

# COVID-19 & Down Syndrome Resource

Updated March 1, 2021



## SUPPORTING ORGANIZATIONS:

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

Over a year ago, the spread of the coronavirus (COVID-19) brought extraordinary challenges that continue to affect communities around the world. In our case, the pandemic called for a united response to better understand its impact on the Down syndrome community. In response, our organizations have developed a series of Q&As on this topic. Much of the information from prior Q&As is still relevant and can be located on any of the six supporting organizations' websites. This new *COVID-19 and Down Syndrome Resource* emphasizes important updates and contains important new information about COVID-19 vaccinations.

Information in this resource may be used to help you or to support a loved one with Down syndrome. We encourage you to share the information in this document with your family, friends, doctors, nurses, therapists, teachers, and others in the Down syndrome community.

At the time of this update, many areas of the United States are experiencing high levels of community spread and hospitalizations. At the same time, the first approved COVID-19 vaccines are becoming available. This document discusses answers to important questions for our Down syndrome community. In this document, you will find information about:

- What to think about when considering the COVID-19 vaccine
- How to support mental health challenges during the ongoing pandemic
- What we have learned about the virus that may be unique to people with Down syndrome
- How to help stop the spread of the virus and stay safe
- Things to consider when making decisions to participate in activities.

*Copying or posting of this document is prohibited. However, providing a link to the website of any of the six organizations who published this document is permissible. Free individual downloads and printing from the websites of any of the six organizations is also permissible.*

Many organizations and professionals contributed to this resource by providing their expertise on Down syndrome and applying it to what we know about COVID-19. As we learn more about COVID-19, its prevention and treatment, and how it may affect people with Down syndrome, we will continue to provide important updates.

To be clear, this resource is only informational. It is not medical advice. We hope the information is useful to you as you make decisions and look for medical, educational, or other recommendations. This document should NOT replace advice from your health care provider. You should speak with your own doctor or other health care professional(s) for medical advice.

Please take care that the information you receive about COVID-19 is from reliable, trusted, and recognized sources. We recommend the [Centers for Disease Control and Prevention \(CDC\)](#), the [Food and Drug Administration \(FDA\)](#), and websites ending with “.gov” in the United States. International, federal, and state health department websites should be the most reliable. We also encourage you to visit websites of organizations that support the Down syndrome community listed at the end of this resource.

## IMPORTANT REMINDERS

Please call your health care professional as soon as possible if you think that you, a loved one, or someone in your care may have COVID-19. We strongly recommend calling your doctor before traveling to an office or hospital, as time spent there may increase exposure to COVID-19 for you and others. Each person can react differently to the COVID-19 virus and may experience a variety of symptoms. Keep in touch with your physician and seek advice as to how to proceed.

If you are a parent or caregiver, please remember to take care of yourself. It is hard (and sometimes impossible) to care for others if you are sick or too tired. Also, it is important not to spread your sickness. Stay healthy for the people who depend on you.

We also encourage you to check in with family and friends—especially those who may be struggling during this health emergency. A phone call or text message goes a long way to show someone you care.

**In the event of an emergency, U.S. residents should call 911.**

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## 1. Basic Information

- COVID-19 is the illness caused by a new coronavirus (called SARS-CoV-2). Information about COVID-19 and its variants for the general population also applies to people with Down syndrome. This includes information on symptoms, how the disease is spread, protection and vaccinations, and supportive treatment.
- Based on what we know today, public health professionals and infectious disease experts warn that certain individuals are more likely to get severely ill and need treatment in the hospital if they get sick with COVID-19. These individuals are considered “high risk.”<sup>1</sup>
- In December 2020, CDC added Down syndrome to the [list of high-risk conditions](#) that increase a person’s risk of becoming severely ill and needing to go to the hospital if they are sick with COVID-19.
- In addition, people with Down syndrome often have underlying medical conditions that make individuals “at increased risk” or possibly at increased risk for severe illness from COVID-19 according to CDC.<sup>1</sup> This includes:
  - » Cancer
  - » Overweight and obesity
  - » Heart conditions
  - » Immunocompromised state (weakened immune system) from bone transplant, immune deficiencies, or use of other immune weakening medications
  - » Types 1 and 2 diabetes
  - » Neurological conditions, such as dementia.

