GLOBAL
DOWN SYNDROME FOUNDATION®

GLOBAL DOWN SYNDROME FOUNDATION
MEDICAL CARE GUIDELINES
for ADULTS WITH DOWN SYNDROME

Family-Friendly Version

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INTRODUCTION

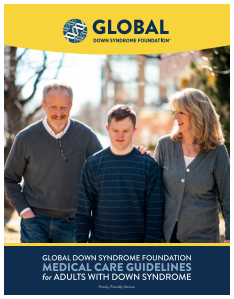
People with Down syndrome have different medical needs than people without Down syndrome.

For example, there are some medical conditions they are more likely to have, and some conditions they are less likely to have, compared to people without Down syndrome. So, their annual check-ups and sometimes their course of treatments may be different.

There are healthcare guidelines for children with Down syndrome ages 0-21 that are updated from time to time,[1,2] which are very different from healthcare guidelines for children without Down syndrome. Although healthcare guidelines for adults with Down syndrome were written in 1999[3] and 2001,[4] they were based only on clinician experience and were not updated, even though there have since been advances and changes to standards of care.

In 2014, the Global Down Syndrome Foundation (GLOBAL) organized a task group of adults with Down syndrome, their families/caregivers, and Down syndrome experts for the purpose of establishing a medical care center for adults with Down syndrome. The feedback from that task group identified medical guidelines for adults with Down syndrome as an important tool for medical clinics and healthcare professionals to help provide more accurate evaluation and care.

As a result, the Global Down Syndrome Foundation Medical Care Guidelines for Adults with Down Syndrome Workgroup (GLOBAL Workgroup) was formed in 2016 to create these first ever evidence-based guidelines for adults with Down syndrome to improve the health of adults with Down syndrome. The Global Medical Care Guidelines for Adults with Down Syndrome (GLOBAL Adult Guideline) was published in JAMA (Journal of the American Medical Association) in October 2020.[5] That was a very important milestone since medical professionals rely on trusted journals like JAMA and can easily find and implement the guidelines for their adult patients with Down syndrome. The GLOBAL Adult Guideline published in JAMA (2020) can be found online here: *https://bit.ly/GLOBAL-Adult-Guideline-JAMA*



This is the family-friendly version of the GLOBAL Adult Guideline. The original, full length GLOBAL Adult Guideline was written for a highly technical, medical audience. A version specifically for self-advocates is a future project. The recommendations in the family-friendly version are the same, but the content has been modified, with research components greatly abbreviated, and the technical methodology mostly removed. The original GLOBAL Adult Guideline can be found online here: *https://www.globaldownsyndrome.org/medical-care-guidelines-for-adults/.*

All images are approved GLOBAL models.

WHAT IS DOWN SYNDROME?

There Are Three Types Of Down Syndrome:

TRISOMY 21 About 95% of people with Down syndrome have Trisomy 21[6] – a condition in which a person is born with three copies of chromosome 21 instead of the usual two copies in every cell.

TRANSLOCATION DOWN SYNDROME About 3% of people with Down syndrome have Translocation Down syndrome. This is when part or all of chromosome 21 attaches (translocates) onto another chromosome.

MOSAIC DOWN SYNDROME About 2% of people with Down syndrome have Mosaic Down syndrome.[6] This is when only some (not all) of a person's cells have an extra copy of chromosome 21.

Down syndrome is the most common chromosomal condition[7] and cause of developmental delay in the United States. Down syndrome is a genetic condition, not a disease. About 1 in every 691 babies born has it.[8] Most of the time, Down syndrome is random and not inherited.[9] How and why people have Down syndrome is largely unknown.

SINCE IT AFFECTS ALL OF THE BODY'S SYSTEMS, PEOPLE WHO HAVE DOWN SYNDROME ARE MORE LIKELY TO GET CERTAIN DISEASES THAN PEOPLE WITHOUT DOWN SYNDROME, AND LESS LIKELY TO GET OTHERS, SO THEY NEED SPECIAL MEDICAL CARE.

People with Down syndrome are less likely to have solid malignancies (cancerous tumors) or atherosclerotic cardiovascular disease (clogged arteries) than people without Down syndrome.[10,11] The medical problems that people with Down syndrome are more likely to have include autoimmune conditions, leukemia, respiratory infections, sleep apnea, hearing and vision loss, and dementia. This does not mean that everyone with Down syndrome will have any or all of these problems. In addition, most of these problems can be found and treated early, which means people with Down syndrome who have them can still enjoy a good quality of life.[12]

Most people with Down syndrome have some intellectual disability.[2] Down syndrome affects everyone differently, but some common features include limited language skills, delayed muscle coordination, and reduced executive functioning. Other social and environmental difficulties, like finding knowledgeable healthcare or lack of access, may make things even harder and should also be taken into account as part of the care for adults with Down syndrome.

ABOUT THIS GUIDELINE

The GLOBAL Adult Guideline focuses on adults over age 21 with the type of Down syndrome called Trisomy 21. Since Down syndrome affects every part of the body,[17] it was not possible to cover every medical area in this first edition of the guidelines. The GLOBAL Workgroup decided to focus on nine of the most common and concerning issues, which are:

1. Behavior
2. Dementia
3. Diabetes
4. Cardiovascular Disease
5. Obesity
6. Atlantoaxial Instability
7. Osteoporosis
8. Thyroid
9. Celiac Disease

Since there are still many other medical areas that we believe are important and unique to people with Down syndrome, GLOBAL has committed to invest the time, energy and funds to update the GLOBAL Adult Guideline every 5-6 years with new medical areas and updates to the original nine. Currently, the GLOBAL Workgroup is also researching sleep apnea, solid tumors, leukemia, other autoimmune disorders, vision and eye issues, and physical therapy and fitness.

As a direct result of GLOBAL's advocacy in Washington, DC, the amount of funding for Down syndrome research increased from $27 million in 2016 to $115 million in 2022. GLOBAL expects this increase in funding will continue, and we will keep asking for support to elongate life and improve health outcomes with an additional focus on adults with Down syndrome. In the future, we also want to study the dual diagnosis of Autism and Down syndrome, Mosaic Down syndrome, and health disparities across gender and race in adults with Down syndrome.

