How the CDC Supports People with Down Syndrome & An Update on COVID-19 Vaccinations

Welcome Remarks from

Michelle Sie Whitten
President & CEO, GLOBAL

Thursday, July 29, 2021 • 12:00pm - 1:00pm MT
Today’s Speaker - Dr. Karen Remley

Karen Remley, MD, MBA, MPH, FAAP, Director of the Centers for Disease Control and Prevention’s National Center on Birth Defects and Developmental Disabilities

Dr. Remley has more than 30 years of experience in public health and health care. Her “north star” has always been children and families, and she has shaped her career around helping every family have the best opportunity for health and well-being.
How the CDC Supports People with Down Syndrome & An Update on COVID-19 Vaccinations

Welcome Remarks from

Yadira Carrillo
Fierce GLOBAL Advocate

Thursday, July 29, 2021 • 12:00pm - 1:00pm MT
Welcome!

- Welcome to GLOBAL’s Summer Webinar! Thank you, Michelle and GLOBAL for bringing us this wonderful Webinar Series.

- My name is Yadira Carrillo. I’m from Colorado, and I love working with GLOBAL. I spoke at their AcceptAbility Gala, co-hosted GLOBAL’s Morning Social, and modeled in the famous Be Beautiful Be Yourself Fashion Show. I’m so happy to be working with GLOBAL again for this webinar with the CDC!

- This webinar is very important to me personally, because in November 2020, I contracted Covid-19 and was hospitalized with pneumonia for a week. It was scary for me and my family, but I recovered and am now healthy and vaccinated.

- I am thankful to the CDC for prioritizing people with Down syndrome for the COVID-19 vaccine and to GLOBAL for creating the COVID-19 & Down syndrome Resource so that people with Down syndrome could be as safe as possible during the pandemic.
Thanks to research and medical care supported by GLOBAL, I can continue living a full life to my motto, “Down with Style and Uniqueness!”

And thanks to the CDC’s COVID-19 efforts and work to improve the health of people with Down syndrome, other people with Down syndrome are getting vaccinated and living healthier lives, too!

Today’s webinar on How the CDC Supports People with Down Syndrome & An Update on COVID-19 Vaccinations will help show us how much progress is being made and what’s next for Down syndrome research and advocacy!

And now I am pleased to introduce today’s speaker, Dr. Remley!
CDC Efforts to Promote the Health of People with Down Syndrome

July 29, 2021

Karen Remley, MD, MBA, MPH, FAAP
Director
National Center on Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention
Why I am here...
The Children’s Health Act of 2000 established the CDC’s National Center on Birth Defects and Developmental Disabilities (NCBDDDD).
NCBDDD FY 2021 Appropriations (in thousands)

<table>
<thead>
<tr>
<th>Program</th>
<th>Appropriation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Birth Defects</td>
<td>$19,000</td>
</tr>
<tr>
<td>Fetal Death</td>
<td>$900</td>
</tr>
<tr>
<td>Fetal Alcohol Syndrome</td>
<td>$11,000</td>
</tr>
<tr>
<td>Folic Acid</td>
<td>$3,150</td>
</tr>
<tr>
<td>Infant Health</td>
<td>$8,650</td>
</tr>
<tr>
<td>Autism</td>
<td>$23,100</td>
</tr>
<tr>
<td>Neonatal Abstinence Syndrome</td>
<td>$2,250</td>
</tr>
<tr>
<td>Surveillance for Emerging Threats to Mothers and Babies</td>
<td>$10,000</td>
</tr>
<tr>
<td>Disability and Health</td>
<td>$36,000</td>
</tr>
<tr>
<td>Tourette Syndrome</td>
<td>$2,000</td>
</tr>
<tr>
<td>EHDI</td>
<td>$10,760</td>
</tr>
<tr>
<td>Muscular Dystrophy</td>
<td>$6,000</td>
</tr>
<tr>
<td>ADHD</td>
<td>$1,900</td>
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<tr>
<td>Fragile X</td>
<td>$2,000</td>
</tr>
<tr>
<td>Spina Bifida</td>
<td>$7,000</td>
</tr>
<tr>
<td>Congenital Heart Failure</td>
<td>$7,000</td>
</tr>
<tr>
<td>Public Health Approach to Blood Disorders</td>
<td>$4,400</td>
</tr>
<tr>
<td>Sickle Cell Disease Research</td>
<td>$2,000</td>
</tr>
<tr>
<td>Hemophilia CDC Activities</td>
<td>$3,500</td>
</tr>
<tr>
<td>Hemophilia Treatment Centers</td>
<td>$5,100</td>
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<tr>
<td>Thalassemia</td>
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<tr>
<td>Surveillance for Emerging Threats to Mothers and Babies</td>
<td>$10,000</td>
</tr>
<tr>
<td>Disability and Health</td>
<td>$36,000</td>
</tr>
<tr>
<td>NCBDDD Total</td>
<td>$167,810</td>
</tr>
</tbody>
</table>

