

Talking Points about COVID-19 vaccines and Down syndrome:

- Equitable distribution of available vaccines to adults with Down syndrome.
- <u>Call-to-Action</u> campaign asking people to contact NC Health and Human Services (NCHHS) Secretary Dr. Many Cohen, Governor Roy Cooper, and members of the North Carolina General Assembly.
- Centers for Disease Control (CDC) <u>added Down syndrome</u> to the list of conditions of increased risk of severe illness due to COVID-19.
- Patients with Down syndrome have an estimated <u>4-fold increased risk</u> for COVID-19–related hospitalization.
- Patients with Down syndrome have an estimated <u>10-fold increased risk</u> for COVID-19–related death.
- The <u>risk of death increases</u> for patients with Down syndrome age 40 and older (similar to patients without Down syndrome age 80 and older).
- Adults with Down syndrome are at increased risk for severe illness. <u>Severe illness from COVID-19</u> is defined as hospitalization, admission to the ICU, intubation or mechanical ventilation, or death.
- Based on the CDC's announcement, people with Down syndrome in NC were <u>originally placed in</u> <u>Group 2</u> for priority for vaccination.
- The recent restructuring of the vaccine priority list in North Carolina moved people with Down syndrome to Group 4.
- The response from the NC HHS contends that adults with Down Syndrome are already included in Groups 1, 2, and 3:
 - Group 1 Most adults with Down syndrome do not live in long-term care congregate settings such as group homes, adult care homes or <u>receive supports and services</u>
 - Group 2 Average <u>life expectancy</u> of a person with Down syndrome is 60 years of age
 - Group 3 The <u>unemployment rate</u> for people with disabilities is nearly 80%
- The number of adults with Down syndrome living in North Carolina who anticipate receiving the vaccination would not put an undue burden on system versus the number of care givers per adult with Down syndrome eligible for the vaccine under Group 1.
- Individuals with Down syndrome having severe illness will impact the healthcare system as well as lead to poor healthcare outcomes and higher rates of mortality.



Tips for speaking to the media:

- Be prepared and be concise long answers may get cut off when broadcast.
- When interviewing parents, reporters are usually looking for personal stories. Think about how this situation impacts your family.
- Avoid disability jargon and acronyms.
- Be ready to answer seemingly off-topic questions.
- Whether a phone or video conversation, the conversation will be recorded.
- If you do not know the answer to a question, say so. Refer the reporter to NCDSA or the organization who connected you for further information.
- If you do not want to answer a question, say so.
- If you want to share information but not be quoted, you can state it is "off the record."
- Expect to be interviewed for at least ten minutes. However, your comments will be cut down to anywhere from 30 seconds to two minutes.
- Parents can offer to send a picture their loved one or one of the family.
- Thank them for the opportunity to bring focus to this issue.