

TVDSA NEWSLETTER



TREASURE VALLEY
DOWN SYNDROME ASSOCIATION

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Our Mission

To enhance the quality of life for persons with Down syndrome by promoting inclusive environments as well as advocating respect, dignity, and appropriate supports for people with Down syndrome to ensure that the world sees them as we do — Equal.

Our Vision

A world where full inclusion is a reality rather than a goal.



A Message from the Board

Hello all,

The TVDSA Board and team leads hope you are yours are doing well during this difficult time. I am sure everyone is aware of the COVID-19 pandemic sweeping the nation and have, to one degree or another, been affected by it. In the spirit of complete transparency, TVDSA has no medical experts, so we are following the state and federal guidance and using an abundance of caution in all our decision making. Our number one priority is the safety of our entire TVDSA family.

After some discussion and consideration, the Board has decided to cancel/postpone all TVDSA sponsored events effective immediately until further notice.

You have most likely been notified by the respective leaders of the groups you participate with that specific events have been canceled. We are aware that many of our groups are small and may be under the guidance of no more than 10 people gathering together; however, given the makeup of our members and the possibility we are all potential infection vectors to high-risk individuals, we feel it is important to err on the side of caution and cancel all functions. Also in light of the recent State of Idaho Stay at Home order, this reinforces that decision. One of the pros in our case is that as an all-volunteer organization, we are already physically distanced during our normal business operations.

We are also taking the following actions. Until further notice:

- All TVDSA Board meetings will be held via video/phone conference.
- All TVDSA Library requests will be suspended.
- All New Parent Basket distribution will be suspended.

We encourage you to stay in touch with your respective groups via social media and be assured that TVDSA is not going anywhere. We are hopeful that by staying connected via social media, we can help maintain some normalcy for those who attended our events regularly.

For now, TVDSA has the following planned:

- Idaho Gives is May 7 and still in the works. By its nature, it is mostly virtual, but we have participated in onsite events as well. At this point we will not attend onsite events unless the current guidance changes by May.
- The annual picnic is currently set for June 17. Even though that is a way off, it is possible for some restrictions to stay until then. We will look at options for that event and will let everyone know as soon as we know.
- We have a few other things in the works beyond July (August Golf Tournament/October celebration) and planning will continue on those but may change later.

Continued on page 2.

Q&A on COVID-19 & Down Syndrome:

A Collaboration of the NDSC and National Organizations

The unprecedented spread of COVID-19 presents the world with a unique challenge and calls for a united response to better understand its impact on the Down syndrome community. NDSC is proud to collaborate with Down Syndrome Medical Interest Group-USA (DSMIG), Global Down Syndrome Foundation (Global), LuMind IDSC, National Down Syndrome Society (NDSS), National Task Group on Intellectual Disabilities and Dementia Practices (NTG), and Down syndrome medical experts to publish a new resource, the Q&A on COVID-19 and Down Syndrome.

This new resource, with both **abbreviated (6 pg.)** and **expanded (21 pg.)** versions, which was developed and reviewed by numerous clinicians, family members of individuals with Down syndrome, and the above contributing organizations, includes answers to questions such as the following:

- What may be unique about the virus in people with Down syndrome
- How to help prevent the spread of the virus
- What are some common symptoms
- What to think about when making decisions

Among many other topics, the Q&A addresses the Centers for Disease Control and Prevention (CDC) and the National Institutes of Health (NIH) definition of people at “high risk”; those with certain underlying medical conditions who are more likely to become severely ill and need hospitalization when infected with COVID-19.

Individuals with Down syndrome are among this “high risk” group, as they are much more likely to have one or more of these underlying

medical conditions compared to those without Down syndrome. However, to be clear, some people with Down syndrome will not have any of these underlying medical conditions. These underlying medical conditions include lung disease and respiratory difficulties (e.g., asthma, sleep apnea), ongoing heart disease or heart failure, obesity, diabetes, or having a lower immune function (e.g., people undergoing cancer treatment or taking drugs for rheumatoid arthritis or lupus that lower immune function).

While there are still many unknowns, we hope you find this Q&A a useful resource. The Q&A organizers are committed to updating this important resource in the following weeks as more information becomes available about COVID-19, regulations related to the disease, and how this affects people with Down syndrome. The Q&A is informational only and not intended to provide medical or related advice. This Q&A should NOT be considered a substitute for the advice of medical or other professionals. Consult with your doctor or other healthcare professional(s) for medical advice.