*All dollar amounts are in thousands.*
NCBDDD’s Thematic Areas

- **SAVING BABIES**
  - Through birth defects prevention and research

- **HELPING CHILDREN**
  - Live to the fullest by understanding developmental disabilities

- **PROTECTING PEOPLE**
  - And preventing complications of blood disorders

- **IMPROVING HEALTH**
  - Of people with disabilities
Stigma – Hidden and Seen Disability

Mental health of children and parents—a strong connection

Bullying

Delayed Identification of Infants and Children

Some disabilities may be hidden or not easy to see.
CDC collects data on Down syndrome, as well as additional co-occurring major birth defects. Data improve planning for needed services and supports.
Congenital Heart Defect: Areas of Focus

**Prevalence**
Estimate the number of babies born with and people living with heart defects

**Physical Health**
Understand the physical health and long-term survival of people with heart defects

**Risk Factors**
Identify environmental and genetic factors that may cause heart defects

**Reproductive Health**
Understand the reproductive health of women with heart defects

**Screening**
Study the impact of newborn screening for critical congenital heart defects, as well as ways to improve screening

**Quality of Life**
Characterize the quality of life of people living with heart defects, including social, educational, and behavioral aspects

**Healthcare Access & Use**
 Characterize healthcare access and use among people living with heart defects

**Awareness**
Disseminate information about heart defects as a lifelong condition
Among 13,376 children with Down syndrome, 75% had at least one reported co-occurring birth defect diagnosis code.

Among 6,210 of these children identified by active tracking programs, 66% had a heart defect.

Up-to-date population-based data on birth defects among children with Down syndrome can aid clinical evaluation and monitoring.

CDC researchers and partners are looking at survival of people with Down syndrome who do or do not have critical congenital heart defects.

Infant Hearing loss

More and more babies who are born deaf or hard of hearing are being identified early in the United States.

<table>
<thead>
<tr>
<th>Year</th>
<th>Number of Babies</th>
</tr>
</thead>
<tbody>
<tr>
<td>2005</td>
<td>2,634 babies</td>
</tr>
<tr>
<td>2019</td>
<td>5,934 babies</td>
</tr>
</tbody>
</table>

1. Before one month of age: Hearing Screening
2. Before three months of age: Hearing Evaluation
3. Before six months of age: Early Intervention
Disability and Health

One in four American adults has a disability.*

*2016 Behavioral Risk Factor Surveillance System (BRFSS)
Special Olympics International: Creating a Tipping Point towards Inclusive Health for People with Intellectual Disabilities
Disability and Health State Programs
COVID-19: Major Implications for NCBDDD populations

CLD_GSU @CLD_GSU · Jul 26
Hear from Evan & his DSP, Andrew, about why they got the COVID-19 vaccine.
CLD is working with @AUCDNews to ensure all eligible people with disabilities have access to the COVID-19 vaccine by the #ADA anniversary today. youtube.com/watch?v=giBAYQ...
#VaccinateByADA #AUCDSleeveUP

Erin Vinoski Thomas, PhD, MPH (she/her) and 6 others
People with Certain Medical Conditions

Updated May 13, 2021

Vaccine information for People with Certain Medical Conditions.