PREVALENCE & LIFE COURSE

In the US, people with Down syndrome are living longer now than ever before. The lifespan of a person with Down syndrome has increased from 25 years in the 1980's[13] to 60 years today.[14]

People with Down syndrome are living longer because they are no longer institutionalized, and there have been great improvements in treating pediatric heart problems, hypothyroidism and lung disease, as well as better access to medical care, education, community support, and other opportunities. There are also more babies being born with Down syndrome.[8, 15]

The government doesn't keep track of how many people have Down syndrome, so nobody knows the total population for sure. An estimate from 2010 said that there are 206,000 people with Down syndrome in the United States, which includes 125,000 adults.[16] If we update those figures for today, there could be over 400,000 people with Down syndrome.

Even though there are more people with Down syndrome living longer, we need to do a lot more work in the areas of research and medical care to help keep people with Down syndrome healthy throughout adulthood.

GLOBAL ADULT GUIDELINE CHALLENGES

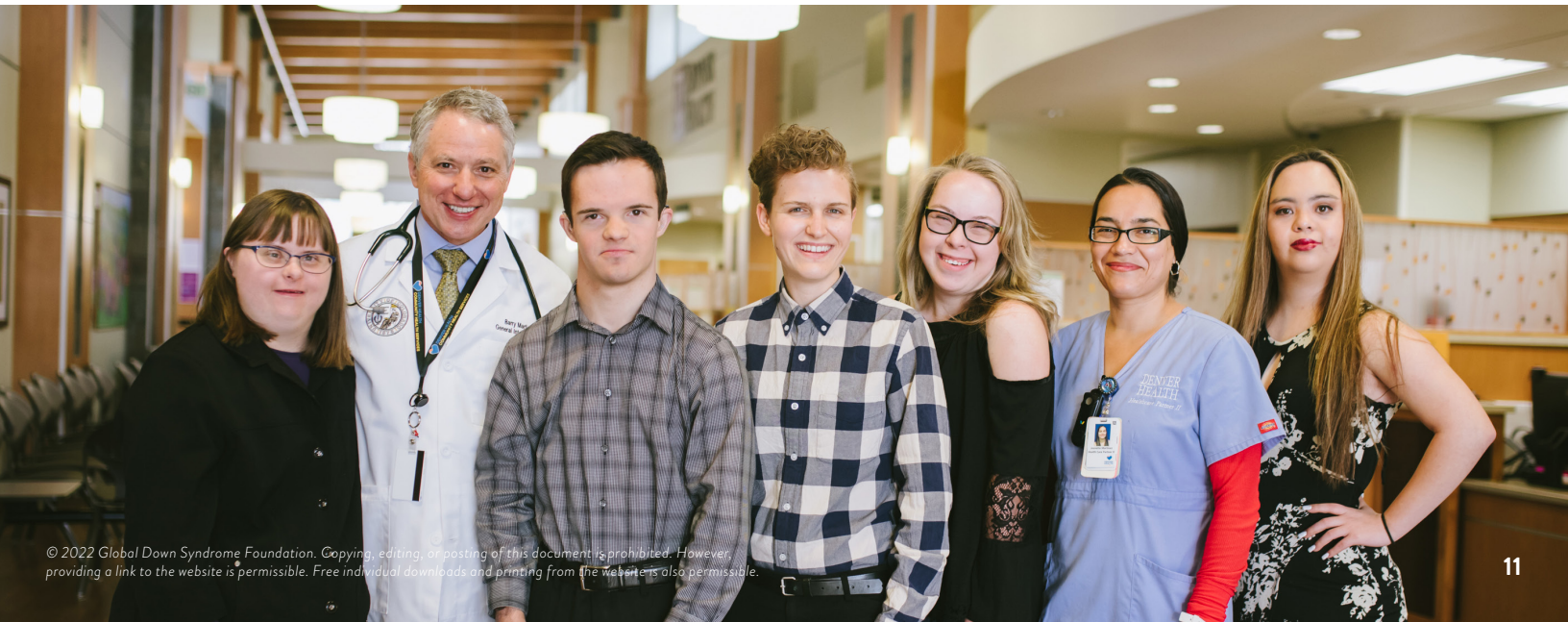
The biggest challenge when writing the GLOBAL Adult Guideline was not finding enough good research on Down syndrome or research that includes people with Down syndrome. More research is needed to support the way medical care is actually provided and in order to make better guideline recommendations. This research needs to be funded by the National Institutes of Health (NIH) along with universities, hospitals and any other advocacy and medical organizations in the Down syndrome community. Even without that research, the GLOBAL Workgroup was able to provide sound recommendations based on decades of clinical experience and the limited research available. When there wasn't enough research on adults with Down syndrome, we looked at research from other groups of people, such as children with Down syndrome or adults with other disabilities to decide if those guidelines could apply.[18]

METHODS

What makes the GLOBAL Adult Guideline first-in-kind is that it is evidence-based, meaning the authors reviewed research articles, identified articles they determined were of high quality, and then based their recommendations off what they found in the research. To be evidence-based, the GLOBAL Workgroup recruited guideline experts at ECRI and followed a very specific best practice called the GRADE Evidence to Decision Making Framework.

Once the guideline was written, we asked adults with Down syndrome and their family members for feedback via an online survey. GLOBAL also asked medical professionals from the American Academy of Developmental Medicine and Dentistry to review the draft guideline and provide feedback. Based on the survey and the feedback, the GLOBAL Workgroup made some important changes to the GLOBAL Adult Guideline before it was published.

To review the complete methodology, please visit the full GLOBAL Adult Guideline here:
https://www.globaldownsyndrome.org/medical-care-guidelines-for-adults/



1

BEHAVIOR

Statement of Good Practice 1 A review of behavioral, functional, adaptive, and psychosocial factors should be performed as part of an annual history that clinicians obtain from all adults with Down syndrome, their families, and caregivers.

