

For Immediate Release

Patient Advocacy Groups Press CDC to Implement Inclusive COVID-19 Isolation and Prevention Guidelines

CDC Engages in Discussions on How to Protect High-Risk Communities with Pan End It!, MaskTogetherAmerica, and Long COVID Justice

Leaders of Pan End It!, MaskTogetherAmerica, and Long COVID Justice met recently with Centers for Disease Control and Prevention (CDC) officials to discuss urgent recommendations on COVID-19 isolation and prevention guidelines. Seeking policies to protect the health of millions of Americans, these patient-led groups expressed deep concerns about the CDC's March 2024 Respiratory Virus Guidance that abandoned most recommendations for isolation, testing, and masking. The groups stressed that a science-based strategy is vital to protect people who are disabled, immunocompromised, or otherwise medically vulnerable; workers; students; and everyone (in recognition that Long COVID is common among people with no specific prior vulnerabilities). CDC must take the opportunity to establish better recommendations in light of recent illness levels, including the growth of H5N1, and establish a better foundation for public health in the future.

Recently, a couple months after meeting with the three disability organizations, the CDC has published some [social media posts](#) that promote a more layered approach to prevention, such as better messaging on [masking](#), shifting slightly from the vaccine-only strategy the groups have heavily criticized. However, the CDC's messaging still doesn't mention isolation as a critical prevention tool and warns about "respiratory virus season," equating COVID-19 and influenza and ignoring that COVID-19 spreads year-round.

The disability organizations appreciated the opportunity to meet with CDC officials during the 9 August Zoom meeting, including Chief of Staff Kate Wolff; Dr. Shannon Griffin-Blake, Chief Disability Officer; Dr. Priti Patel, CDC Senior Advisor for Long COVID; and Rebecca Greco Koné, Deputy Director for Management, Operations, Communications, and Policy, CDC National Center for Immunization and Respiratory Diseases (NCIRD). During the meeting, the CDC pledged to hold a future meeting regarding Long COVID and to engage about improving CDC messaging.

The groups are concerned about aspects of the CDC's approaches discussed during the meeting, including:

- Stating that the CDC does not have plans to update its isolation guidance in the short term, suggesting to watch the current "respiratory virus season"

- Saying it feels like that the CDC already talks often about masking, which does not match the experiences of disabled people and our careful review of CDC materials and statements
- In relation to the request to speak out against mask bans, expressing that the CDC has to walk a fine line legislatively, despite the compelling example of CDC [speaking out against HIV criminalization](#)
- Not being able to provide information about specific disability organizations they have engaged with in a formal way.

“The CDC’s isolation guidance is one founded in political and business interests, not in the science for preventing disease and protecting public health,” said Pan End It!, a disabled, ill, and immunocompromised-led group that advocates for public health precautions. “The isolation guidance does nothing to address the ongoing pandemic and the real problems people face when infected with COVID-19; people will continue to be ill with COVID-19, but now with less ability to rest and isolate when needed. Instead of following the science and advocating for better policies, the CDC is putting people at further risk and reducing their ability to protect their health and advocate for themselves and others.”

“MaskTogetherAmerica is deeply concerned about the CDC’s decision to stop recommending a 5 day isolation period for COVID-19. This change undermines effective prevention and disregards the scientific evidence that people can transmit the virus well beyond a few days,” said Sarah Cahill, Coordinator of MaskTogetherAmerica, a national grassroots advocacy group committed to masking and public health safety. “Our community faces heightened challenges in accessing safe indoor spaces, healthcare, and essential services, particularly given the high rates of respiratory illnesses. Inclusive, prevention-focused policies would greatly enhance health equity for disabled people across the U.S.”

“We have not seen a single robust national education campaign on Long COVID, which already affects over 6% of Americans and millions of children, so it’s not surprising that the public doesn’t understand the risks they are taking with every COVID-19 infection and reinfection. While we appreciated the opportunity to meet with CDC, many of our questions remain unanswered,” says Emi Kane, co-director of Long COVID Justice. “Fundamentally, their isolation guidance and suggestions for situational masking are impossible to implement -- they say it’s important to protect those at highest risk of harms by masking around us, but that’s not something anyone can know about the people near them on the subway, in pharmacies, and at healthcare visits. We need public policies and widespread education based on data and that clearly communicate acute and chronic risks.”

During the August meeting, Pan End It!, MaskTogetherAmerica, and Long COVID Justice outlined critical steps to protect the health of high-risk Americans, including:

1. **Reinstate Extended Isolation Guidelines** to curb virus spread and protect public health.

2. **Directly and Meaningfully Include Disabled People** impacted by COVID-19 into CDC decision-making processes, such as the development of isolation and masking guidance and messaging materials.
3. **Launch a Nationwide Long COVID Awareness Campaign** to highlight the virus's long-term impact on patients.
4. **Establish Mask Requirements in Healthcare** to ensure that disabled people and everyone can access healthcare without healthcare-acquired infections (HAIs).
5. **Oppose Mask Bans**, ensuring that everyone can protect their health and others.

