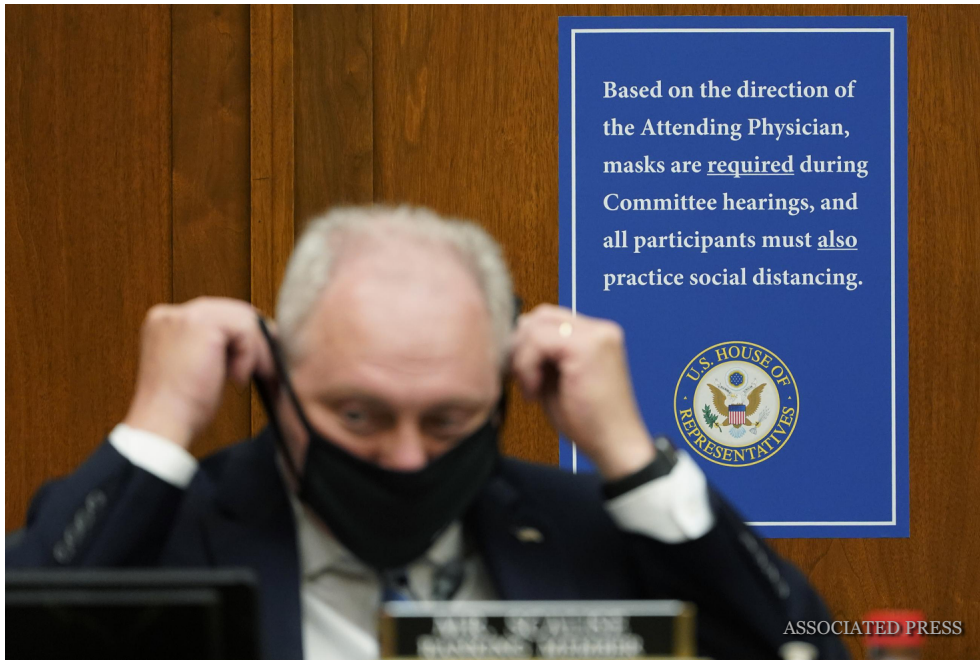




Patient advocates plan for post-COVID Congress

People with compromised immune systems and other underlying health conditions may have to keep COVID-19 safety precautions, but many groups don't think that will interfere with their advocacy.



House Select Coronavirus Crisis Subcommittee ranking member Rep. Steve Scalise during a Wednesday hearing



Erin Durkin

🕒 May 23, 2021, 8 p.m.

For patient advocates living with certain underlying health conditions and compromised immune systems, heading back to Capitol Hill and state legislatures may be a difficult decision.

The Centers for Disease Control and Prevention [says](https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/people-with-medical-conditions.html) that people who are immunocompromised are at higher risk of getting a severe case of COVID-19. The agency also [advises](https://www.cdc.gov/coronavirus/2019-ncov/vaccines/recommendations/underlying-conditions.html?_cid=10483:immunocompromised%20covid%20vaccine:sem,ga:p:RG:GM:gen:PTN:FY21)

that there isn't information available about the safety of the COVID-19 vaccines for people with weakened immune systems and they could potentially have reduced immune responses when given the vaccine.

While individual advocates will have to weigh the risks and benefits of meeting with lawmakers in person, multiple groups told *National Journal* that the pandemic has also opened doors for people to connect remotely. Some are anticipating moving to a hybrid system where the virtual options are used by advocates who can't speak to lawmakers in person.

"The pandemic highlighted the many ways advocates can engage with elected officials remotely," said Lisa Lacasse, president of the American Cancer Society Cancer Action Network in an emailed statement. "While we're still learning about the ongoing impact of COVID-19 for people with cancer, our hope is that even when it is safe to reopen, lawmakers continue to be receptive to remote conversations."

"All constituents—especially those who are immunocompromised—should be able to continue important conversations and advocacy around issues that impact their health in the safest, most accessible way possible," she added.

The American Association of Kidney Patients had already started using virtual platforms to accommodate their patient advocates before the pandemic hit the U.S. "We, as a national strategy, developed the technologies and techniques to make certain that kidney patients didn't always have to fly into Washington, D.C. to make an impact because so many of our folks who are in dialysis chairs, it's a real burden for them," said Paul Conway, chair of policy and global affairs for the group.

Their virtual advocacy in 2020 helped lead to a legislative victory, according to the group. Conway said advocates focused on a bill that extended Medicare coverage for immunosuppressive drugs for transplant patients so their bodies don't reject the organ. The bill passed as part of the large omnibus legislation in December.