Adults with Down syndrome should get the same level of medical care as adults without Down syndrome. This should include an annual review of all relevant behavioral (mood, attention, and activity level), functional-adaptive (social, communication, and daily living skills), and psychosocial (major life events, loss/grief, and trauma) factors that may affect physical and mental well-being. Since adults with Down syndrome may not be able to explain these things well, the family, caregivers and significant others should tell medical professionals about anything they've noticed that has changed in the mood or behavior of the adult with Down syndrome. If there are no big changes, that information can be used to establish a baseline.

Statement of Good Practice 2 When concern for a mental health disorder in adults with Down syndrome is present, medical professionals should evaluate for medical conditions that may present with psychiatric and behavioral symptoms.

Behavior and mental health conditions are common in adults with Down syndrome[19] and are a cause for concern with families and caregivers.

WHEN THERE IS A CHANGE IN THE ADULT WITH DOWN SYNDROME'S BEHAVIOR OR FUNCTION, IT IS BEST TO HAVE A MEDICAL AND MENTAL HEALTH EVALUATION THAT LOOKS AT OTHER MEDICAL PROBLEMS THAT COULD CAUSE THOSE SYMPTOMS, SINCE SOMETIMES MEDICAL CONDITIONS MAY LOOK LIKE A BEHAVIORAL ISSUE.[20-23]

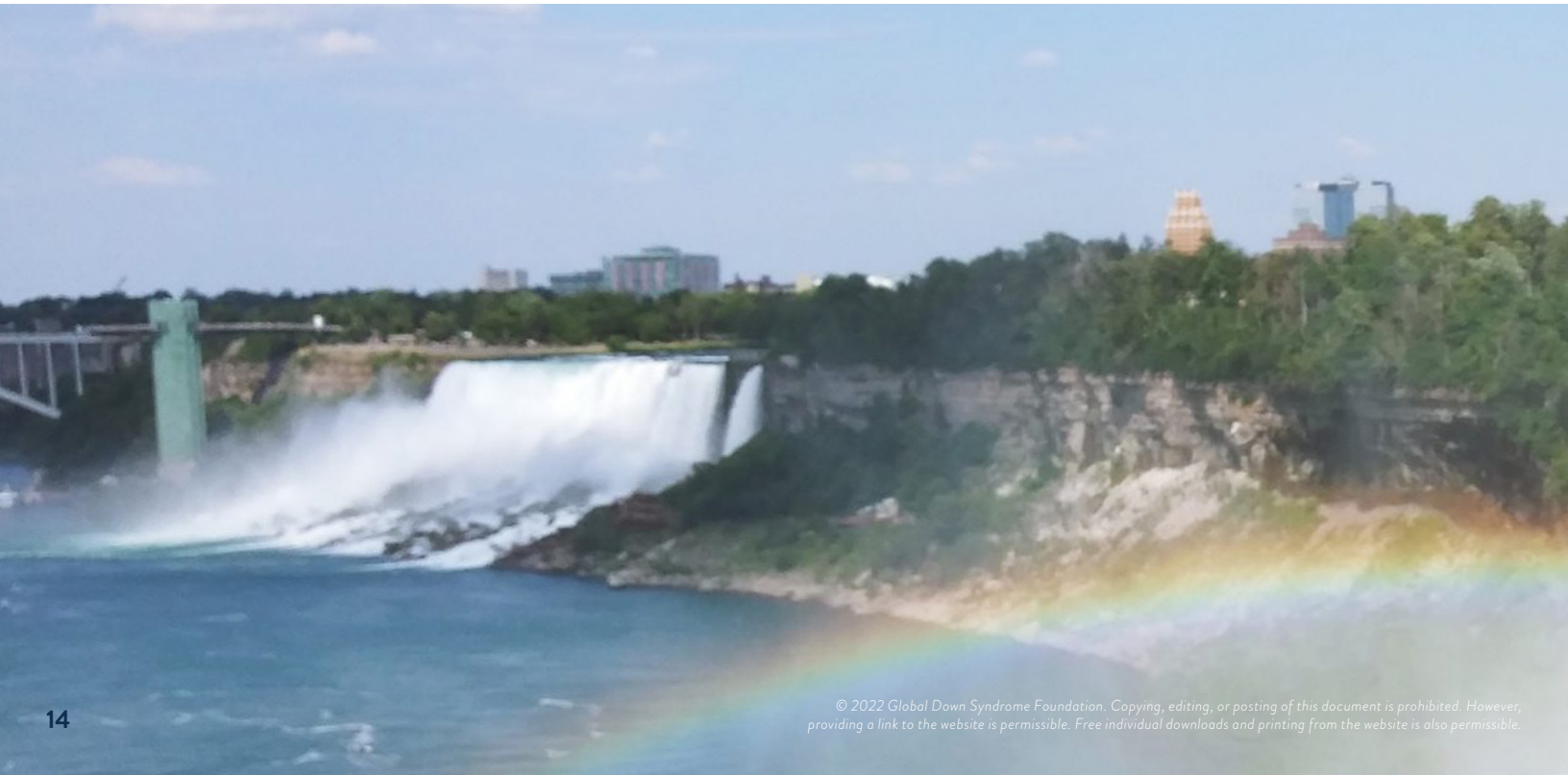
For example, head-banging when a person has a migraine, or not participating in an activity because they feel sick in their stomach.

RECOMMENDATION 1

When concern for a mental health disorder in adults with Down syndrome is present, medical professionals should refer to a clinician knowledgeable about the medical, mental health disorders, and common behavioral characteristics of adults with Down syndrome.

Behavior and mental health conditions are common in adults with Down syndrome[19] and are a cause for concern with families and caregivers. An accurate diagnosis of a mental health disorder is important so as to provide quick and effective treatment. It is also important as to avoid misdiagnosing adaptive behavior as a disorder and providing the incorrect treatment. Assessment for underlying medical conditions significantly improves understanding the causes for changes in behavior or mental health and improves treatment.

