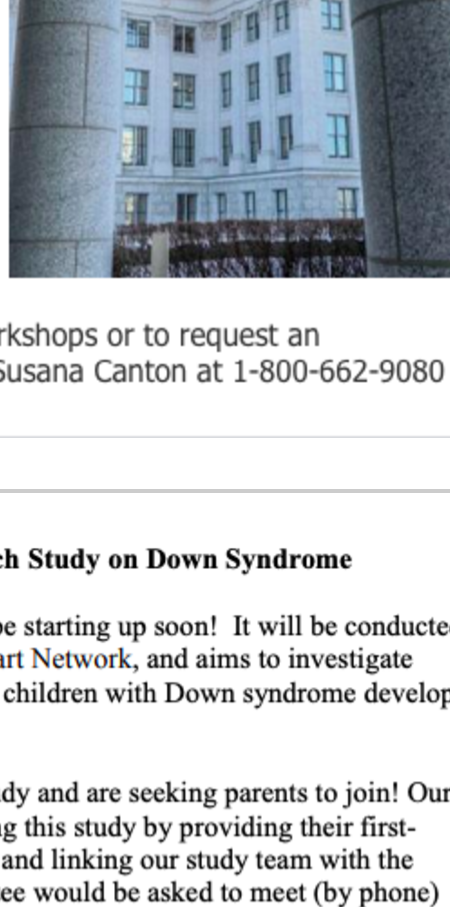
The Utah Developmental Disabilities Council
uddc@utah.gov 801.245.7350 utahddcouncil.org



Utah Disability Advocacy Day

Disability Advocacy Day is an opportunity to highlight the issues and concerns facing people with disabilities in Utah. Disability Advocacy Day includes workshops, speakers, informational exhibits, and networking opportunities with legislators and other advocates. This event will provide opportunities for self-advocates and families to learn about the legislative process, and will give them opportunities to make their voices heard by legislators about policy and budget issues that affect their services and supports.

Date: January 30th
Cost: Free, but limited seating
Self Advocate Training: 9:30 am-11:30 am
Utah State Capital,
East Senate Bldg. Copper room;
12:45-3:30 pm see agenda [here](#)



To register for the free legislative advocacy workshops or to request an accommodation to participate, please contact Susana Canton at 1-800-662-9080 or scanton@disabilitylawcenter.org

Parent Advisory Committee for New Research Study on Down Syndrome

A new study funded by the NIH INCLUDE Project will be starting up soon! It will be conducted as part of the National Institutes of Health's Pediatric Heart Network, and aims to investigate whether having heart surgery as an infant affects the way children with Down syndrome develop and learn.

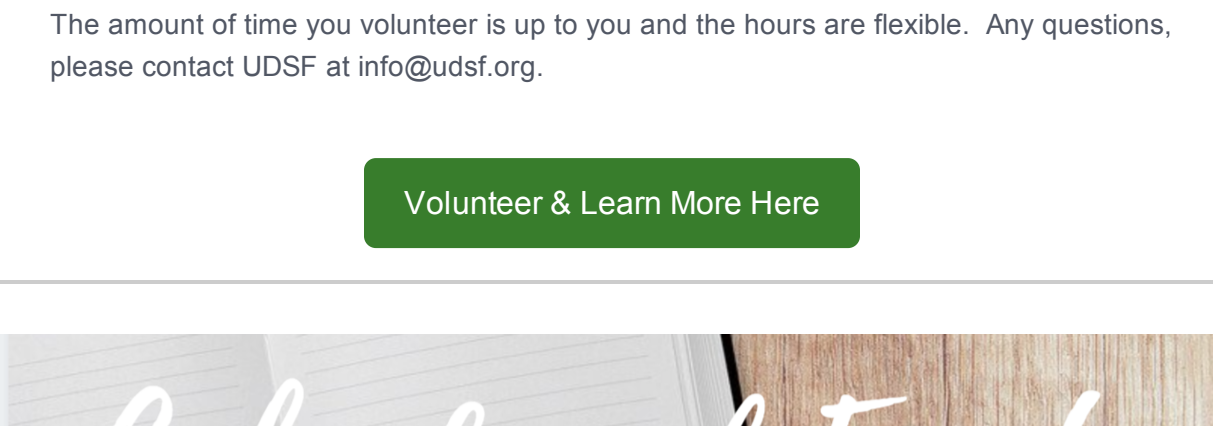
We are creating a Parent Advisory Committee for this study and are seeking parents to join! Our hope is that family members will be partners in conducting this study by providing their first-hand insight and by serving as ambassadors for the study and linking our study team with the community. Individuals on our Parent Advisory Committee would be asked to meet (by phone) and complete online surveys to help us complete the following activities throughout the project:

- Provide input and feedback on study and recruitment materials.
- Review outlines, concepts and interactive approaches while the study is being conducted.
- Provide insight and teaching to study teams regarding strategies for working with individuals with Down syndrome and their parents.
- Review issues, address concerns and answer questions referred to the Parent Advisory Committee by the study team.
- Advise on dissemination strategies for the study.