## 2. Research Updates about COVID-19 and Down Syndrome

- More data about COVID-19 and its impact on people with Down syndrome are needed, but limited published findings so far suggest that:
  - » Individuals with Down syndrome over the age of 40 are more likely to need hospitalization, have serious illness, or die from COVID-19 compared with the general population of the same age.<sup>2,3</sup>
  - » Individuals with Down syndrome with COVID-19 exhibit many similar symptoms to those in the general population (fever and cough). However, people with Down syndrome seem more likely to have breathing- and respiratory-related complications and may experience increased mental confusion.<sup>3</sup>
  - » Children with or without Down syndrome do not usually get severely sick from the virus.<sup>3</sup>
  - » Immune dysregulation in people with Down syndrome may increase the risk for poor outcomes.<sup>4</sup>
- For additional information, below are several websites and podcasts you may find useful:
  - » Science Magazine’s article [“COVID-19 is Ten Times Deadlier for People with Down Syndrome, Raising Calls for Early Vaccination.”](#)
  - » Preliminary results from the [Trisomy 21 Research Society \(T21RS\) COVID-19 Taskforce Survey and Report](#).
  - » [“Does Having Down Syndrome Lead to Higher Risk in COVID?”](#) a podcast by Dr. Kishore Vellody, Medical Director of the Down Syndrome Center at Children’s Hospital of Pittsburgh, and Dr. Andrew Nowalk, a pediatric infectious disease expert.
  - » [“Update: COVID & Down Syndrome, January 8, 2021,”](#) a Matthew Foundation webinar featuring Dr. Brian Chicoine, Medical Director of Advocate Medical Group Adult Down Syndrome Center, and Dr. Andre Strydom, President of the Trisomy 21 Research Society.

### 3. COVID-19 Vaccine

#### A. General Information

- For the most recent information about the COVID-19 vaccine, please visit [CDC's COVID-19 vaccination resource](#) and [FDA's COVID-19 vaccination review](#).
- Because the number of vaccines is limited, people are being vaccinated in phases. Some people, including health care workers and residents in nursing homes, are being prioritized to receive the vaccine first. Eligibility to receive the vaccine in each of the phases is being decided on a state-by-state basis and is optional. You can review your state's vaccine distribution plan on your [state department of health website](#).
- If you previously had COVID-19 and recovered, CDC still recommends that you receive the COVID-19 vaccine.<sup>5</sup> **While vaccine supply remains limited**, individuals with recent acute SARS-CoV-2 infection may choose to delay vaccination temporarily.<sup>6</sup> However, there is a risk of reinfection, and the need for vaccination may increase over time. For patients who received passive antibody therapy, CDC recommends avoiding vaccination for at least 90 days as a precaution.<sup>6</sup> Check with your health care provider to determine the best timing to receive the vaccine.
- It is recommended that no other vaccine (for example, flu or shingles vaccine) be given two weeks before or after receiving either COVID-19 vaccine dose. Review where people with Down syndrome fit into your state's vaccination plan and when they may be able to be vaccinated for COVID-19. Other vaccines should be planned accordingly.

#### B. How the Vaccines Work

- Three vaccines are currently available in the United States:
  1. [Pfizer COVID-19 vaccine](#):<sup>7</sup>
    - » Recommended for individuals 16 years or older.
    - » Requires two doses given via an injection in the arm 21 days apart.

## 2. [Moderna COVID-19 vaccine](#):<sup>8</sup>

- » Recommended for individuals 18 years or older.
- » Requires two doses given via an injection in the arm 1 month apart.