We did not find any appropriate evidence-based studies that compare symptoms of mental health conditions in adults with Down syndrome to adults without Down syndrome. However, medical professionals who do not have a lot of experience in caring for adults with Down syndrome may find it challenging to treat them correctly. For example, adults with Down syndrome are very sensitive to certain drugs. Treatment is better if medical professionals know about the drug tolerances and intolerances people with Down syndrome have and how to balance those differences. It can be hard to find a medical professional who knows about these differences, but you can find the Down syndrome clinic nearest you here: ***https://www.globaldownsyndrome.org/research-medical-care/medical-care-providers/***



RECOMMENDATION 2

When concern for a mental health disorder in adults with Down syndrome is present, medical professionals should follow guidelines for diagnosis in the Diagnostic and Statistical Manual of Mental Disorders (5th Ed; DSM-5).[24] **The Diagnostic Manual-Intellectual Disability 2** (DM-ID-2)[25] **also may be used to adapt diagnostic criteria from the DSM-5.**

It can be challenging to diagnose mental health conditions in adults with Down syndrome because their behavior may look different from adults without Down syndrome. These differences may include limited speaking skills, difficultly adapting to changes, having more than one medical problem, and not being able to see a medical professional who is familiar with mental health in adults with Down syndrome. In our experience, adults with Down syndrome frequently use self-talk, have vivid imaginary/fantasy worlds, and stick to certain routines. Certain types of behavior may be common in adults with Down syndrome (e.g., self-talk), while other behaviors may be a sign of a treatable mental health condition (e.g., agitation, irritability). Medical professionals should be careful about assuming these behaviors are part of a mental health disorder in adults with Down syndrome. Instead of relying on an adult with Down syndrome to self-report their emotional problems, it is important for medical professionals to know that maladaptive behavior may be an indicator.

If skills decline in an adult with Down syndrome, it should be looked into. Loss of function may be a sign of a medical or mental health disorder. Diagnosis should take into consideration common behaviors and be based on observed behavior in addition to self-reporting.[26-30]

2

DEMENTIA

RECOMMENDATION 3

Caution is needed when diagnosing age-related, Alzheimer's-type dementia in adults with Down syndrome younger than age 40 due to its low prevalence before this age.

Dementia describes the symptoms of memory loss and changes in language, thinking, and/or functional skills. Alzheimer's disease is a type of a dementia. This recommendation is intended to decrease the misdiagnosis of age-related, Alzheimer's-type dementia in adults with Down syndrome. Misdiagnosis of age-related dementia in adults with Down syndrome may occur if medical professionals do not carefully evaluate for other medical conditions that can also cause functional decline. Adults with Down syndrome are more likely to have dementia, but it is uncommon to show signs before age 40. It is important for medical professionals working with patients of all ages to consider other causes to avoid misdiagnosis of Alzheimer's-type dementia. Misdiagnosis keeps people from getting correct treatment. We support careful and thorough medical evaluation to see if there are other causes of dementia-type symptoms in adults with Down syndrome under 40 years old. While there are no medical treatments for dementia, there are many guidelines or treatments for helping with behaviors, quality of life, and depression, which may occur.

RECOMMENDATION 4

Medical professionals should assess adults with Down syndrome and interview their primary caregivers about changes from baseline function annually beginning at age 40. Decline in the following six domains, as per the National Task Group – Early Detection Screen for Dementia (NTG-EDSD),[31] **should be used to identify early-stage age-related Alzheimer's-type dementia and/or a potentially reversible medical condition:**

- Cognition, memory, and executive function
- Behavior and personality
- Communication
- Adaptive functioning
- Ambulation and motor skills
- General decline in established skills

Age-related dementia is a common concern for most families and caregivers of adults with Down syndrome due to its impact on quality of life. Dementia is more common after age 40 in Down syndrome.[32, 33] However, not everyone gets dementia as they get older. There is no way to diagnose dementia for sure. Some conditions and symptoms commonly mistaken for dementia include cerebrovascular (for example: stroke, aneurysms, narrowing of blood vesels, and moyamoya disease) disease, severe sleep apnea, metabolism problems or medication side effects.[31, 34]

DEMENTIA IS VERY RARE BEFORE AGE 40 IN PEOPLE WITH DOWN SYNDROME AND CHANGES BEFORE THAT AGE ARE MORE LIKELY TO BE DUE TO ANOTHER CONDITION.

We believe that an accurate diagnosis of dementia is based on more than just changes in behavior or personality. There will usually be changes in more than one area, including memory, self-control, behavior, personality, language, communication, daily living activities, continence (bladder control), and sleep patterns. Other signs of dementia in adults with Down syndrome include seizures, twitching, uncontrolled muscle movements, or loss of walking ability.

3

DIABETES

RECOMMENDATION 5

For asymptomatic adults with Down syndrome, screening for type 2 diabetes mellitus (T2DM) **using hemoglobin A1c** (HbA1c) **or fasting plasma glucose should be performed every 3 years beginning at age 30.**

RECOMMENDATION 6

For any adult with Down syndrome and comorbid obesity, screening for T2DM using HbA1c or fasting plasma glucose should be performed every 2-3 years beginning at age 21.

Type 2 diabetes occurs when a person's body has difficulty using sugar (glucose). In order to regulate their sugar levels, they need to take medication and be very careful with their diet. Diabetes is a common concern for adults with Down syndrome, their families, and caregivers since many people with Down syndrome are obese, which can cause diabetes. One study found that adults with Down syndrome are much more likely to have diabetes than adults without Down syndrome.[35] We believe that the benefits of screening adults with Down syndrome for diabetes to avoid other complications, such as brain, eye or kidney problems, are greater than the potential harms from diabetes treatment (such as medication side effects).

The American Diabetes Association (ADA) recommends screening all adults for diabetes beginning at age 45.[36] However, since adults with Down syndrome tend to age faster and get some conditions (e.g., cataracts) earlier, we recommend that all adults with Down syndrome get screening every 3 years beginning at age 30 for diabetes.[37-39] Also, obese adults with Down syndrome should be screened even younger and more frequently, every 2-3 years beginning at age 21. Earlier screening may result in more blood draws and over-treatment of diabetes after diagnosis. However, we believe the benefits are greater than the consequences of undiagnosed diabetes.

