COVID-19 & Down Syndrome Resource

Updated November 16, 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

The spread of the coronavirus (COVID-19) has 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 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 version of the *COVID-19 and Down Syndrome Resource* emphasizes important updates since May 2021.

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, vaccinations are widely available in the United States, yet community spread and hospitalizations continue in areas with low vaccination rates, mostly driven by the Delta variant. This document discusses answers to important questions for our Down syndrome community. In this document, you will find information about:

- What we have learned about the virus and vaccines that may be unique in people with Down syndrome
- Vaccinations for children ages 5-11
- The Delta variant
- Who may qualify for COVID-19 vaccine additional doses and the plans for boosters.

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 and its variants, 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. Internationally, national and regional governmental and health ministries' 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. 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.

Table of Contents

1. Important Updates
   - A. Delta Variant
   - B. Booster Shots
   - C. Vaccines for Children
2. Basic Information
3. Research Updates about COVID-19 & Down Syndrome
4. COVID-19 Vaccine
   - A. General Information
   - B. How the Vaccines Work
   - C. Safety
   - D. Additional Resources on COVID-19 Vaccine
5. Testing
6. Ways to Stay Safe
   - A. Basics
   - B. What to Do if Someone Gets Sick
   - C. Precautions for Travel and Returning to Activity
   - D. Mask Wearing & Handwashing
7. Mental Health
8. Advocacy Matters
   - A. Hospital Visitation & Access to Care
   - B. Education
9. International Updates
10. Contributors
11. References

1. Important Updates

A. Delta Variant

- The Delta variant is a new strain of COVID-19 which is causing concern as cases of COVID-19 are again increasing.
- Symptoms from the Delta variant are the same as earlier strains of the coronavirus, however, it is more contagious. The Delta variant can cause more infections and spread faster.[1]
- Unvaccinated people are at higher risk for infection and severe outcomes, particularly in areas with low vaccination rates.[1]
- COVID-19 vaccines protect people and reduce the likelihood of hospitalization and death. This includes protection against Delta and other variants.[1]
- Most people who get COVID-19 are unvaccinated, but a small number of people may experience a "**breakthrough infection**." A breakthrough infection is when a person who is vaccinated becomes infected. Breakthrough cases are generally mild, and some people may not feel any symptoms at all.[2]
- Vaccinated individuals who experience even very mild breakthrough cases can spread the virus to others. This is why even vaccinated individuals, in areas of high or substantial community spread, should maintain social distancing, wear masks indoors, and follow safety measures.[1]
- For additional information about the Delta variant and people with Down syndrome, please visit the resource below:
  - "COVID, Delta, and Ds," 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.

B. Booster Shots

- Booster shots are now available for all three vaccines currently in use in the US including individuals who were initially fully vaccinated with:[3]
  - Pfizer & Moderna - At this time people age 18+ with underlying medical conditions are eligible for boosters 6 months after their second dose of Pfizer or Moderna, including people with Down syndrome.[3]
  - Johnson & Johnson - All people age 18+ are eligible two months after their

initial dose of Johnson & Johnson, including people with Down syndrome.[3]

- In addition, the CDC approved "Mix-& Matching" of booster shots, which means your booster does not have to be the same vaccination brand as your initial vaccine series.[3] For example, if your first 2 doses were from Pfizer, you can receive a Moderna booster. Consult your medical provider if you have questions.
  - » Based on CDC guidance, you may consider getting a Pfizer or Moderna booster if you previously received Johnson & Johnson.
- Studies are still underway to determine exactly how long vaccines protect people from COVID-19.
- There have been concerns that people with Down syndrome may not receive the same protection from the COVID-19 vaccines as people without Down syndrome. Recent studies suggest people with Down syndrome may be more likely to experience a breakthrough infection, despite vaccination status, compared to the general population.[4,5]
  - » **However, protection is still much greater if vaccinated than unvaccinated.**

C. Vaccines for Children

- CDC recommends that children 5 to 11 years old be vaccinated against COVID-19 with the Pfizer pediatric vaccine.[5]
- The pediatric Pfizer vaccine contains 1/3rd the dose as the vaccine for individuals age 12 and older, but still requires 2 shots 21 days apart.
- Currently, Pfizer is the only pediatric vaccine approved, but other pediatric vaccine trial are underway and may be approved soon.[5]
- Pediatric vaccines underwent very rigorous safety testing and were found to be safe and very effective at preventing COVID-19 in children.[5]

2. 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."[6]
- 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.[6] 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
    - » Type 1 and 2 diabetes
    - » Neurological conditions, such as dementia.

3. 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:
  - » People with Down syndrome are more likely than the general population to experience a "breakthrough" COVID-19 infection and/or experience more severe outcomes during a breakthrough infection. Please note that adults with Down syndrome who are older and overweight are at higher risk for severe outcomes.[4]
  - » People with Down syndrome can be vaccinated and can now get a booster (if of age and the appropriate time has past since their initial series).
  - » 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.[7,8]
  - » 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.[8]
  - » Children can get sick from COVID-19.[5] Anecdotal experience from clinicians has supported the thought that children with Down syndrome who do get COVID are at risk from severe illness, although risk for severe outcome increases with age.
  - » Immune dysregulation in people with Down syndrome may increase the risk for poor outcomes.[9]
- For additional information, below are several websites and podcasts you may find useful:
  - » CDC's Toolkit of "COVID-19 Materials for People with Intellectual and Developmental Disabilities and Care Providers." This link contains visual aids and social stories covering important COVID-19 issues like masking, vaccines, and handwashing.
  - » "COVID Vaccine for Younger Children and Boosters for Adults," 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.

