



**GLOBAL**  
DOWN SYNDROME FOUNDATION®

## GLOBAL Research & Medical Care Roundtable

Our Response to COVID-19 and the  
“COVID 19 & Down Syndrome Q&A” Collaborative

Michelle Sie Whitten, President & CEO

*NDSC Annual Convention From Your Couch - Thursday, June 25, 2020*

# A Quick Overview

- ❖ Welcome GLOBAL Research & Medical Care Roundtable Attendees
- ❖ THANK YOU NDSC, DeOndra Dixon, Karen Gaffney, Frank Stephens & Other Esteemed Speakers
- ❖ Inspiration & Catalyst to start GLOBAL
- ❖ GLOBAL's COVID-19 Work
- ❖ An Important Community Resource: COVID-19 and Down Syndrome Q&A
  - Who is “High Risk” and what does that mean?
  - Are people with DS High Risk?
  - Examples of specific questions the Q&A answers
  - A Consortium of National Organizations
  - Q&A Updates - timing in July



# The Inspiration behind GLOBAL



“Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it's the only thing that ever has.” -Margaret Mead

# The Catalyst to start GLOBAL

*People with DS have a Radically Different Disease Spectrum*

Cancer

Heart disease

Coronary Artery Disease  
Atherosclerosis  
Hypertension  
Angiopathies



Alzheimer's

Autoimmunity

Autism  
Epilepsy, Infantile Spasms  
Congenital Heart  
Defects  
Autoimmune Disorders:  
Celiac, Hashimoto's, T1D,  
Vitiligo, Alopecia Areata, etc  
Vision Problems  
Hearing Problems  
Intestinal Atresia  
Sleep Apnea

**The >350,000 Americans with trisomy 21 may hold the key  
to major medical conditions**

# The Catalyst to start GLOBAL

*A life-threatening disparity*

Year	NIH Budget (Millions)	CF Research Funding	Fragile X Research Funding	Autism Research Funding	Ds Research Funding	Ds Research Funding to NIH Budget
2000	↑ 17,840				27	0.0015
2001	20,459				29	0.0014
2002	23,321				28	0.0012
2003	27,166				23	0.0008
2004	28,037				19	0.0007
2005	28,594				15	0.0005
2006	28,560				14	0.0005
2007	29,178				16	0.0006
2008	29,607				17	0.0006
2009	30,545				18	0.0006
2010	31,238				22	↓ 0.0007
2011	30,916				20	0.0006
2012	30,860	86	27	192	20	0.0006
2013	29,129	78	30	186	18	0.0006
2014	30,019	77	36	186	18	0.0006
2015	30,293	80	38	208	24	0.0008
2016	30,293	83	40	216	25	0.0008
2017 Est	30,293	83	40	216	25	0.0008

# Global Down Syndrome Foundation

## *A Unique Affiliate Model*



The Global Down Syndrome Foundation is the largest non-profit in the U.S. working to save lives and dramatically improve health outcomes for people with Down syndrome. GLOBAL has donated more than \$32 million to establish the first Down syndrome research institute supporting over 400 scientists and over 2,000 patients with Down syndrome from 28 states and 10 countries.

Working closely with Congress and the National Institutes of Health, GLOBAL is the lead advocacy organization in the U.S. for Down syndrome research and care.

GLOBAL has a membership of over 100 Down syndrome organizations worldwide and is part of a network of Affiliates - the Crnic Institute for Down Syndrome, the Sie Center for Down Syndrome, and the University of Colorado Alzheimer's and Cognition Center - all on the Anschutz Medical Campus.