4

CARDIOVASCULAR DISEASE

RECOMMENDATION 7

For adults with Down syndrome without a history of atherosclerotic cardiovascular disease (ASCVD), **the appropriateness of statin therapy should be assessed every 5 years starting at age 40 and using a 10-year risk calculator as recommended for adults without Down syndrome by the U.S. Preventive Services Task Force** (USPSTF)**.**[40]

Heart disease is the leading cause of death in the United States, and atherosclerotic cardiovascular disease (ASCVD) is the top cause of heart disease.[41] ASCVD is a build-up of cholesterol or fat in the arteries, which makes it hard for blood to flow. There isn't much data regarding ASCVD in people with Down syndrome. However, the available data shows adults with Down syndrome have a lower risk of heart disease, which is consistent with our experience.[35, 42] The USPSTF recommends that all adults aged 40-75 get screened for hyperlipidemia (fat in the blood including cholesterol) to assess the risk of heart disease.[40] Even though adults with Down syndrome are less likely to get heart disease, there isn't enough research to say that adults with Down syndrome should be treated differently than adults without Down syndrome in this regard. Your provider can calculate the risk with their patient by using a 10-year cardiac risk calculator. Patients can also calculate the risk directly since these calculators are available on the internet and as apps. Calculating the risk can help guide decisions such as whether to take a medication to lower cholesterol. The USPSTF recommendation for measuring cholesterol and determining risk ends at age 75 because we do not know for sure if it is helpful to treat people after age 75 or people with a limited life expectancy.[43] Since adults with Down syndrome have a shorter life expectancy (60 years) than adults without Down syndrome, stopping screening at a younger age than adults without Down syndrome should be considered. Other risk factors for ASCVD in people with Down syndrome are not yet clear. Unlike adults without Down syndrome, there is no evidence that family history of ASCVD is a risk factor of adults with Down syndrome. In addition, while obesity is more common, ASCVD is less common in people with Down syndrome, suggesting other factors may be more significant in ASCVD in people with Down syndrome.

RECOMMENDATION 8

For adults with Down syndrome, risk factors for stroke should be managed as specified by the American Heart Association/American Stroke Association's Guidelines for the Primary Prevention of Stroke.[44]

RECOMMENDATION 9

In adults with Down syndrome with a history of congenital heart disease, given the elevated risk of cardioembolic stroke, a periodic cardiac evaluation and a corresponding monitoring plan should be reviewed by a cardiologist.

Congenital heart disease is more common in people with Down syndrome. About 50% of children with Down syndrome are born with congenital heart disease.[45, 46] This may include "holes in the heart" or abnormalities of the heart valves. Adults with Down syndrome who had congenital heart disease (whether it was repaired or not) are at a higher risk for a stroke.[42] A stroke causes damage to the brain due to the blockage of blood flow or the bursting of a blood vessel in the brain. One study found the average age for the first stroke was 41.8 years in those with Down syndrome and 57.1 years in those without Down syndrome.[42]

Although congenital heart disease is more common, some other risk factors for stroke are less common including hypertension (high blood pressure) and atherosclerosis.[47-49] Since the data are limited regarding the risk of stroke for adults with Down syndrome without a history of congenital heart disease, we recommend screening for stroke risk for adults with Down syndrome similarly to those without Down syndrome. However, since those with Down syndrome with congenital heart disease have a higher risk, we recommend additional screening and precaution via appropriate assessment, monitoring, and treatment of the risk factors, even though there is not yet research completed on whether this will reduce strokes. Each person being evaluated and treated for risk factors and strokes is different. Individual risk factors should be discussed with the adult with Down syndrome, their family, caregivers, and health care provider.

5

OBESITY

Statement of Good Practice 3 Healthy diet, regular exercise, and calorie management should be followed by all adults with Down syndrome as part of a comprehensive approach to weight management, appetite control, and enhancement of quality of life.

Obesity is generally considered having a body mass index (BMI) equal to or greater than 30. BMI is a measure of body proportion based on a person's weight and height. Of course, since people with Down syndrome tend to be shorter and may gain weight more easily, they may have a higher chance of their BMI being greater than 30. Many adults with Down syndrome are obese, so the health consequences of obesity are a common concern for adults with Down syndrome, their families, and caregivers. In order to have good health and quality of life, it is very important to have a healthy diet, portion control, have meals at the same time every day and get regular exercise. We also recommend getting daily exercise that includes socializing with others. Adults with Down syndrome, their families, caretakers, and medical professionals should make decisions together about planning their food and exercise choices.