This information is intended for a general audience. Healthcare providers should see Underlying Medical Conditions Associated with High Risk for Severe COVID-19 for more detailed information.

Down syndrome

Having Down syndrome can make you more likely to get severely ill from COVID-19.

Get more information:

- Down syndrome | CDC

SLEEVES UP, NOLA!
The COVID vaccine is our shot to get back to normal.

Disability is a part of vaccine equity
Addressing Needs of People with Disabilities in COVID-19 Local Preparedness Planning, Mitigation and Recovery
COVID Data Tracker

United States
At a Glance

Cases Total: 34,548,847
Deaths Total: 609,012

69.1% of Adults with At Least One Vaccination

Community Transmission: High
COVID-19 Daily Case Trend - US

Daily Trends in Number of COVID-19 Cases in the United States Reported to CDC

July 8, 2020 – July 26, 2021

https://covid.cdc.gov/covid-data-tracker/#trends_dailytrendscases
COVID-19 Hospitalizations

New Admissions of Patients with Confirmed COVID-19, United States
August 01, 2020 – July 25, 2021

2,369,943
Total Admissions
Aug 01, 2020 – Jul 25, 2021

4,981
Current 7-Day Average
Jul 19, 2021 – Jul 25, 2021

3,376
Prior 7-Day Average
Jul 12, 2021 – Jul 18, 2021

16,492
Peak 7-Day Average
Jan 03, 2021 – Jan 09, 2021

+47.5%
Percent change from prior 7-day avg. of Jul 12, 2021 – Jul 18, 2021

-69.8%
Percent change from peak 7-day avg. of Jan 03, 2021 – Jan 09, 2021

Daily Trends in COVID-19 Cases in the United States Reported to CDC
Emerging Variant Virus Cases in the United States
As of July 28, 2021


Regional proportions from specimens collected the two weeks ending 7/17/2021.

US Territories not shown are included in HHS regions:
PR, VI - Region 2
AS, FM, GU, MH, MP, PW - Region 9

https://covid.cdc.gov/covid-data-tracker/#variant-proportions
COVID-19 Incidence among Adolescents

March 1, 2020 – April 30, 2021

>1.5 million cases among adolescents 12-17 years of age

https://covid.cdc.gov/covid-data-tracker/#demographicsovertime
#VaccinateByADA

Join AUCD in Celebrating ADA 31
Americans with Disabilities Act
July 26, 2021
Currently Authorized Vaccines

- Pfizer-BioNTech
- Moderna
- Johnson & Johnson/Janssen

All three vaccines were tested in tens of thousands of adults from diverse backgrounds, including older adults and communities of color.

All three vaccines have been proven effective at preventing serious illness, hospitalization, and death from COVID-19 disease.

It is unknown how long protection from vaccines might last.

How mRNA COVID-19 Vaccines Work

What is mRNA?
Messenger RNA, or mRNA, is genetic material that tells your body how to make proteins.

What is in the vaccine?
The vaccine is made of mRNA wrapped in a coating that makes delivery easy and keeps the body from damaging it.

How does the vaccine work?
The mRNA in the vaccine teaches your cells how to make copies of the spike protein. If you are exposed to the real virus later, your body will recognize it and know how to fight it off.

How Viral Vector COVID-19 Vaccines Work

What is a viral vector vaccine?
A viral vector vaccine uses a harmless version of a different virus, called a “vector,” to deliver information to the body that helps it protect you.

How does the vaccine work?
The vaccine teaches your body how to make copies of the spike proteins. If you are exposed to the real virus later, your body will recognize it and know how to fight it off.

