



March 1, 2021

Governor Janet Mills
1 State House Station
Augusta, ME 04333

Cc: DHHS Commissioner Jeanne Lambrew
Cc: Maine CDC Director Dr. Nirav Shah

Dear Governor Mills, Commissioner Lambrew, and Dr. Shah:

We are a network of over 300 Maine families, professionals, and community members who share the common goal of promoting awareness and acceptance of people with Down syndrome.

We appreciate the challenges that are inherent in the task of making decisions that will be in the best interest of the entire population in our state. However, we are deeply concerned that moving Maine's vaccine eligibility to a strictly age-based system is neglecting to recognize a quietly vulnerable group: our community members who are living with Down syndrome.

The current life expectancy for our family and friends who have Down syndrome is only ~60 years, nearly 19 years less than the general population. Placing young adults with Down syndrome at the end of the list based solely on their age overlooks much of what we know about their lifespan, aging process, health, and medical needs, including those related to COVID-19.

The U.S. Centers for Disease Control and Prevention has cautioned that "having Down syndrome increases your risk of severe illness from COVID-19" (CDC, 2020). There is a growing body of scientific evidence that people who have Down syndrome are at significantly higher risk of dying from COVID-19 than the general population. [One study](#) found that the risk of death from COVID-19 for a 40-year-old person with Down syndrome was equal to the risk of an 80-year-old person who does not have Down syndrome (Trisomy 21 Research Society, 2020). [Another study](#) of eight million individuals, over 4,000 of whom had Down syndrome, found that "the hazard ratio for COVID-19-related death for individuals with Down syndrome (versus without) was 10.39 (CI, 7.08 to 15.23), after adjusting for age, sex, ethnicity, BMI, dementia diagnosis, care home residency, congenital heart disease, and a range of other comorbid conditions and treatments" (Clift et. al., 2020).

We respect your commitment to basing Maine's pandemic response on the best available science, and understand that when calculating risk for the general population, grouping by age may matter most. We urge you to look at the medical evidence about our citizens with Down syndrome that shows they are a distinct group, with a different lifespan, and a significantly higher level of risk if they contract COVID-19.

Providing vaccines for this group exclusively by age is not an equitable approach: younger adults who have Down syndrome will remain vulnerable for months longer than many fellow citizens who have a much lower risk of serious complications or death.

Governor Mills has made it clear that our most important mission throughout this pandemic is to “save lives and protect Maine’s most vulnerable people.” We are asking our state’s health leaders to learn more about our citizens who have Down syndrome, and to examine the medical evidence that clearly demonstrates the need for these important members of our community to be protected. If we can provide assistance in any way, please don’t hesitate to contact our board president Jen Greslick jen@dsmaine.org or board member Debra Dunlap deb@dsmaine.org.