# GLOBAL's COVID-19 RELATED WORK In Just 9 WEEKS



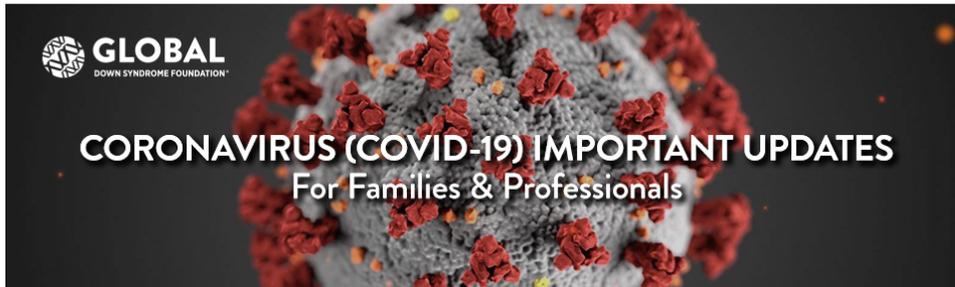
**"Impossible is just an opinion."**

~ Paulo Coelho

# GLOBAL's COVID-19 RELATED WORK

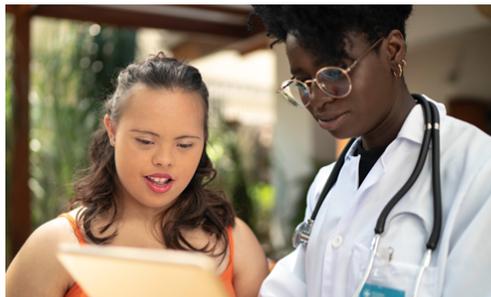
*GLOBAL's Website Provides Up to Date Info*

## Everything You Need to Know About COVID-19 & Down Syndrome



Most people with Down syndrome are at "high risk" for COVID-19 because they have certain underlying medical conditions such as sleep apnea. GLOBAL has created or supports these important resources to help answer your questions.

### SUPPORT GLOBAL'S COVID-19 WORK



[Trending COVID-19 News Stories:](#)

#### IMPORTANT Down Syndrome and COVID-19 Q&A



#### Down Syndrome and COVID-19 Q&A: (Updated 4/29)

- [English Expanded](#)
- [English Abbreviated](#)
- [Spanish Expanded](#)
- [Spanish Abbreviated](#)
- [Albanian Expanded](#)

## OTHER IMPORTANT RESOURCES

[Important Statistics & Updates:](#)



#### [Coronavirus by the Numbers](#)

*Updated by the Hour* - Stay up to date on the world's reported coronavirus cases and statistics by country



#### [The Latest updates from the Centers for Disease Control \(CDC\)](#)

*Updated Daily* - Stay up to date on the latest information regarding symptoms, preparation, protecting yourself, and more



#### [Recommendations for High Risk Individuals](#)

3/20/2020 - What the Centers for Disease Control and Prevention (CDC) recommends for sickness prevention

### [Trending COVID-19 News Stories:](#)

[Rationing Plans in Coronavirus Crisis Draw Growing Discrimination Complaints](#)  
6/10/2020



[Intellectual Disability Raises COVID-19 Death Risk](#)  
6/8/2020



[Feds Pump Millions Into Disability Housing As Part Of Coronavirus Relief](#)  
6/9/2020



[Coronavirus: 'Our son with Down's syndrome is thriving in lockdown'](#)  
6/3/2020



[See More](#)

WILL PEOPLE WITH DOWN SYNDROME BE DENIED COVID-19 MEDICAL CARE?  
Colorado is a role model in fighting Medical Care Rationing Discrimination



LINKS TO OTHER IMPORTANT RESOURCES

COVID-19 EMERGENCY RELIEF GRANTS APPLICATIONS CLOSED



FIGHTING DISCRIMINATION: Medical Care Rationing



# GLOBAL's COVID-19 RELATED WORK

*People with DS are High Risk AND Vulnerable*

**GLOBAL led 140 orgs to support our CO Governor in protecting people with disabilities during crisis triage of care**



NDSC Annual Convention - Thursday 6/25/2020



**Press Contacts**

GLOBAL: Anca Call  
[acall@globaldownsyndrome.org](mailto:acall@globaldownsyndrome.org)  
 (720) 320-3832

CCDC: Julie Reiskin  
[jreiskin@ccdconline.org](mailto:jreiskin@ccdconline.org)  
 (303) 667-4216

The Arc of Colorado: Christiano Sosa  
[csosa@thearcofco.org](mailto:csosa@thearcofco.org)  
 (970) 219-5925

**IN THE FACE OF ETHICAL ABERRATIONS IN SEVERAL STATES  
 COLORADO STANDS STRONG AGAINST DISCRIMINATION IN COVID-19 CARE**

*140 Organizations Help Ensure People with Disabilities Will Receive Equitable Treatment under Colorado's Newly Published "Critical Care Triage Guidance for Crisis Standards of Care"*

DENVER, April 9, 2020 - The Governor's Expert Emergency Epidemic Response Committee developed Crisis Standards of Care (CSC) after collaboration with experts and communities. Governor Polis has authorized the Colorado Department of Public Health and Environment to enact the standards when or if necessary.