The vaccine DOES NOT contain the virus that causes COVID-19 and cannot give you COVID-19. It also cannot make you sick from the virus that is used as the vector. It cannot change your DNA in any way.
All three vaccines authorized for use in US are effective at preventing COVID-19.

Pfizer-BioNTech and Moderna vaccines had >94% vaccine effectiveness (VE) in phase 3 clinical trials.
- 100% VE against severe disease
- No deaths occurred in the vaccinated group.

Johnson & Johnson's Janssen vaccine had 72% VE in U.S. clinical trial sites and 66% worldwide.
- 85% VE against severe disease
- No deaths occurred in the vaccinated group.
Vaccine Safety Monitoring

Safety Monitoring Timeline

- Vaccination Start

Active/passive surveillance, case consults

- Active surveillance
- Passive surveillance
- Individual case consults

Large linked database monitoring

- VA EHR & data warehouse
- VSD: Vaccine Safety Datalink
- VAERS: Vaccine Adverse Event Reporting System
- DoD VAECs
- VA ADERS
- NHSN: National Healthcare Safety Network
- CISA: Clinical Immunization Safety Assessment (CISA) Project
- CDC + FDA

DoD DMSS: Defense Medical Surveillance System

- Federal Partners
- BEST Initiative
- PRISM: Vaccine Surveillance Medical Institute
Possible Side-Effects After Getting a COVID-19 Vaccine

Common side effects:

On the arm where you got the shot:
- Pain
- Redness
- Swelling

Throughout the rest of your body:
- Tiredness
- Headache
- Muscle pain
- Chills
- Fever
- Nausea

You may consider:

To reduce pain and discomfort where you got the shot
- Apply a clean, cool, wet washcloth over the area.
- Use or exercise your arm.

To reduce discomfort from fever
- Drink plenty of fluids.
- Dress lightly.

It is not recommended you take over-the-counter medicine such as ibuprofen, aspirin, or acetaminophen before vaccination for the purpose of trying to prevent vaccine-related side-effects.

• Vaccine may be administered to persons with underlying medical conditions who have no contraindications to vaccination

• Clinical trials demonstrate similar safety and efficacy profiles in persons with underlying medical conditions, including those that place them at increased risk for severe COVID-19, compared to persons without comorbidities

<table>
<thead>
<tr>
<th>People Vaccinated</th>
<th>At Least One Dose</th>
<th>Fully Vaccinated</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total</td>
<td>189,494,180</td>
<td>163,588,042</td>
</tr>
<tr>
<td>% of Total Population</td>
<td>57.1%</td>
<td>49.3%</td>
</tr>
<tr>
<td>Population ≥ 12 Years of Age</td>
<td>189,271,132</td>
<td>163,458,560</td>
</tr>
<tr>
<td>% of Population ≥ 12 Years of Age</td>
<td>66.8%</td>
<td>57.6%</td>
</tr>
<tr>
<td>Population ≥ 18 Years of Age</td>
<td>178,887,734</td>
<td>155,409,480</td>
</tr>
<tr>
<td>% of Population ≥ 18 Years of Age</td>
<td>69.3%</td>
<td>60.2%</td>
</tr>
<tr>
<td>Population ≥ 65 Years of Age</td>
<td>49,008,552</td>
<td>43,678,577</td>
</tr>
<tr>
<td>% of Population ≥ 65 Years of Age</td>
<td>89.6%</td>
<td>79.9%</td>
</tr>
</tbody>
</table>

Learn more about the distribution of vaccines.

163.6M People fully vaccinated

About these data

CDC | Data as of: July 28, 2021 6:00am ET. Posted: Wednesday, July 28, 2021 2:40 PM ET
1) Children with developmental disabilities (DDs) may be at higher risk from COVID-19 illness because of increased prevalence of underlying health conditions, suboptimal vaccination rates, and systemic inequities.

2) Strategies can be implemented and supported by pediatricians to ensure that children with DDs, their caregivers, family members, and service providers receive the COVID-19 vaccine to reduce negative outcomes.