## 3. [Johnson & Johnson COVID-19 vaccine](#):<sup>9</sup>

- » Recommended for individuals 18 years or older.
- » Requires one dose given via an injection in the arm.

- All three vaccines currently available in the United States are extremely effective at preventing severe illness from COVID-19 resulting in hospitalization and death.<sup>7-9</sup>
- Both the Moderna and Pfizer vaccines require two doses. You must receive the same vaccine for both doses. You should work with your health care provider to schedule your second dose within the suggested time frame based on the vaccine you receive. The vaccine's full protection will not be reached until several weeks after you have received the second dose.<sup>10</sup>
- Both the Moderna and Pfizer vaccines are mRNA vaccines, which cause your cells to make a harmless piece of the "spike protein" of the COVID-19 virus.<sup>11</sup> The immune system then develops immunity against the protein. These two COVID-19 vaccines do not use live virus and do not change or interact with your genes or DNA.<sup>11</sup>
- The Johnson & Johnson vaccine requires one dose and is a "viral vector vaccine". A vector is like a carrier. It works by using inactivated and harmless virus to help "carry in" a genetic code for the "spike protein" of the COVID-19 virus. The immune system then creates antibodies to protect against Coronavirus.<sup>12</sup>
- You can still contract COVID-19 after being vaccinated but based on early research and what we know about other vaccines, it may prevent you from becoming seriously ill.<sup>13</sup>
- Studies are ongoing to determine whether asymptomatic individuals (people with no symptoms) can spread the virus after they have been vaccinated.<sup>14</sup>



- Multiple new coronavirus variants have been discovered; these include the United Kingdom (U.K.), South African, Brazil, and California variants. Although researchers are hopeful the vaccines will be effective against these variants, they are concerned that the level of protection may be reduced. Studies are now underway to test whether the vaccines are effective against the new strains. In addition, Moderna and Pfizer have begun work on boosters to increase immunity toward the new variants.<sup>15-18</sup>
- Even after you are vaccinated, it is still very important to follow prevention measures, such as maintaining 6 feet social distance, wearing masks, and washing hands after being out in public since scientists are not sure that a vaccinated person does not spread the virus.<sup>10</sup>

### C. Safety

- The COVID-19 vaccine has been recommended for almost all adults. As far as we know, the vaccine trials did not specifically include individuals with Down syndrome, but they are recommended to receive the vaccine.<sup>19</sup>
- In the United States, the Pfizer, Moderna, and Johnson & Johnson COVID-19 vaccines are not available to children and may not be recommended for those with a history of severe allergic reaction. If you have specific concerns, consult your medical professional for more information.
- The vaccines were tested on several thousands of people, and FDA has authorized them as safe and effective for individuals age 18 years or over (Moderna and Johnson & Johnson)<sup>8,9</sup> or age 16 years or over (Pfizer).<sup>7</sup> These ages were determined based on the ages of the individuals included in the trials (i.e., no one under these ages was included in either trial). The vaccine is now being studied in younger individuals.
- Side effects, including arm pain, swelling, fever, and tiredness, have been reported as mild and temporary by some individuals who have received the vaccine.<sup>20</sup> To help researchers learn more about the vaccine and its side effects, we encourage anyone who has received the vaccine to register any side effects they experience at the [Vaccine Adverse Event Reporting System](#) website co-managed by CDC and FDA.

- For additional information on vaccine safety and people with Down syndrome, you can review the [DSMIG-USA IDD COVID-19 Vaccination Position Statement](#).<sup>19</sup>

#### D. Additional Resources on COVID-19 Vaccine

- For additional information, here is a podcasts you may find helpful: “[COVID-19 Vaccine in People with Down Syndrome](#),” by Dr. Kishore Vellody, Medical Director of the Down Syndrome Center at Children’s Hospital of Pittsburgh, and Dr. Andrew Nowalk, a pediatric infectious disease expert.
- Here are a few resources to consider reviewing to help a person with Down syndrome understand what a COVID-19 vaccine is and to support individuals who may experience anxiety around needles:
  - » “[Getting a COVID-19 Vaccine Social Story](#)”- From Rutgers University Robert Wood Johnson Medical School
  - » “[Preparing to Get the COVID-19 Vaccine: Strategies to Help if You Are Nervous about Needles](#)” - Video by Mackenzie Health