The [Colorado Cross Disability Coalition](#) (CCDC), [The Arc of Colorado](#), and [over 140 organizations](#) thank Gov. Jared Polis for ensuring that people with disabilities and other vulnerable populations receive equitable care under the CSC during the COVID-19 epidemic and other crisis situations.

Specifically, the revised CSC Plan provides standards that hospitals and other health care practitioners should implement once activated by the Chief Medical Officer for the Colorado Department of Public Health and Environment (CDPHE): (1) disallow medical "rationing" based on



# GLOBAL's COVID-19 RELATED WORK

## *PPE for Group & Host Homes in Colorado*

### **Group Homes in NYC with people with Intellectual & Developmental Disabilities are ravaged by COVID-19.**

<https://www.nytimes.com/2020/04/08/nyregion/coronavirus-disabilities-group-homes.html>

- ❖ Only 2,500 masks have been provided by the state of CO so far
- ❖ Global and Key Donors are working with the CO Government
  - 20,000 disposable masks
  - 6,000 washable cotton masks
  - 3,100 disposable gloves
  - 1,500 disposable gowns
  - 250 KN95 masks
- ❖ Working with vendors in China and the US



# GLOBAL's COVID-19 RELATED WORK

## *Emergency Relief Global Grants to Members*



- ❖ **COVID-19 Emergency Family Relief Global Grants** - Global Organizational Members of any size can apply for these grants up to \$1,000 per family. We will review eligible Family Relief grant applications and provide them on a first-come-first-serve-basis until we run out of such funds.
- ❖ **COVID-19 Emergency Organizational Relief Global Grants** - Only Global Organizational Members with annual revenue under \$250,000 can apply for this general operating grant up to \$5,000.



# GLOBAL/CRNIC Institute Leading JAK inhibition in COVID-19 on the AMC



• HOME / • INVESTORS / • LILLY BEGINS CLINICAL TESTING OF THERAPIES FOR COVID-19

## Lilly Begins Clinical Testing of Therapies for COVID-19

04/10/2020

- Baricitinib Research Commences in NIH-led Adaptive COVID-19 Treatment Trial

 [Download PDF](#)

Several clinical trials, including NIAID's ACTT, are now testing JAK inhibition in COVID-19