RECOMMENDATION 10

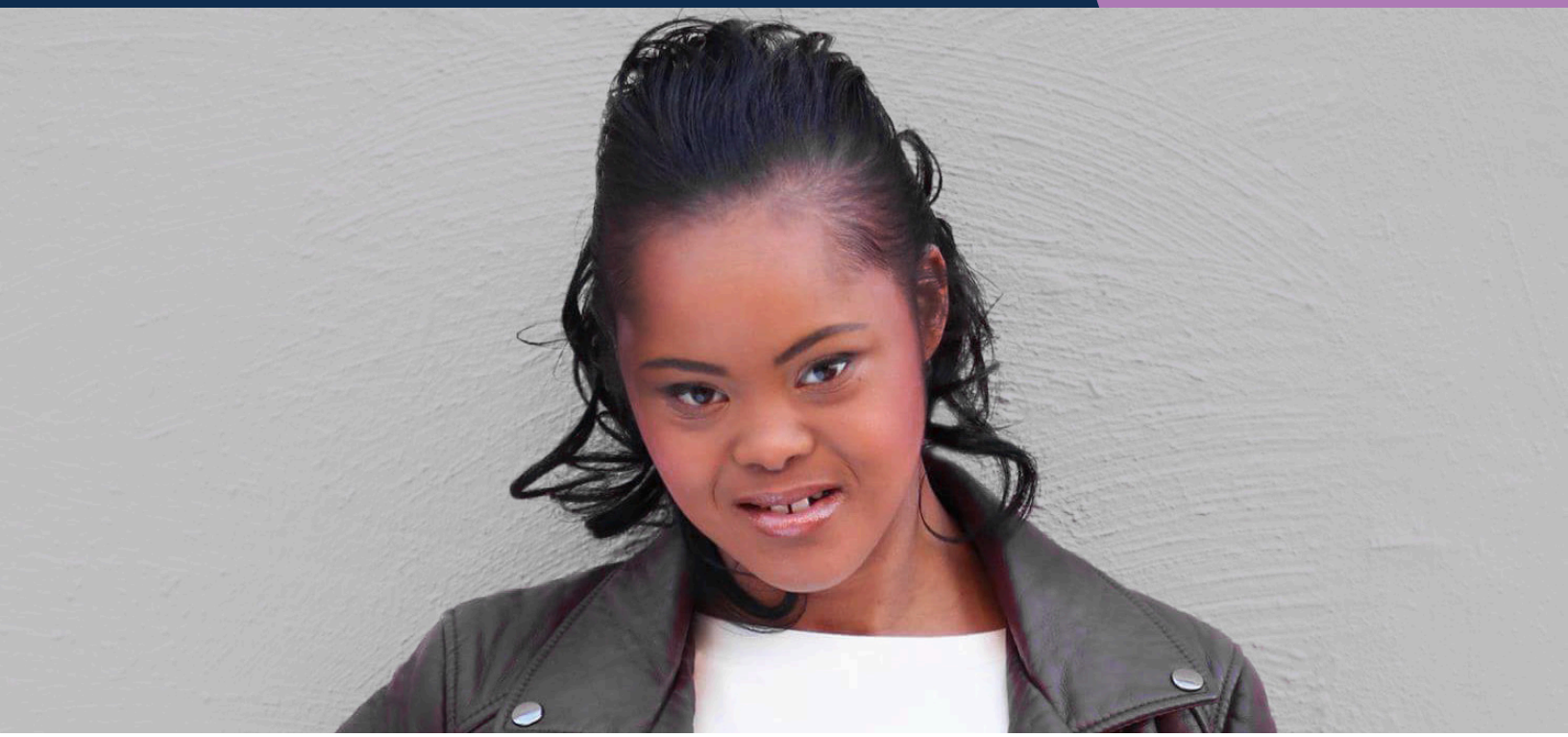
Monitoring for weight change and obesity should be performed annually by calculating body mass index (BMI) **in adults with Down syndrome. The U.S. Preventive Services Task Force** (USPSTF) ***Behavioral Weight Loss Interventions to Prevent Obesity-Related Morbidity and Mortality in Adults*** **should be followed.**[50]

Many adults with Down syndrome are obese, so the health consequences of obesity are a common concern for adults with Down syndrome, their families, and caregivers. We did not find any specific studies on the effects of obese adults with Down syndrome following a healthy diet, practicing portion control and exercising regularly. This is because most studies focus on exercise only and not on portion control, or focus on both for adults without Down syndrome.[51] The studies that focused on exercise only for adults with Down syndrome showed that it improved their balance, muscle strength and endurance.[52]

Some factors that contribute to obesity in adults with Down syndrome are lack of physical activity and nutritional guidance, and lack of control over their environment and food choices. Some medical issues and medications also contribute to gaining weight.[53, 54] Adults with Down syndrome face many obstacles when it comes to getting enough exercise,[55] but not all of them become obese. Families can help their family member with Down syndrome keep healthy and/or lose weight. We have noticed that social group activities like dancing, Zumba, working with a personal trainer, or team sports through the Special Olympics have been very successful.

6

ATLANTOAXIAL INSTABILITY



RECOMMENDATION 11

In adults with Down syndrome, routine cervical spine X-rays should not be used to screen for risk of spinal cord injury in asymptomatic individuals. Instead, annual screening of adults with Down syndrome should include a review of signs and symptoms of cervical myelopathy using targeted history and physical exam.

Atlantoaxial instability (AAI) occurs when the bones at the base of the skull and top of the neck are unstable. About 10% of adults with Down syndrome are found to have AAI when they are X-rayed, but they don't seem to have spinal cord injuries. There are no studies that prove there is a connection between having AAI as seen on an X-ray and having spinal cord injuries. Looking for signs of spinal cord injury during a physical exam is low cost and low risk. There are not many cases of spinal cord injury in people with Down syndrome due to AAI. Special Olympics organizers have reported no spinal cord injuries from over 50,000 individuals with Down syndrome participating in Special Olympics activities over 20 years.[56]

It is important to avoid a spinal cord injury because it can cause other medical problems and even death. However, X-ray findings are not specific and could result in restricting activity unnecessarily. A physical exam should be the first step if they don't show symptoms of spinal cord injury. Some adults with Down syndrome and families/caregivers may feel differently, so it's important to make the decision together. If there are symptoms or signs of spinal cord injury, then X-rays and other tests should be run. Some symptoms of spinal cord injury include walking differently, weaker legs or hands (dropping objects), incontinence, and difficulty holding ones head up.