## 4. Testing

- Testing is used to determine whether you have been infected with the COVID-19 virus. Testing is generally available in the United States, although wait times, type of tests available, and how quickly results are reported may differ depending on your city or state. You can find your nearest testing site by visiting your [state health department](#) or calling your medical provider.
- Current CDC guidelines<sup>21</sup> recommend people should be tested for COVID-19 if they:
  - » Are experiencing [COVID-19 symptoms](#).
  - » Have been in close contact (defined by CDC as within 6 feet for 15 or more minutes over a 24-hour period) with someone with confirmed COVID-19 infection.
  - » Have taken part in activities that put them at higher risk for COVID-19 (for example, activities that do not allow socially distancing, such as traveling, attending large social or mass gatherings, or being in crowded indoor settings).
  - » Are referred for testing by their doctor or state health department.
- To determine if you have a **current** infection (meaning you are currently positive for COVID-19), a viral test for the virus that causes COVID-19 can be performed.<sup>21</sup> Two broad types of tests are available to determine whether infection is present:
  - » Nucleic acid testing (also called polymerase chain reaction [PCR] testing): A swab of the nose, mouth, or saliva is collected. Lab tests then determine if parts of the virus's genetic material are present.<sup>21,22</sup>
  - » Antigen testing: These tests determine if antigens specific to the virus itself (called proteins) are present; results are typically available in an hour or less.<sup>23</sup>
- To determine if you had a **past** infection (meaning you previously had COVID-19 and have since recovered), the following test can be performed:
  - » Antibody testing: This is a **blood test** that will determine if you have antibodies, which may mean you had a **past** infection.<sup>24</sup> It is still not known if having antibodies will protect you from future infections or how long any possible protection (also called immunity) may last. Preventive measures are still important to protect yourself and others.

- The most common COVID-19 tests are performed using a nasal swab, in which a long cotton swab is inserted into both nostrils by a health worker or medical professional. This may cause momentary discomfort, but it may be especially distressing for people with Down syndrome who may be anxious about how the test is performed or have sensory issues.
- If an individual with Down syndrome needs testing, parents or caregivers may consider using one of the following strategies to prepare:
  - » Talk about the process, how it is done, and what they should expect. Allow them to ask questions or express concerns.
  - » Use a social story to talk through the testing process, like this one from [Autism Services, Education Resources and Training](#).
  - » Watch videos of the test being performed, like [this one](#).
  - » Allow them to watch you or a loved one have the test performed first.
- You may hear about schools, hospitals, airlines, or other organizations using random testing as a prevention measure or requiring a negative test to participate. In these cases, the tests are viral (nose or throat swab, or saliva) tests, not antibody (blood) tests.
- All individuals (with or without Down syndrome) may test positive for antibodies related to COVID-19 and have had symptoms that were mild or unnoticed.
- It is possible to be infected with COVID-19 and receive a negative viral test result. This is called a “false negative.” This can happen if you are tested before there was enough infection in the body to be detected. It is also possible to become infected after taking a test while waiting for results. For this and other reasons, a negative COVID-19 test result should not be the only factor to consider when making important health decisions, such as visiting high-risk relatives or traveling.<sup>21,25</sup>