Sincerely,

Jen Greslick
Parent
Windham
MDSN Board President

Debra Dunlap
Parent
Gorham
MDSN Board Member

Abby Pearson
Parent
Bath
MDSN Board Member

Corin Swift
Parent
Cape Elizabeth
MDSN Outreach Co-Coordinator

Lisa Rancourt
Parent
Hermon
MDSN Board Member

Erica Koch
Parent
Litchfield
MDSN Board Member

Allyson Denyer
Aunt, Cousin, Friend
Bath
MDSN Board Member

Ben Greslick
Parent
Windham
Past MDSN Board Member

Cindy Stuchbury
Parent
Windham
Past MDSN (Founding) Board Member

John Tabb
Parent
Portland
Past MDSN Board Member

Crystal Cochran
Parent
Windham
Past MDSN Board Member

Cathy Frederick
Grandparent/Legal Guardian
Warren
Past MDSN Board Member

Shawn Small
Parent
Windham
Past MDSN Board Member

Amy Saffian
Parent
Cumberland
Past MDSN Board Member

Jim Saffian
Parent
Cumberland
Past MDSN Board Member

Elizabeth Mahoney
Parent
Kennebunk
Past MDSN Board Member

Mary Greslick
Self-Advocate
Windham

Caleb Dunlap
Self-Advocate
Portland

| | | |
|--|--|--|
| Brenna O'Sullivan Sibling Portland | Jeremiah Rancourt Parent Hermon | Alice Bradeen Parent and Educator Casco |
| Bill and Charlotte Brewington Parents Cape Elizabeth | Calvin Mahoney Self-Advocate Kennebunk | Daniel Mahoney Parent Kennebunk |
| Lisa McGlone Parent, Educator Limington | Olivia Tabb Self-Advocate Portland | Teagan McGlone Self-Advocate Limington |
| Jennifer Christensen Parent South Portland | Jack Christensen Self Advocate South Portland | Maureen McGlone Parent Limington |
| Aidan McGlone Sibling, Unified Partner Old Town | Richard Christensen Parent South Portland | Cassandra Manson Parent Bowdoin |
| Steve Frederick Grandparent/Legal Guardian Warren | Crystal Burke Parent Hancock | Sydney Owen Unified Partner Old Town |
| Myles Frederick Self-Advocate Warren | Tom and Christina Bourdeaux Parents Cape Elizabeth | Robert Meyers Grandparent Bath |
| Amy Tague Parent Portland | Margaret Meyers Grandparent Bath | Karen G. Pelletier Parent Portland |
| Ted LaCrone Parent Portland | Elizabeth Small Parent, Educator Windham | Sharon Cook Parent Yarmouth |
| Eric Flinkstrom Parent South Berwick | Doris Poland Parent, Community Windham | Marcia Flinkstrom Parent South Berwick |
| Kayla Flinkstrom Self Advocate South Berwick | Lori Poland Caretaker, Community Advocate Windham | Maryellen and Charlie Tarling Parents Cape Elizabeth |
| Charlie Saffian Self-Advocate Cumberland | Peter Tarling Self-Advocate Cape Elizabeth | Linda Bonnar Educator, Supporter Brunswick |