# GLOBAL/CRNIC Institute Galvanizing the International Consortium for JAK Inhibition in COVID-19



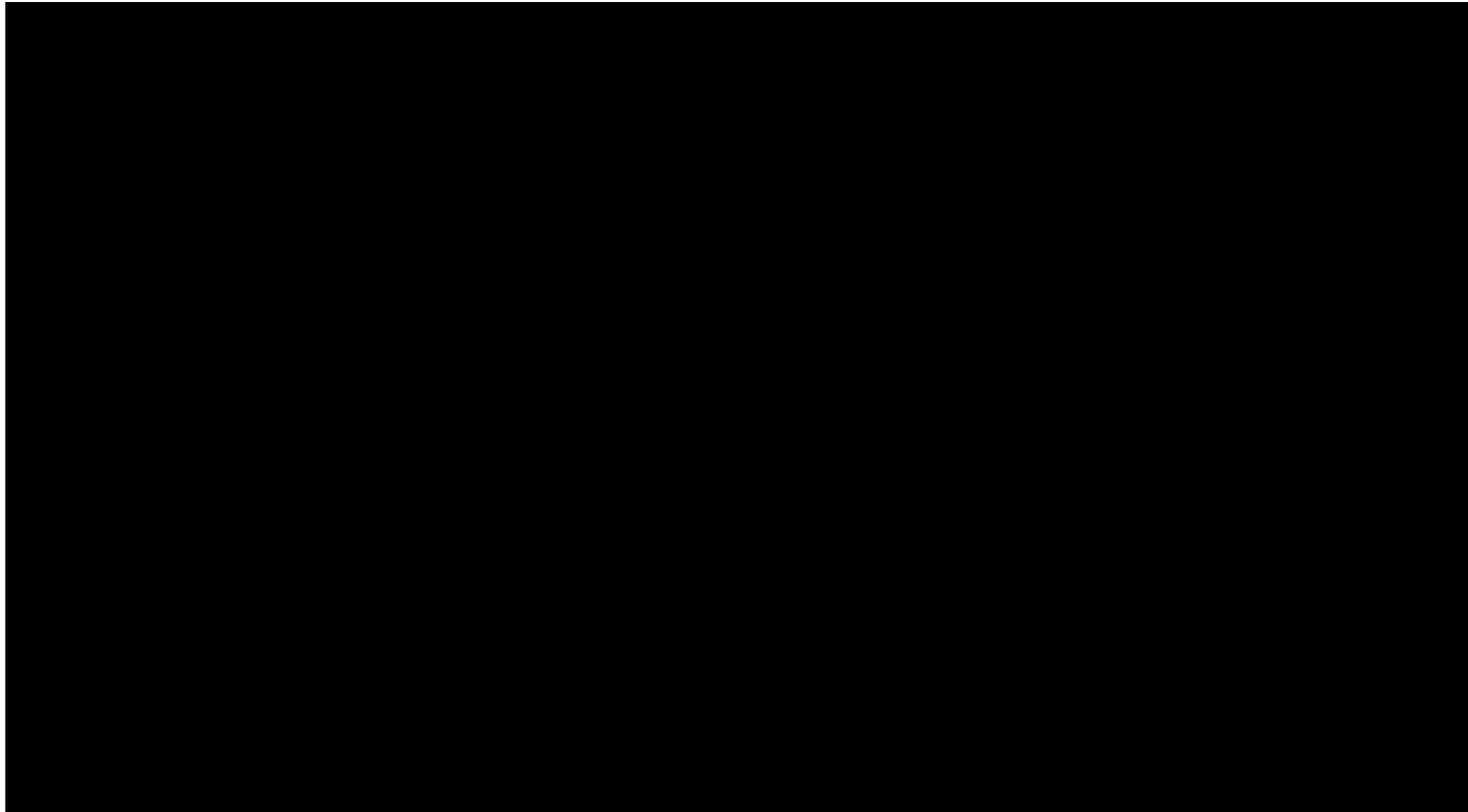
International Consortium for JAK Inhibition in COVID-19

Home Who We Are Clinical Trials Publications News Contact Us

The banner features a navigation menu at the top right and a background image of a hand holding a globe.