## 5. Ways to Stay Safe

### A. Basics

- Experts at CDC and the National Institutes of Health (NIH) believe individuals can be infected by COVID-19 and spread the virus *even if they have no symptoms*. Therefore, it is important to follow the recommendations (listed below) to prevent spread even if you do not feel sick.
- According to [CDC](#), we can reduce the spread of this disease by:<sup>26</sup>
  - » Staying home as much as possible.
  - » If you must go out, [wear a mask covering your nose and mouth](#). Avoid other people who are not wearing a mask.
  - » Practice physical distancing by staying at least 6 feet away from other people.
  - » Wash your hands often with soap and water for at least 20 seconds after being out in public.
  - » If soap and water are not readily available, use an alcohol-based hand sanitizer with at least 60% alcohol. FDA has published a guide to acceptable products.<sup>27</sup>
  - » Avoid touching your eyes, nose, and mouth.
  - » Avoid close contact with people who are sick, and stay home when you are sick.

### B. What to do if someone gets sick

- If someone in your home has mild symptoms that could be caused by COVID-19, medical providers/doctors will likely advise them to get tested, stay home, and take care of their symptoms. It is very important to try to observe CDC guidelines on isolation for that person in the home. It is particularly important to limit or stop contact between the person with symptoms and any other individual with Down syndrome, who is at higher risk for severe infection. See also the CDC advisory, [“Caring for Someone Sick at Home: Advice for Caregivers in Non-healthcare Settings \(2020\).”](#)
- Make a plan for someone else (a family member, a personal care worker, or a respite worker) to help provide any day-to-day care that you or your child or adult with Down syndrome may need in case you are hospitalized.

- If a child or adult with Down syndrome has mild symptoms (like sniffles or congestion but is otherwise eating and drinking normally and is having no trouble breathing), contact your doctor as soon as possible for guidance. If there are more severe symptoms and a doctor is needed, it is very important to call the doctor or hospital first.

**In the event of an emergency, U.S. residents should call 911.**

### C. Precautions for Travel and Returning to Activities

- At this time, nonessential travel is strongly discouraged. Specific regulations may differ state-by-state. For information about travel both within and outside the United States, we recommend reviewing the [CDC website](#).
- Like all people, individuals with Down syndrome should stay at home when they can and travel only when necessary. If travel is necessary, follow the local rules, try to use your personal vehicle, or take transportation that is less likely to be crowded or during a time when there are smaller crowds. Remember to wash hands frequently or use hand sanitizer with a minimum 60% alcohol base<sup>27</sup> and wear a mask.
- Before resuming activities outside the home, *anyone* with Down syndrome with significant health issues should take extra precautions and discuss with family members, agency caregivers, a physician, and/or health professional how to safely return.
- There is no way to ensure complete safety for any activity. However, some strategies may reduce risk and harm. It may be helpful to consider the following factors when planning different activities:
  - » *Personal/individual risk factors:* Consider your child's or adult's health history, including any factors that may make them higher risk, like older age or certain medical conditions. Consider whether they can follow safety precautions, such as maintaining a safe distance and wearing a mask. Discuss personal factors with your loved one's health care professional.

- » *Factors specific to the activity:* Some activities are higher risk than others. For example, indoor activities in large crowds without masks present are higher risk, while outdoor activities in which people wear masks or stay 6 feet apart are lower risk.<sup>26</sup> Many communities are now requiring everyone to wear masks in any indoor area. You should comply with these requirements to keep everyone safe.
- » *Public health factors:* Consider the COVID-19 health trends in your state and community. Consider whether the number of new infections is increasing or decreasing and what your community's capacity is for monitoring and testing.

#### D. Mask Wearing & Handwashing

- [CDC recommends](#) wearing masks in public settings and remaining 6 feet from others. While research now reports that virus “pick-up” is low from surfaces,<sup>26</sup> handwashing is still important. Ensure that handwashing is completed immediately upon returning home from a trip outside or having been in public.
- CDC recommends choosing a mask with two or more layers of washable, breathable fabric. Review [CDC's Your Guide to Masks](#) for further guidance. Using two masks (“double masking”) has also been suggested as an effective strategy.<sup>28</sup>
- Some people with Down syndrome may have sensory issues that make it difficult or uncomfortable to have something touching their face. Below are tips that may help your child or adult with Down syndrome tolerate a mask:
  - » Allow the person to choose a mask from two or three options. If you plan to make the masks, allow them to pick the design and even decorate it.
  - » Use a first-then directive to tell the person that you will “first practice wearing the covering and then (state a preferred activity).”
  - » Model wearing a face covering during a family or group activity even at home and have everyone practice wearing masks at the same time.
  - » Before leaving your house, make it a habit to ask, “Does everyone have their mask?”
  - » [Easterseals](#) has created social stories specifically about wearing a mask that you can watch together.