7

OSTEOPOROSIS

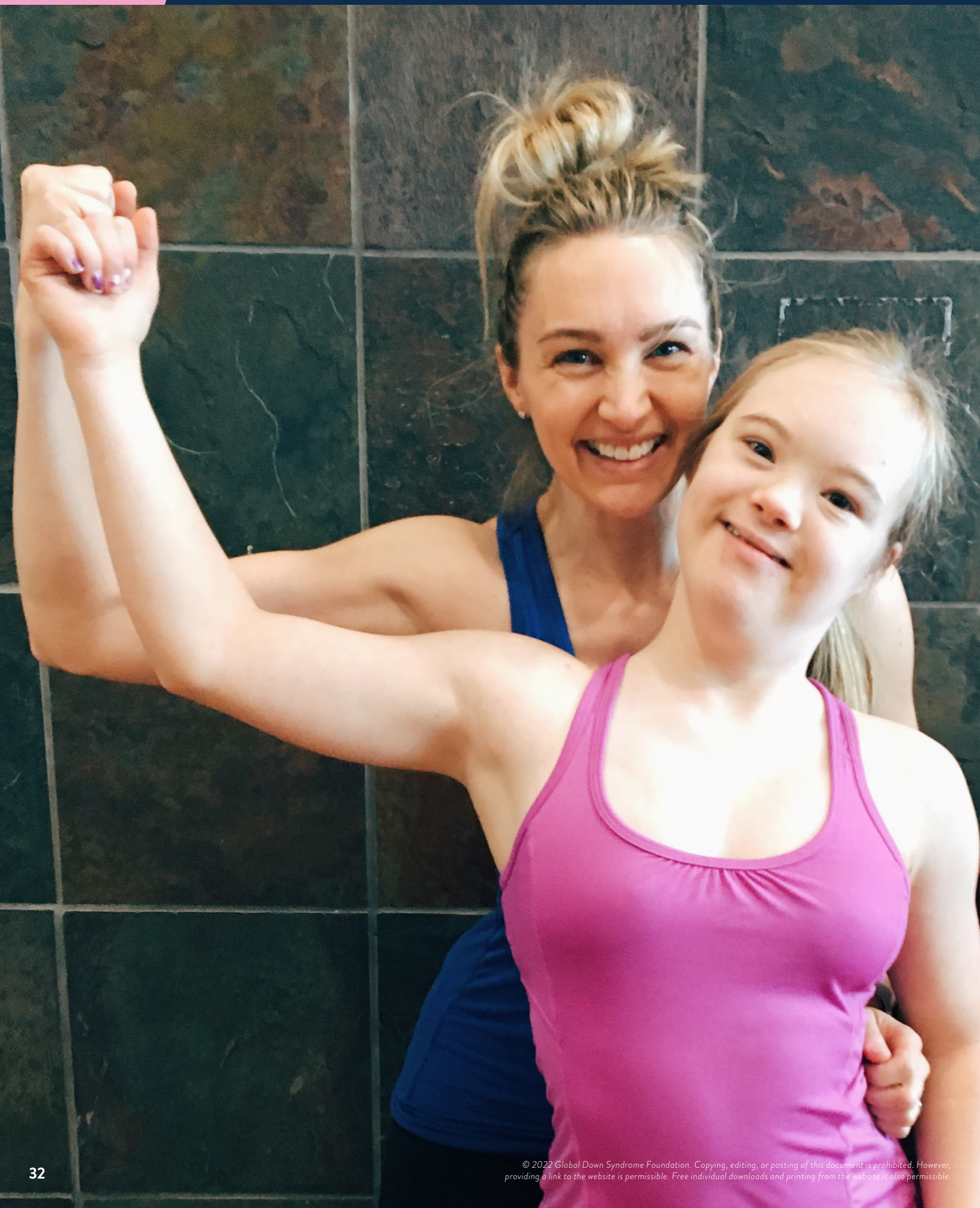
RECOMMENDATION 12

For primary prevention of osteoporotic fractures in adults with Down syndrome, there is insufficient evidence to recommend for or against applying established osteoporosis screening guidelines, including fracture risk estimation; thus, good clinical practice would support a shared decision-making approach to this issue.

Osteoporosis is a bone disease that gets more severe as a person gets older. It happens when the bones lose minerals and become weaker, which causes the bones to break more easily. There is not enough evidence on how to prevent osteoporosis in adults with Down syndrome, and the data available is from adults without Down syndrome. The most common tools for predicting bone breakage (DEXA Scan) were designed for adults without Down syndrome, so they may not work well for adults with Down syndrome. Additionally, we don't know much about how or how many adults with Down syndrome break their bones due to fragility, but it may be very different from adults without Down syndrome.

The most common drugs for preventing and treating osteoporosis may not be the most effective, and may even be dangerous for adults with Down syndrome.[57] We are concerned that diagnosing and treating adults with Down syndrome for osteoporosis the same way as adults without Down syndrome could cause problems, so we recommend that each family makes the decision together with their medical professional on the potential risks, benefits and uncertainties around osteoporosis screening and prevention, including medications, exercise, and vitamin D.

WE DO RECOMMEND MUSCLE STRENGTHENING EXERCISES, AS THEY ARE GOOD FOR BONE HEALTH AND ARE USUALLY SAFE FOR ADULTS WITH DOWN SYNDROME.[52]



RECOMMENDATION 13

All adults with Down syndrome who sustain a fragility fracture should be evaluated for secondary causes of osteoporosis, including screening for hyperthyroidism, celiac disease, vitamin D deficiency, hyperparathyroidism and medications associated with adverse effects on bone health.

Potential secondary causes of osteoporosis are more prevalent in adults with Down syndrome than in adults without Down syndrome. Lack of exercise and certain medical conditions can lead to adults with Down syndrome breaking a bone due to osteoporosis.[58-62] Many of these conditions can be corrected and bone health can be improved with healthy habits. Researchers are studying if vitamin D supplementation works for preventing and treating osteoporosis in adults without Down syndrome.[63] It is common for adults with Down syndrome to have low vitamin D. Vitamin D might help their bones and doesn't seem to cause harm.[64] In addition to vitamin D, we recommend looking at all options for preventing osteoporosis as is recommended for adults without Down syndrome, including getting enough calcium, preventing falls, improving vision, and lifting weights.[65]

8

THYROID

RECOMMENDATION 14

Screening adults with Down syndrome for hypothyroidism should be performed every 1-2 years using a serum thyroid-stimulating hormone (TSH) **test beginning at age 21.**

The thyroid gland is located in the neck and produces hormones related to activity, metabolism and heart rate. If the thyroid makes too much hormone, that is called hyperthyroidism. If the thyroid makes too little hormone, that is called hypothyroidism. Three studies show that adults with Down syndrome are more likely to have thyroid problems than adults without Down syndrome.[35, 66, 67] It is common for adults with Down syndrome to have hypothyroidism and is more common as they get older.

DIAGNOSING HYPOTHYROIDISM IN ADULTS WITH DOWN SYNDROME CAN BE HARD BECAUSE SOME OF THE SYMPTOMS, FOR EXAMPLE FATIGUE, WEIGHT GAIN AND CONSTIPATION, ARE COMMON IN ADULTS WITH DOWN SYNDROME WHETHER OR NOT THEY HAVE THYROID PROBLEMS.