# The Changing Rules Around COVID-19

*A Funny Video...*



<https://www.youtube.com/watch?v=wVs5AyjzWRM>

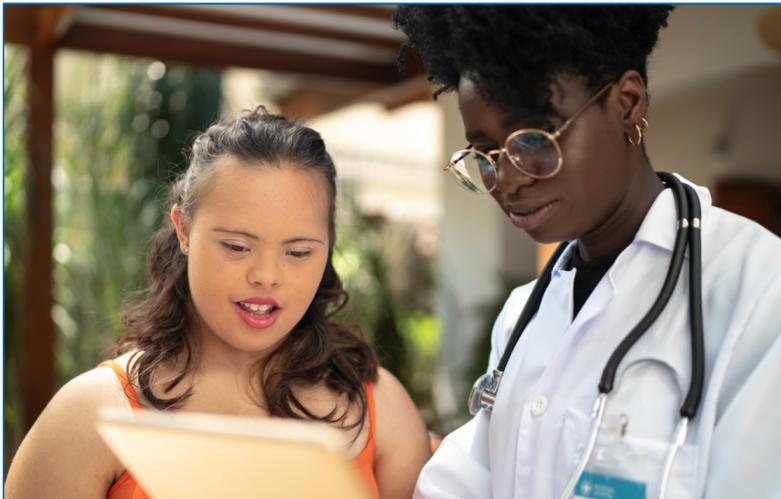
# GLOBAL's COVID-19 RELATED WORK

*People with DS are High Risk AND Vulnerable*

## GLOBAL is helping spearhead the consortium & is a lead author

NATIONAL DOWN SYNDROME ORGANIZATIONS COMBINE EFFORTS TO PUBLISH Q&A ON COVID-19 AND DOWN SYNDROME

*An Important Resource for Families During Unprecedented and Uncertain Times*



**DMIG-USA**  
Down Syndrome Medical Interest Group-USA

**GLOBAL**  
DOWN SYNDROME FOUNDATION\*

**Lumind**  
idsc

**NATIONAL DOWN SYNDROME CONGRESS**

**ndss**  
national down syndrome society

**ontg**  
National Task Group on Intellectual Disabilities and Dementia Practices



### Q&A on COVID-19 and Down Syndrome

Expanded Version • From March 26, 2020

#### ORGANIZERS:

**DMIG-USA**  
Down Syndrome Medical Interest Group-USA

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DOWN SYNDROME FOUNDATION\*

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**NATIONAL DOWN SYNDROME CONGRESS**

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**ontg**  
National Task Group on Intellectual Disabilities and Dementia Practices

#### SUPPORTING ORGANIZATIONS:

Down Syndrome Affiliates in Action, GiGi's Playhouse, International Mosaic Down Syndrome Association, Jerome Lejeune Foundation, T21 Research Society

The unprecedented spread of the Coronavirus Disease 2019 (COVID-19) is presenting the world with a unique challenge and, in our case, calls for a united response to better understand its impact on the Down syndrome community.

Information in this Question and Answer (Q&A) document can be used to help you support your loved one with Down syndrome. It is our hope that this information will help us get through this health challenge. We encourage you to share the information in this document with your family, friends, educational and medical providers, and others within the Down syndrome community.

We have done our best to answer questions that are currently being asked and anticipate other important questions relevant to our Down syndrome community. In this document you'll find information about:

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

This Expanded Version and an Abbreviated Version of this Q&A are available. Many organizations and professionals have contributed to both versions by providing their expertise on Down syndrome and applying it to what we know about COVID-19 at this time. As we learn more about COVID-19 in general, and about how it may or may not affect people with Down syndrome, we will continue to update this Q&A.

To be clear, this Q&A is informational only and not intended to provide medical advice or related advice. It is intended to provide information that we hope is useful as you confront decisions and consider seeking medical, educational, or other recommendations. This Q&A should NOT be considered a substitute for the advice of a medical or related professional. You should consult with your own doctor or other healthcare professional(s) for medical advice.

# Center for Disease Control & Prevention (CDC)

## Who is Considered High Risk for COVID-19?

- ❖ <https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/people-at-higher-risk.html>
- ❖ COVID-19 is a new disease and there is limited information regarding risk factors for severe disease.
- ❖ **Higher risk means a person may be more likely to suffer severe illness from COVID-19.**
- ❖ Currently available information and clinical expertise categorize the following groups as higher risk for severe illness from COVID-19:
  - 1) Older adults (65 and up); 8 out of 10 deaths reported in the U.S. have been in adults 65 years old and older as of April 2, 2020.
  - 2) People in nursing homes or long-term care facilities.
  - 3) People of any age who have serious underlying medical conditions



Older Adults



At Risk For Severe Illness



People with Liver Disease



People with Asthma



People with HIV



People Who Are Immunocompromised

# CDC: “Underlying Medical Conditions” that are High Risk for COVID-19

High Risk = People of all ages with underlying medical conditions, particularly if not well controlled, including:

- 1) **People with chronic lung disease or moderate to severe asthma**
  - Includes obstructive sleep apnea (OSA) and chronic obstructive pulmonary disease (COPD) that can lead to both lung and heart disease
  - NIH emphasizes respiratory difficulties
- 2) **People who have serious heart conditions**
- 3) **People who are immunocompromised**
  - Many conditions can cause a person to be immunocompromised, including cancer treatment, smoking, bone marrow or organ transplantation, immune deficiencies, poorly controlled HIV or AIDS, and prolonged use of corticosteroids and other immune weakening medications
- 4) **People with severe obesity (body mass index [BMI] of 40 or higher)**
- 5) **People with diabetes**
- 6) **People with chronic kidney disease undergoing dialysis**
- 7) **People with liver disease**

# Why most people with Down syndrome will be considered High Risk for COVID-19

- ❖ Many adults with Down syndrome, especially in urban areas, live in **Group Homes** that are considered High Risk
  - <https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/older-adults.html>
  - To protect these vulnerable friends and family members, the CDC has advised that long-term care facilities:
    - 1) Restrict visitors,
    - 2) Regularly check healthcare workers and residents for fevers and symptoms, and
    - 3) Limit activities within the facility to keep residents safe.
- ❖ **Additional Thoughts** (Please see DS/COVID-19 Q&A Resource)
  - It may be more difficult for people with Down syndrome and IDD to comply with safeguards like social distancing or wearing masks.
  - It may be more difficult for people with Down syndrome to articulate if they are feeling sick or how they are feeling.
  - Behaviors associated with disrupted routines may be difficult.