- Here are some tips that may help a child or adult with Down syndrome maintain proper handwashing hygiene:
  - » Schedule times for handwashing throughout the day, in addition to the typical times hands are washed (after eating, after going to the bathroom, etc.). These scheduled times can be placed on a visual schedule as a reminder.
  - » Use a first-then directive to motivate the individual with Down syndrome to wash their hands: First wash hands, then (state the preferred activity).
  - » Talk about proper handwashing. Using the chorus of a favorite song to help your child or adult with Down syndrome understand how long to wash their hands (about 20 seconds) can be helpful. Practice the procedure together.



## 6. Mental Health

- The ongoing pandemic has led to increases in anxiety, depression, and other mental health challenges for many people, including families, caregivers, and people with Down syndrome.
- People with Down syndrome can be very sensitive to sudden changes to their routine and environment, which may cause stress and anxiety. Common behaviors that families/caregivers may see that could indicate a child or adult with Down syndrome is experiencing stress during the pandemic include the following:
  - » Behavioral changes or regression/loss of certain previous skills (e.g., incontinence when previously toilet trained, no longer wanting to or unable to complete activities of daily living that they were previously able to do).
  - » Increase in “self-talk.”
  - » Increased isolation or desire to be alone.
  - » Rapid shifts in mood or tearfulness.
  - » Disruptive behaviors or angry reactions not present before the pandemic.
  - » Specific fears, anxieties, or phobias not present before the pandemic.
- Families and/or caregivers can try the following to support a person with Down syndrome during the challenges presented by the pandemic:
  - » Maintain routines/structure as much as possible with visual schedules and checklists.
  - » Find approved ways to help the person with Down syndrome stay connected, including video chat, texting, phone calls, and letters.
  - » Make a list of activities that *are* allowed, both indoors and outdoors, such as bike rides, or virtual dance parties where it is possible to stay physically distanced. Posting the list of activities around your home can also be a helpful reminder.
  - » Put together a memory photo book about the people or activities that are missed.
  - » Use a social story explaining the situation in simple, first-person terms.
  - » Validate the person’s feelings, no matter what they are feeling. Be reassuring and try not to convey your own anxieties.

- » People with Down syndrome may be more easily influenced by the emotions of others, so be mindful of how your own emotions may be affecting the person with Down syndrome.
- » Talk to a psychologist, therapist, or other professional familiar with your child or adult with Down syndrome about how to help process the “new norm.”
- The pandemic has created incredible stress and challenges for parents and caregivers, as well as individuals with Down syndrome. It has been a very difficult year trying to balance employment, general uncertainty, remote learning, and more. Make sure to take time for yourself, reach out to your social networks for support, and identify respite care if needed.

## 7. Advocacy Matters

### A. Hospital Visitation and Access to Care

- Due to the early spread of the virus, many hospitals created strict rules that hospitalized patients could not have many visitors. This policy was meant to save lives and reduce further spread of COVID-19. However, as of June 2020, [federal law requires](#) that hospitals modify policies to allow people with disabilities to have access to support from a parent or caregiver if needed while in the hospital.<sup>29</sup> Under the new federal hospital accommodation law, hospitals and other health care facilities are required to allow designated individuals (family members, staff, or others) to support any patient that may need such support and to provide personal protective equipment to these individuals.
- If you feel your child or adult with Down syndrome is experiencing discriminatory care, please contact any of the organizations listed on this document or contact the relevant national organizations involved in this issue, including:
  - » [The Arc](#)
  - » [Center for Public Representation](#)
  - » [National Disability Rights Network](#)
  - » [Office of Civil Rights](#)