3) Highlighting the unique considerations for COVID-19 vaccination for children with DDs can support equitable access of vaccination for children with DDs and their families.
**SHOULD I BE CONCERNED ABOUT THE DELTA VARIANT?**

New data show Delta is different than past versions of the virus: it is much more contagious.

- Vaccinated people can get breakthrough infections of Delta variant and may be contagious.
- Vaccinated individuals represent a very small amount of total transmission.

**DO I NEED TO WEAR A MASK?**

In areas of substantial or high transmission, everyone should wear a mask in public indoor settings to help prevent the spread of Delta variant and protect others.
ARE VACCINES EFFECTIVE?
Yes! Getting vaccinated prevents severe illness, hospitalization, and death; it also helps reduce the spread of the virus in communities.
With the Delta variant, vaccination is more urgent than ever.

<table>
<thead>
<tr>
<th>Protected from</th>
<th>Vaccinated</th>
<th>Unvaccinated</th>
</tr>
</thead>
<tbody>
<tr>
<td>Severe Symptoms</td>
<td>✔️</td>
<td>☓</td>
</tr>
<tr>
<td>Hospitalization</td>
<td>✔️</td>
<td>☓</td>
</tr>
<tr>
<td>Death</td>
<td>✔️</td>
<td>☓</td>
</tr>
</tbody>
</table>

cdc.gov/coronavirus

WHAT SHOULD SCHOOLS DO?
CDC recommends universal indoor masking for all teachers, staff, students, and visitors to K-12 schools, regardless of vaccination status. Children should return to full-time in-person learning in the fall with layered prevention strategies in place.
cdc.gov/coronavirus
Looking Ahead

COVID-19 vaccine implementation efforts are focused on:

- **Continued surveillance of variant viruses**: To prepare and adapt with a vaccine response.
- **Continued vaccine effectiveness studies**: To understand how the vaccines are working.
- **Expanding vaccine-eligible populations**: To vaccinate groups like children and adolescents.
- **Combating vaccine hesitancy**: And offering vaccines to groups that declined initially.
- **Continuing focus on vaccine equity**: To include disproportionately affected communities.
To help the United States succeed against COVID-19, CDC is working with state, territorial, local, and tribal partners, and community-serving organizations, to ensure all public health actions address health disparities for all populations.

**Populations of Focus**
- Racial and ethnic minority populations
- People living in rural or frontier areas
- People experiencing homelessness
- People with disabilities
- People with substance use disorders
- People who are justice-involved

**Primary Care Providers’ Level of Preparedness for Recommending Physical Activity to Adults with Disabilities**

Are Primary Care Providers Recommending Physical Activity to Patients with Disabilities?

The Centers for Disease Control and Prevention (CDC’s) Preventing Chronic Disease journal published a new study that looked at how prepared primary care providers (PCPs) feel to recommend physical activity to adults with disabilities. CDC scientists found that PCPs, specifically family doctors, internists, and nurse practitioners, are more likely to recommend physical activity to their patients with disabilities on a regular basis if they feel prepared to do so. However, just over 1 in 3 PCPs strongly agreed that they felt prepared to discuss physical activity with their adult patients with disabilities. Currently, half of PCPs recommend physical activity to their patients with disabilities at most visits.
Additional Resources for Healthcare Providers

- NIH Treatment Guidelines: https://www.covid19treatmentguidelines.nih.gov/therapeutic-management/
CDC Webpages on Underlying Conditions

- CDC webpages on underlying conditions
  - For clinicians:
MAKING A DIFFERENCE ACROSS THE LIFESPAN
National Center on Birth Defects and Developmental Disabilities
Thank you for attending!

❖ Additional Resources:

➢ GLOBAL Medical Guidelines for Adults with Down Syndrome
➢ COVID-19 & Down Syndrome Resource
➢ GLOBAL COVID-19 & Down Syndrome Vaccine Tracker by State