If you are interested, we ask for a brief letter that states your background/experience, and your interest in being part of the advisory committee. No previous experience is needed.

Please let us know if you have any questions! We are excited to get this group together.

Angela Lombardo, Committee Chair
Nicole Baumer, Co-Principal Investigator
857-218-4329 angela.lombardo@childrens.harvard.edu



“Volunteers do not necessarily have the time; they just have the heart.” ~Elizabeth Andrew

Meet new people, make new friends, advocate for Down syndrome, and feel good all at the same time - come join UDSF's team of volunteers! Together we can "Love.Lift.Launch" individuals with Down syndrome and their families.

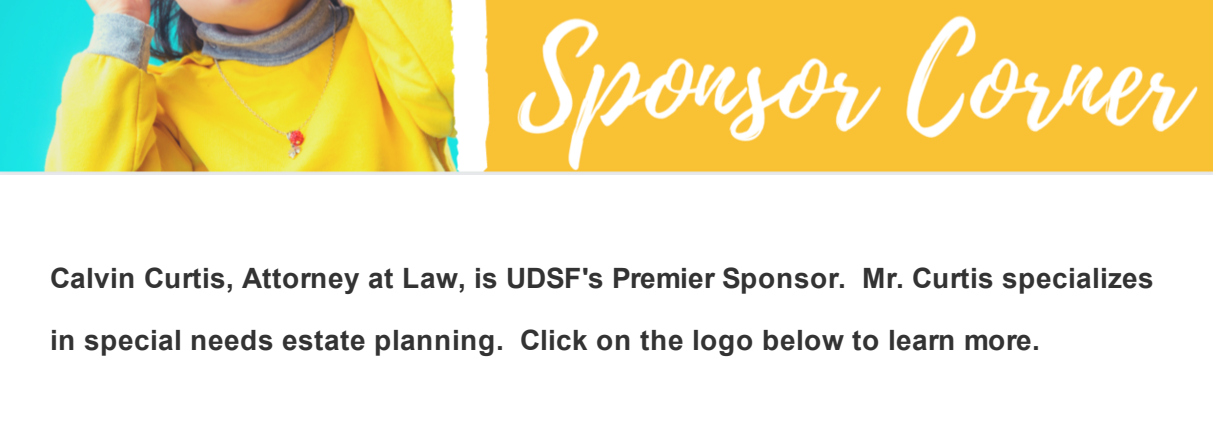
UDSF Volunteer Opportunities to be Filled by February 1st

(no experience necessary just a willing heart--training provided)

- Volunteer Coordinator for the foundation.
- Salt Lake activities committee members.
- Mighty Steps for Down Syndrome Walk committee members.
- Utah County activities committee members.
- Utah County, program for adults (18+ with Ds) committee chair & members.
- Wasatch activities committee members.

The amount of time you volunteer is up to you and the hours are flexible. Any questions, please contact UDSF at info@udsf.org.

[Volunteer & Learn More Here](#)



Happy New Year UDSF!

UDSF has a new website (udsf.org) where you can access the calendar for all community events across the state. Simply click on the "Upcoming Events" tab on the home page. Event registration is also available via the calendar by clicking on the date of the event. No more searching through emails or waiting for the LowDown newsletter to see what's going on at UDSF!

Here's a sneak peek at what's happening in January 2020...

- Start the New Year off with a splash at the SLC/Tooole community group indoor swim celebration, this Saturday, January 11th.
- Adults with Down syndrome 18+, karaoke the night away on January 17th.
- Join our Kindergarten Kickoff classes in Salt Lake and online on January 25th & 27th.
- Mothers, don't miss out on this month's luncheon in Davis County!

Please click on the calendar link below to view event details.

[UDSF Calendar](#)

Calvin Curtis, Attorney at Law, is UDSF's Premier Sponsor. Mr. Curtis specializes in special needs estate planning. Click on the logo below to learn more.