Dr. Angelique Corthals, MaskTogetherAmerica's Scientific Advisor, emphasized, "Our nation's current COVID policies do not adequately safeguard our most vulnerable populations. Reducing isolation periods and de-emphasizing comprehensive testing and masking guidance jeopardizes community health and overlooks the science of virus transmission. The CDC must acknowledge the airborne nature of COVID-19 and align its guidance to reflect this, protecting high-risk populations and promoting health equity."

A Call for Stronger Public Awareness on Prevention

In a [July sign-on letter](#) that the three disability organizations submitted to the CDC together with over 1200 individuals and organizations, the CDC was urged to remove its harmful Respiratory Virus Guidance and put in place a more protective isolation guidance that focuses on the prevention of COVID-19 infections. Preventing infection is key to preventing serious illness, including the development of Long COVID, and death. The letter and the meeting also emphasized the need for masking and testing as core prevention strategies.

The CDC's recent public messaging has shifted slightly away from the vaccine-only strategy for respiratory viruses that the patient advocacy groups heavily criticized in the August meeting. A post shared on the CDC's [social media](#) on 17 October aims to promote the layered approach, emphasizing preventive strategies including using a mask, cleaning the air, and immunization. [Some recent tweets](#) from the CDC Cancer account [feature graphics](#) depicting a healthcare worker and patient meeting together, with both people masked.

Though this seems to be an improvement, the CDC's communication about COVID-19 still presents major issues. First, CDC guidance minimizes the need for masking, testing, and isolation — the most important measures for source control. Further, the sign-on letter and the groups' recommendations presented on 9 August have been ignored. In addition, even though the CDC has [acknowledged](#) that COVID-19 can spread year-round, the agency treats SARS-CoV-2 as a seasonal virus, lumping it together with seasonal viruses such as the flu and RSV in the Respiratory Virus Guidance, public messaging, and [reporting on its website](#).

Elsewhere in the federal government, the [NIH](#) is bringing back mask and test requirements in its clinics. Yet, the CDC has not established effective infection control guidance like masking in healthcare, and the CDC's leadership refuses to lead by example. Recently, CDC Director Dr. Mandy Cohen posted a selfie where she and the person vaccinating her were maskless, [tweeting](#) a misleading message that COVID-19 vaccines are the best way to prevent serious

illness and Long COVID. Although the CDC has started to mention Long COVID more, its message about vaccines preventing Long COVID is flawed, as many studies show that people develop Long COVID conditions whether or not they are vaccinated. The best way to prevent severe sickness and Long COVID is to avoid infections through the use of precautions.

Julie Lam, founder of MaskTogetherAmerica, a Long COVID patient and representative of NIH RECOVER, stressed the importance of public awareness of COVID-19's lasting impacts: "Most Americans are unaware of the lasting damage COVID-19 can cause to organs. We urgently need a Long COVID awareness campaign, featuring real stories from affected people and comprehensive education on preventive measures."

The organizations are also concerned with recent proposals from the CDC's Healthcare Infection Control Practices Advisory Committee (HICPAC). This November, members of HICPAC voted against recommending universal masking in healthcare and N95 use by healthcare workers for airborne diseases. They also submitted a proposal to the CDC to allow healthcare workers who may be infectious back to work as soon as after Day 3, no testing required, with the use of "source control" masking through only Day 7. This proposal does not define "source control" and treats surgical masks equally to N95s for use by potentially infectious healthcare workers working with patients. This puts patients at even greater risk.

Broader Public Health and Workplace Protections

During the CDC meeting, the advocacy groups emphasized that stronger workplace protections, such as paid sick leave and clean air legislation, are crucial to preventing workplace outbreaks and protecting people reliant on them for their health and safety, such as students, patients, and those in carceral or institutional settings. They also called for federal support to ensure access to essential COVID-19 resources and Long COVID research:

- Accelerated access to Social Security Disability benefits
- Laws to protect people's right to mask
- Federal investment in Test-to-Treat programs and COVID-19 mitigation efforts
- Focus on worker safety, including paid sick leave
- Expanded clean air laws aligning with ASHRAE 241 standards.

A Call for More Accessible COVID-19 Tools and Resources

In the meeting, the groups emphasized the need for federal support to bring back the Test-to-Treat program and enhance access to free vaccines, PCR tests, N95 respirators, and rapid COVID-19 treatment. They pointed out that ending the NIH-sponsored Test-to-Treat program in April left millions in the US without easy access to critical COVID-19 resources. Other important elements include prioritizing FDA testing recommendations by encouraging two negative antigen tests before ending isolation and implementing clean air standards along with real-time CO2 monitoring in public indoor spaces.

“The CDC’s guidance should serve all Americans, particularly those at risk of severe illness,” said the representatives from Pan End It, MaskTogetherAmerica, and Long COVID Justice. “We urge the CDC to support robust, prevention-focused public health policies that safeguard the health of all Americans.”

For more information about Pan End It!, see <https://www.panendit.com> and https://www.instagram.com/pan_end_it/.

For more information about MaskTogetherAmerica’s advocacy, visit masktogetheramerica.org and <https://www.instagram.com/masktogetheramerica/>.

For more information about Long COVID Justice, see <https://longcovidjustice.org> and <https://www.instagram.com/longcovidjustice/>.

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