"We feel, and our patients clearly feel like, we got a huge win," said Conway. "The whole kidney community worked on this, but the patient element of it, they're ecstatic. They made an impact in the middle of COVID."

Conway added that even if the technologies used on Capitol Hill change, he feels like staff on the Hill and in local offices understand "the spirit of reasonable accommodations for kidney patients."

Extra precautions may still need to be taken for transplant patients. A [study](https://www.hopkinsmedicine.org/news/newsroom/news-releases/organ-transplant-recipients-remain-vulnerable-to-covid-19-even-after-second-vaccine-dose) (https://www.hopkinsmedicine.org/news/newsroom/news-releases/organ-transplant-recipients-remain-vulnerable-to-covid-19-even-after-second-vaccine-dose) from Johns Hopkins University researchers showed that transplant patients may not develop sufficient immunity after receiving the Pfizer or Moderna vaccines.

Tammy Black, vice president of communications at the Immune Deficiency Foundation, said the group is optimistic that they will not be disadvantaged when legislators and staff start going back to in-person meetings, noting that many caregivers, family members, and the group's staff can participate in person while protecting those who can't take the risk.

“Interestingly, the pandemic has raised awareness for risks associated with compromised immune systems,” said Black in an email to *National Journal*. “As we continue to inform policymakers about issues important to us, they seem more amenable to making accommodations. I think that legislators realize that digital technologies allow them to learn from more diverse audiences than ever when travel is no longer a barrier.”

She hopes that by 2022 the group will be able to use a hybrid approach for in-person and remote meetings.

Elizabeth Franklin, president of the Cancer Support Community, said she is also anticipating moving to a hybrid system. The group held an all-virtual advocacy day on May 5, which Franklin described as a success.

“We are still gathering evidence about the ways in which cancer patients and survivors are reacting to the vaccine,” she said. “We’ve seen some stories that especially [blood-cancer patients](https://www.hematology.org/newsroom/press-releases/2021/blood-herishanu-covid-vaccine-and-cll) (https://www.hematology.org/newsroom/press-releases/2021/blood-herishanu-covid-vaccine-and-cll) and others may not be seeing the antibodies from the vaccine, and so what exactly that means is still an unknown. We decided this year it was still the safest option to have folks advocate over Zoom and it was incredibly effective. We had more meetings than ever.”

Franklin said the country has gained a “little bit more sympathy and compassion” for people living with compromised immune systems.

“I’ve heard patients who before the pandemic, who had compromised immune systems, talk about when they were wearing masks out in public, everybody would kind of look at them funny, and now of course nobody looks at you funny if you have a mask on,” she said.

But Jenn McNary, who has two sons with muscular dystrophy and one with primary immune deficiency, said with mask requirements being loosened, she felt like her family was being left behind. She is a rare-disease-patient advocate who cochairs the COVID-19 working group for the EveryLife Foundation for Rare Diseases.

“I knew the world was going to move on without us, and here we are, those people that are left behind,” she said. “I’m so tired of reading articles and comments where people are like, if you’re scared, just stay home.”

A fight over mask mandates in the House has erupted after the CDC eased mask recommendations for full vaccinated people. Last week,

[several Republican House members](#)

(<https://www.washingtonpost.com/nation/2021/05/19/maskless-gop-lawmakers-fined-house/>) defied House Speaker Nancy Pelosi’s decision to keep a mask requirement.

“I think it’s just this feeling of privilege, that folks don’t know what it’s like to be chronically sick, and don’t know what it’s like to have minor inconveniences in order to protect health,” said McNary.

McNary said the Republican stunt could influence others to disregard masking measures. “I thought that COVID was going to give people this experience of being panicked about a health condition that was incredibly urgent and deadly, and that maybe there would be added sensitivities around our families,” she said. “But my son actually said to me, ‘Hey. I thought that maybe when I wore a mask to school next year that people would totally understand now, but we’re being called weird for being vaccinated and still wearing a mask.’”

McNary is hoping that opportunities to connect virtually with legislators and the Food and Drug Administration remain. “I don’t know when we can safely travel again,” she said.

Jamie Sullivan, director of public policy at the EveryLife Foundation, said the group definitely wants to get back to the Hill—but also wants to keep the remote approaches that allow for more people to participate in advocacy.

“We need to take all of the things that enabled broader participation and empowerment of the community via the technology that exists and blend that with our in-person advocacy,” she said.

<https://www.nationaljournal.com/s/713819/patient-advocates-plan-for-post-covid-congress/>

Welcome to National Journal!

[LEARN MORE](#)