Kelsie O'Sullivan
Self-Advocate
Portland

Kimberly Post
Educator, Supporter
Raymond

Heather LaFrance
Educator
North Berwick

Shanna Cox
President + CEO, LA Metro
Chamber of Commerce, Parent
Lewiston

Katherine Gagnon
Parent
Old Orchard Beach

Michael Gagnon
Parent
Old Orchard Beach

Paula & Michael Christie
Parents
Portland

Marie Christie
Self-Advocate
Portland

Jacob Hufstader
Self-advocate
Portland

John Hufstader
Parent
Raymond

Charles Dunlap
Parent
Gorham

Sheila Dobson
Grandparent
Portland

Wendy Allen
Friend, Supporter
Norway

Naomi Ellette
Sibling
North Waterboro

Linda Barker
Friend
Gorham

Carole Martin
Friend, Supporter
Friendship

Mark & Teresa Sanborn
Grandparents
Windham

Beth & Rob Benson
Aunt & Uncle
Windham

Fran & Frank Greslick
Grandparents
Windham

Katherine Branch
Friend
South Paris

Aranka Matolcsy
Parent
South Paris

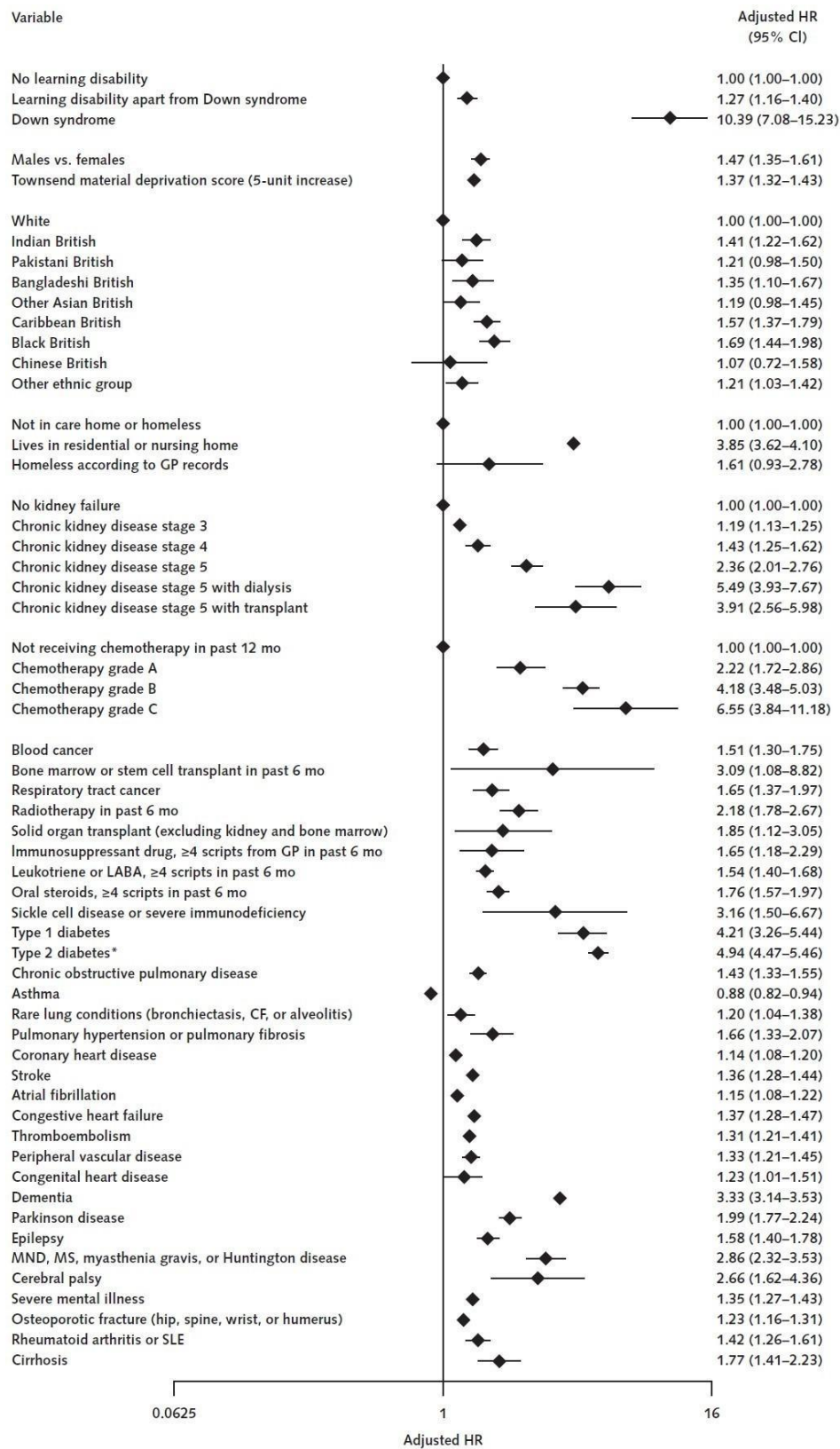
Sarah MacLaughlin
Friend
Windham

Tara Curran
Friend
Portland

Peggy Cloutier
Parent
Portland

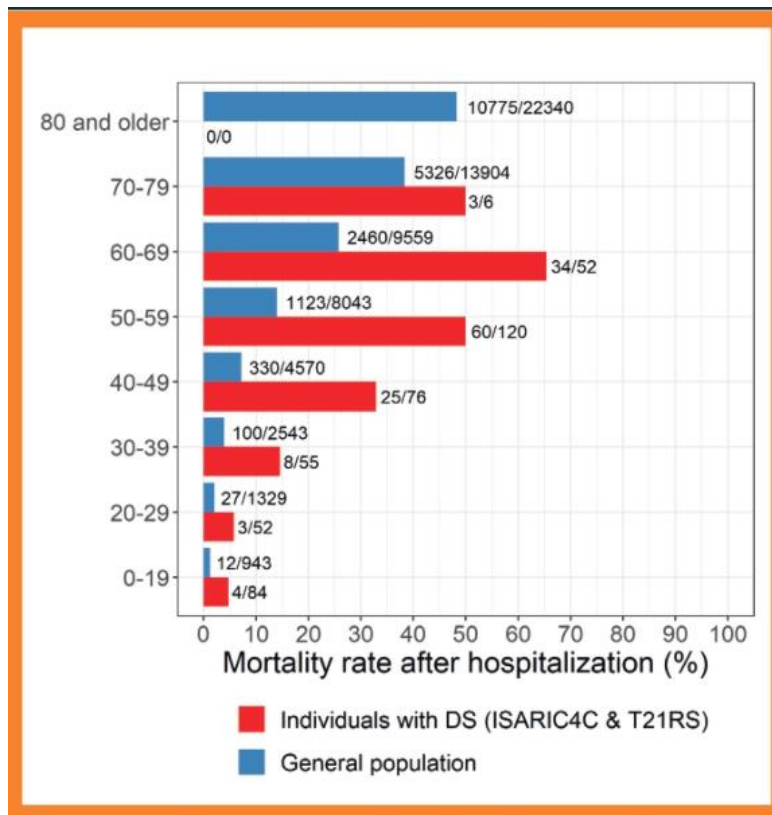
James F. Cloutier
Parent,
Cumberland County Commissioner
Portland

Figure 1.



Source: Clift, Coupland, Keogh, Hemingway, Hippisley-Cox (2020).

Figure 2.



Source: Trisomy 21 Research Society, (2020).

References

Clift, Coupland, Keogh, Hemingway, Hippisley-Cox (2020). *COVID-19 Mortality Risk in Down Syndrome: Results From a Cohort Study of 8 Million Adults*. *Annals of Internal Medicine*. 21 October 2020. Retrieved February 26, 2021. <https://doi.org/10.7326/M20-4986>

Trisomy 21 Research Society, (2020). *Covid-19 and Down Syndrome T21RS Survey, Report October 22, 2020*. Retrieved February 26, 2021. <https://www.t21rs.org/results-from-covid-19-and-down-syndrome-survey/>

CDC, (2020). US Centers for Disease Control and Prevention website. COVID-19 Your Health: People with Certain Medical Conditions. Retrieved February 26, 2021. <https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/people-with-medical-conditions.html#downsyndrome>