### B. Education

- During the COVID-19 pandemic, the [Individuals with Disabilities Education Act](#) is still in place, and schools must continue to provide students with disabilities a free and appropriate public education that includes challenging goals while conducting remote learning.
- Remote learning has been a challenging transition for some students with a disability. A common concern among caregivers is that their child with Down syndrome will lose academic progress. Try to be patient, give yourself grace, and know your child is still learning every day. Consider this an opportunity to teach them valuable life skills that can be taught more easily at home or spend time specifically on one task they want to learn. The CDC has also released a briefing to, "[Help Children Learn at Home.](#)"

- If your child is attending school in-person, make sure the school is following CDC's Considerations on "[Operating Schools During COVID-19](#)."<sup>30</sup>
- The Council of Parent Attorneys and Advocates has issued a comprehensive collection of [frequently asked questions](#), and any family concerned about their child's educational rights may contact an advocate at their local chapter of The Arc or local Down syndrome organization.

## 8. International Updates

- Vaccine brands, availability, access, and recommendations vary by country. If you are outside the United States or its territories, contact your local health authority for local rules and policies.
- New variants of the coronavirus have been detected outside the United States, including in the United Kingdom, South Africa, and Brazil. These new variants appear to be more contagious (they spread more quickly), and research is underway to determine if they cause more severe illness.<sup>31,32</sup> Scientists are currently working to understand the efficacy of current vaccines against the new strains.<sup>15-18</sup>
- Limitations on international travel, community spread rates, and hospitalization rates differ between countries. Consult CDC or a ministry of health website for the country in question to learn more about their specific data.
- For additional international information, see the following report from the United Kingdom: [Advisory from National Health Services, United Kingdom, England, Medical Director for Primary Care on Down Syndrome Prioritization and Shielding.](#)

## 9. Contributors

The following organizations contributed their time, resources, and expertise to this resource. You can download and access this document from their websites:

- [Down Syndrome Medical Interest Group-USA](#) (DSMIG-USA)
- [Global Down Syndrome Foundation](#) (GLOBAL)
- [LuMind IDSC Down Syndrome Foundation](#) (LuMind IDSC)
- [National Down Syndrome Congress](#) (NDSC)
- [National Down Syndrome Society](#) (NDSS)
- [National Task Group on Intellectual Disabilities and Dementia Practices](#) (NTG)

The following individuals contributed their time and expertise to the content of this resource:

Nicole Baumer MD, Marilyn Bull MD, Peter Bulova MD, Rejena Carmichael, Brian Chicoine MD, Bryn Gelaro LSW, Sara Goldberg, Colleen Hatcher, James Hendrix PhD, Hampus Hillerstrom, Matthew Janicki PhD, Seth Keller MD, Megan Lindstrom, Barry Martin MD, Lina Patel PsyD, Kandi Pickard, Mary Pipan MD, Tamara Pursley, Maria Stanley MD, David Tolleson, Kishore Vellody MD, and Michelle Sie Whitten.

Note:

This resource was developed jointly by several national organizations, including the Down Syndrome Medical Interest Group-USA (DSMIG-USA), Global Down Syndrome Foundation (GLOBAL), LuMind IDSC Down Syndrome Foundation (LuMind IDSC), National Down Syndrome Congress (NDSC), National Down Syndrome Society (NDSS), and the National Task Group on Intellectual Disabilities and Dementia Practices (NTG). You can find this resource on each organization's website in the public domain. The document will be updated as new and additional information is presented. We are very thankful for the input received from the many experts who contributed and reviewed the resource and to the prior Q&As. The full listing of individuals who contributed to prior Q&As can be located on any of the six supporting organizations' websites.

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