Relying only on symptoms is not enough, so we believe it is important to use a TSH blood test every 1-2 years. Even though having a blood draw can cause anxiety, getting a correct diagnosis could prevent future behavior changes and weight gain, which are hard to reverse later. Proper treatment can also improve constipation, dry skin, fatigue and more. Treatment is inexpensive, safe, and works better if hypothyroidism is detected early instead of waiting for obvious signs.

9

CELIAC DISEASE

Statement of Good Practice 4 Adults with Down syndrome should receive an annual assessment for gastrointestinal and non-gastrointestinal signs and symptoms of celiac disease using targeted history, physical examination, and clinical judgment of good practice.

Celiac disease is an autoimmune condition where your body has a reaction to gluten (a protein found in foods containing wheat, rye and barley). Studies show that celiac disease is more common in children with Down syndrome.[68, 69] Adult onset of celiac disease, however, has not been well studied in adults with Down syndrome. Diagnosing celiac disease in adults with Down syndrome may be challenging due to communication difficulties and the fact that signs and symptoms of celiac disease can be common symptoms of other conditions. Also, many of the signs and symptoms, like constipation or rashes, are common in Down syndrome, even if they don't have celiac disease. Therefore, in addition to stomach problems, medical professionals should evaluate for celiac disease every year using a physical exam paying attention to behavioral changes, rashes, and symptoms of other possible autoimmune disorders. Confirming a diagnosis of celiac disease requires laboratory testing and a bowel biopsy, so some families who suspect celiac disease may try a gluten-free diet at home to see if it helps.

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GLOBAL DOWN SYNDROME FOUNDATION. The Global Down Syndrome Foundation (GLOBAL) is the largest non-profit in the U.S. working to save lives and dramatically improve health outcomes for people with Down syndrome. GLOBAL established the first Down syndrome research institute supporting over 400 scientists and over 2,200 patients with Down syndrome from 33 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 120 Down syndrome organizations worldwide and is part of a network of Affiliates.

FOR MORE INFORMATION VISIT OUR WEBSITE: https://www.globaldownsyndrome.org/

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MEDICAL CARE GUIDELINES FOR ADULTS WITH DOWN SYNDROME
https://www.globaldownsyndrome.org/medical-care-guidelines-for-adults/

DOWN SYNDROME MEDICAL CARE CENTERS IN THE U.S. BY STATE
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LOCAL DOWN SYNDROME ORGANIZATIONS IN THE U.S. BY STATE
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LINDA CRNIC INSTITUTE FOR DOWN SYNDROME
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** In loving memory of Dr. Kent McKelvey, who dedicated his life to caring for adults with Down syndrome. His leadership and belief in GLOBAL gave us the confidence to create this important guideline. We are forever grateful.*

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https://www.aadmd.org/

DOWN SYNDROME-AUTISM CONNECTION
http://www.ds-asd-connection.org/

DOWN SYNDROME MEDICAL INTEREST GROUP-USA
https://www.dsmig-usa.org/

DS CONNECT® *AN IMPORTANT REGISTRY AND PORTAL CONNECTING PEOPLE WITH DOWN SYNDROME, CLINICIANS, AND RESEARCHERS*
https://dsconnect.nih.gov/

INCLUDE DATA CORDINATING CENTER
https://includedcc.org/

INTERNATIONAL MOSAIC DOWN SYNDROME ASSOCIATION
https://www.imdsa.org/mosaic-down-syndrome

NATIONAL DOWN SYNDROME CONGRESS
https://www.ndsccenter.org/

NATIONAL DOWN SYNDROME SOCIETY
https://www.ndss.org/

NATIONAL INSTITUTES OF HEALTH DOWN SYNDROME CONSORTIUM
https://downsyndrome.nih.gov/

NATIONAL TASK GROUP ON INTELLECTUAL DISABILITIES AND DEMENTIA PRACTICES
https://www.the-ntg.org/

SPECIAL OLYMPICS
https://www.specialolympics.org/

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https://thearc.org/

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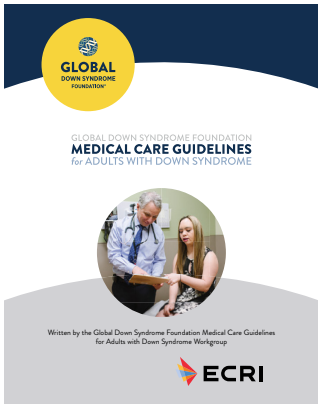
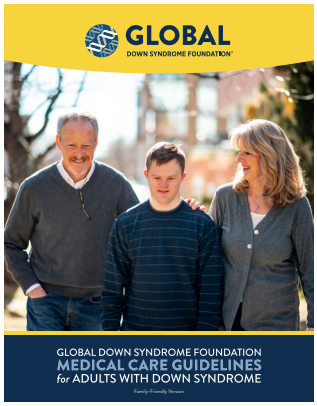
ADDITIONAL GLOBAL RESOURCES

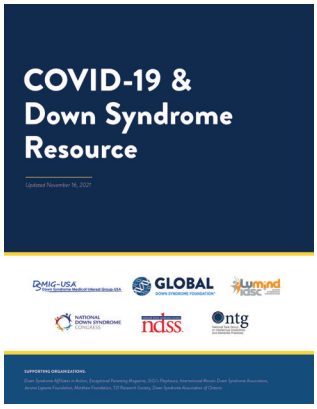


GLOBAL Adult Care Guideline for Clinicians

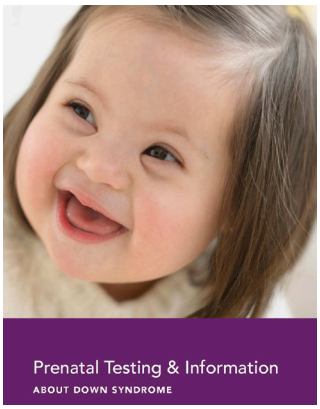


GLOBAL Family,-Friendly Adult Care Guideline

GLOBAL Adult Care Guideline Checklist



COVID-19 & Down Syndrome Resource



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