» Science Magazine's article "COVID-19 is Ten Times Deadlier for People with Down Syndrome, Raising Calls for Early Vaccination."

» Results from the Trisomy 21 Research Society (T21RS) COVID-19 Taskforce Survey and Report. https://www.t21rs.org/results-from-covid-19-and-down-syndrome-survey/

4. 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.
- If you previously had COVID-19 and recovered, CDC still recommends that you receive the COVID-19 vaccine.[10] 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.[11] 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 the initial one or two shots of the COVID-19 vaccines. When receiving the booster shot, it is okay to receive a flu shot at the same time.

B. How the Vaccines Work

- Three vaccines are currently available in the United States:

  1. Pfizer COVID-19 vaccine:[5,12]
     - » Recommended for individuals 5 years or older.
     - » Requires two doses given via an injection in the arm 21 days apart.

  2. Moderna COVID-19 vaccine:[13]
     - » 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:[14]
     - » 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.[12-14]

- Both the Moderna and Pfizer vaccines require two doses. You should 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 two weeks after you have received the second dose.[15]
- 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.[16] 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.[16]
- 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.[17]
- You can still contract COVID-19 after being vaccinated but the vaccine will prevent you from becoming seriously ill.[18] These are called "breakthrough" infections.[2]
- Multiple new coronavirus variants have been discovered but the Delta variant is currently the most dominant strain of virus.[1]
- Individuals who are vaccinated can still spread the Delta variant to others. This is why even after you are vaccinated, it is still very important to follow prevention measures, such as maintaining social distance, wearing masks, and washing hands after being out in public.[1, 2]

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.[24]
- In the United States, only the Pfizer pediatric vaccine is currently recommended for children ages 5 to 11 years of age at 1/3 the dose being given to individuals over 12 years old.
- COVID-19 vaccines 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 found them safe and effective via emergency authorization use for individuals age 18 years or over (Moderna and Johnson & Johnson)[13, 14] or age 5 years or over (Pfizer).[12] 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.
- Boosters are now available for people with Down syndrome. To learn about boosters and who may be eligible, please see Section 1, Part C above.
- Side effects, including arm pain, swelling, fever, and tiredness, have been reported as mild and temporary by some individuals who have received the vaccine.[26] 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.[24]

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

5. 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[27] recommend people should be tested for COVID-19 if they:
  - » Are experiencing COVID-19 symptoms, regardless of vaccination status.
  - » 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.
    - ° Fully vaccinated individuals should be tested 3-5 days after the exposure and wear a mask in public indoor settings for 14 days or until they receive a negative test.
    - ° People who tested positive for COVID-19 within the past 3 months and recovered do not need to get tested following an exposure as long as they do not develop new symptoms.
  - » Are unvaccinated individuals who 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.[27]
- 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.[27] 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.[27, 28]
  - » 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.[29]

- 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.[30] 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.[27, 31]

6. 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 and are vaccinated*. 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:[32]
  - » Getting vaccinated.
  - » When you are indoors, wearing a mask covering your nose and mouth even if you are vaccinated. Try to avoid other people who are not wearing a mask.
  - » Practicing physical distancing by staying at least 6 feet away from other people.
  - » Washing 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, using an alcohol-based hand sanitizer with at least 60% alcohol. FDA has published a guide to acceptable products.[33]
  - » Avoiding touching your eyes, nose, and mouth.
  - » Avoiding 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, specific regulations and guidance 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 and their families should consider safety measures when they travel. 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[33] and wear a mask.
- 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 participate in activities.
- 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.[32] 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 vaccination rate.

D. Mask Wearing & Handwashing

- Mask wearing is no longer mandated in many public places for vaccinated individuals. However, it is strongly encouraged. Ensure that handwashing is completed immediately upon returning home from a trip outside or having been in public.
- If you plan to fly or use public transport, remember that requirements to wear a mask are still in force. If you will fly with your loved one with Down syndrome, be sure that he or she is willing and capable of keeping on a mask during boarding and during the whole flight (except when eating). The airlines are required to enforce the masking rule.
- 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.[34]
- 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.

  - » CDC's Toolkit of "COVID-19 Materials for People with Intellectual and Developmental Disabilities and Care Providers." This link contains visual aids and social stories covering important COVID-19 issues like masking, vaccines, and handwashing.

- 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.
  - » Watch, "How to Wash your Hands," a video from the Adult Down Syndrome Center in Chicago, IL.

7. 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.

8. 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.[35] 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

- At this time, many schools have returned to in-person teaching. Classroom safety is of great concern for many families.
- Remote learning was a challenging transition for some students with a disability. There are many benefits to your student with Down syndrome receiving in-person education if it is possible and safe.
- When your student returns to in-person learning, make sure your child's school is following the American Academy of Pediatrics "COVID-19 Guidance for Safe Schools."[36] Specifically, consider if your child's school or district is doing any or all of the following:
  - Spacing student desks 3 feet.

  - » Requiring masking for students, teachers, and other school staff.
  - » Following good hygiene protocols (ex: frequent handwashing and surface sanitizing).
  - » Providing access to testing.
  - » Incorporating outside instruction or breaks, weather permitting.
  - » Encouraging sick students and staff to stay home.

- 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.
- The Council of Parent Attorneys and Advocates has compiled COVID-19 related resources 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.
- If you are experiencing difficulties with you child with Down syndrome following masking rules at school, review and share the CDC's guidance for exempting, "certain groups of people who may find it difficult to wear a mask" from mask wearing, including people with disabilities, as a possible reasonable accommodation under ADA.

9. 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.
- 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.

10. 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:

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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.

11. References

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