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

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 Catalyst to start GLOBAL
People with DS have a Radically Different Disease Spectrum

NDSC Annual Convention - Thursday 6/25/2020
GLOBAL Research & Medical Care Roundtable
The Catalyst to start GLOBAL
A life-threatening disparity

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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

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
  - 2/26/2020 - When 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
  - The New York Times
  - 6/10/2020
- Intellectual Disability Raises COVID-19 Death Risk
  - WebMD
  - 6/8/2020
- Feds Pump Millions Into Disability Housing As Part Of Coronavirus Relief
  - DS
  - 6/9/2020
- Coronavirus: ‘Our son with Down’s syndrome is thriving in lockdown’
  - BBC
  - 6/3/2020

See More

Links to Other Important Resources
- Will People With Down Syndrome Be Denied COVID-19 Medical Care?
  - Colorado is a role model in fighting Medical Care Rationing Discrimination
- 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

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

DENVER, April 9, 2020 - The Governor’s Expert Emergency Epidemic Response Committee (EERC) released 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) or if social distancing, sheltering-in-place, and self-isolation are no longer possible.

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

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

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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
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
Many adults with Down syndrome, especially in urban areas, live in Group Homes that are considered High Risk

- 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.
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.*
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?
Organizers:

Supporters:

Additional Authors:

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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 26th
- Version 2 - April 29th
- Next update planned for mid-July
THANK YOU!

GLOBAL Research & Medical Care Roundtable