We are thankful for the additional support of the following national and international organizations: Down Syndrome Affiliates in Action, Gigi’s Playhouse, International Mosaic Down Syndrome Association, Jerome Lejeune Foundation, and T21RS.

Although our staff is working remotely, we are still here for you and your family. We are available at ndsc@ndscenter.org or 770-604-9500. For additional information and practical resources to assist you with the adjustment to online learning, links to support services resources, NDSC policy and advocacy updates, and ideas for family fun activities visit the **NDSC COVID-19 Resource Library**.

A Message from the Board

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Regarding other third-party events that have been mentioned in previous newsletters and discussions: While we have heard about several changes to these events, we will not be communicating any updates through our newsletter or website. We want to ensure you are getting 100% accurate and up-to-date information, so we encourage you to contact or refer to the websites of the organizations that were/are holding those events. As with most people, these events may be fluid and can change rapidly.

One final note, we will work on alternatives to events and along with that, our fundraising efforts. Please consider redirecting the funds you might normally give during some of our group events to the Idaho Gives event. There will be more on this later, but Idaho Gives presents unique opportunities to multiply the impact of your donations to TVDSA.

All of us here Thank You for your extraordinary support of TVDSA.

Stay Positive, Stay Clean, Stay Safe.

George Taylor

TVDSA President

If there are any questions or concerns, please don’t hesitate to contact the Board at board@idahodownsyndrome.org.

Join TVDSA Today!

If you are not currently a member or you would like to renew your membership, you can do so **online with the TVDSA Membership Form**. You can contact us at membership@idahodownsyndrome.org to verify your membership status.

Resources to Keep Your Family Busy

Feeling stuck inside? Here are resources for you and your family to keep busy, keep learning, and stay entertained while we all do our part to slow the spread of the virus.

- **Ultimate Guide to Virtual Museums Resources**
- **Indoor Activities for Kids**
- **30 Great Educational Netflix Shows**
- The SAG-AFTRA Foundation's children's literacy website, **Storyline Online**, (streams videos featuring celebrated actors reading children's books).
- Get outside! Take a walk with your family, just remember to stay 6 feet away from others.
- Call family and friends to check in. Hearing a loved one's voice or seeing their face can relieve anxiety.

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Talking with children about COVID-19

CDC.gov

Español

A medida que van aumentando las conversaciones públicas acerca de la enfermedad del coronavirus 2019, los niños podrían sentirse preocupados de que ellos, sus familias y sus amigos se puedan enfermar con el COVID-29. Los padres, los familiares, el personal escolar y otros adultos de su confianza pueden cumplir un papel importante en ayudar a los niños a entender lo que oyen de una manera que sea veraz, precisa y reduzca al mínimo su ansiedad o temor. Los CDC han creado directrices para ayudar a los adultos a tener conversaciones con los niños acerca del COVID-19 y las formas en que pueden evitar contraer y propagar la enfermedad.

Permanezca calmado y tranquilícelos.

Recuerde que los niños reaccionarán tanto a lo que diga como a la forma en que lo diga. Ellos captarán el tono de las conversaciones que tenga con ellos y con otras personas.

Esté disponible para escucharlos y hablar con ellos.

Saque tiempo para hablar. Asegúrese de que los niños sepan que pueden recurrir a usted cuando tengan preguntas.

Evite expresarse de una manera que pueda culpar a otros y llevar al estigma.

Recuerde que los virus pueden enfermar a cualquier persona, independientemente de su raza o grupo étnico. Evite las suposiciones sobre quién podría tener el COVID-19.

Lea el artículo completo en CDC.gov.

English

As public conversations around coronavirus disease 2019 (COVID-19) increase, children may worry about themselves, their family and friends getting ill with COVID-19. Parents, family members, school staff, and other trusted adults can play an important role in helping children make sense of what they hear in a way that is honest, accurate, and minimizes anxiety or fear. CDC has created guidance to help adults have conversations with children about COVID-19 and ways they can avoid getting and spreading the disease.

Remain calm and reassuring.

Remember that children will react to both what you say and how you say it. They will pick up cues from the conversations you have with them and with others.

Make yourself available to listen and to talk.

Make time to talk. Be sure children know they can come to you when they have questions.

Avoid language that might blame others and lead to stigma.

Remember that viruses can make anyone sick, regardless of a person's race or ethnicity. Avoid making assumptions about who might have COVID-19.

Pay attention to what children see or hear on television, radio, or online.

Consider reducing the amount of screen time focused on COVID-19. Too much information on one topic can lead to anxiety.

Read the full article at CDC.gov