# An Important Resource: COVID-19 and Down Syndrome Q&A

## *What 'Underlying Conditions' are most relevant*

**What are the medical problems that people with Down syndrome may have that put them at high risk?**

1. Certain heart problems.
2. Chronic respiratory problems.
3. History of severe respiratory infections.
4. Asthma.
5. Obstructive sleep apnea.
6. People who may have lower immune function, such as:
  - People with *diabetes*.
  - People receiving chemotherapy or undergoing *active treatment for cancer*.
  - People on *certain medications* that lower the function of the immune system (such as for treatment of rheumatoid arthritis, lupus, or psoriasis).

*\*More detailed information about Down syndrome and the underlying medical conditions considered high risk for COVID-19 is available in the Expanded Version of this Q&A.*

# An Important Resource: COVID-19 and Down Syndrome Q&A

## *Questions from the Q&A*

1. Is general COVID-19 information about symptoms, spreading and preventing the virus, and treatment the same for people with Down syndrome?
2. Are individuals with Down syndrome at "high risk" for COVID-19?
3. Are there challenges in preventing or diagnosing COVID-19 in people with Down syndrome?
4. How can I help a person with Down syndrome understand COVID-19 and how to stay healthy?
5. Is travel safe for individuals with Down syndrome?
6. What kind of a plan should I have if I am sick or test positive for COVID-19, or have to go into the hospital, and I am the only caregiver for a person with Down syndrome?
7. With Down syndrome, does having dementia or Alzheimer's disease increase the risk of COVID-19?
8. What is useful in helping people with Down syndrome to reduce stress and stay well?
9. Should people with Down syndrome go to their school/work/day programs and other activities?
10. Are there special considerations for individuals with Down syndrome who are living in group homes or with roommates or support staff?
11. If sick, when should people with Down syndrome go to the doctor or the hospital?

# Down Syndrome & COVID-19 Q&A

*A community collaboration!*

## Organizers:



## Supporters:

*Down Syndrome Affiliates in Action, Exceptional Parenting Magazine, GiGi's Playhouse, International Mosaic Down Syndrome Association, Jerome Lejeune Foundation, Matthew Foundation, T21 Research Society*

## Additional Authors:

Nicole Baumer MD, Thomas Buckley EdD, Marilyn Bull MD, Rejena Carmichael, Brian Chicoine MD, Lawrence Force PhD, Paula Gann, Bryn Gelaro LSW, Sara Goldberg, Colleen Hatcher, Elizabeth Head PhD, Jim Hendrix PhD, Hampus Hillerstrom, Mary Hogan MAT, Matthew Janicki PhD, Nancy Jokinen PhD, Seth Keller MD, Florence Lai MD, Megan Lindstrom, Ronald Lucchino PhD, Benjamin Margolis MD, Barry Martin MD, Philip McCallion PhD, Andrew Nowalk MD, Lina Patel PsyD, Kathryn Pears MPPM, Steve Perlman DDS, Kandi Pickard, Mary Pipan MD, Tamara Pursley, Rick Rader MD, Dennis Rosen MD, Kathryn Service NP, Stephanie Sherman PhD, Brian Skotko MD MPP, Maria Stanley MD, David Tolleson, Dawna Mughal Torres PhD, Amy Van Bergen, Kishore Vellody MD, Michelle Sie Whitten, Alan Wong DDS.

# Down Syndrome & COVID-19 Q&A

## *In Summary*

### ❖ **Includes Important Information:**

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

### ❖ **Global encourages you to share with your family, friends, doctors, nurses, therapists, teachers and others within the Down syndrome community.**

### ❖ **Timeline**

- Version 1 - March 26<sup>th</sup>
- Version 2 - April 29<sup>th</sup>
- Next update planned for mid-July

# THANK YOU!

