Adrian Hernandez:

Hey, this is Adrian Hernandez, and welcome to the NIH Collaboratory Grand Rounds podcast. We're here to give you some extra time with our speaker, and ask him the tough and interesting questions you want to hear most. If you haven't already, we hope you'll watch the full Grand Rounds webinar recording to learn more. All of our Grand Rounds content can be found at rethinkingclinicaltrials.org. Thanks for joining.

Adrian Hernandez:

Hi, this is Adrian Hernandez, and I'm one of the NIH Collaboratory Grand Rounds moderators, and today we're here with several people from Survivor Corps to reflect and discuss what they did recently to address patient experiences seeking medical care around COVID-19. So I'm here with Diana, Natalie, Nick, who will be reflecting on what they've had to do to address these issues. So welcome to our podcast, and let me start off first with Diana, can you just tell us a little bit of how things started?

Diana Berrent:

Yeah, so actually we are the largest patient advocacy movement in the world, but oddly enough, we did not start out as a patient advocacy movement. I was one of the first people in the New York area to get a positive diagnosis of COVID, and one of the first people in the country to come forward with my identity, in early March of 2020. I ended up having a pretty average case of COVID, what I call the Tylenol and Gatorade kind, I was never hospitalized, there's nothing dramatic about it. But what set it apart was that I was early and I was very public with it.

Diana Berrent:

And I got to lot of media following while I was in isolation, and while I was in isolation, I became completely obsessed with the idea of convalescent plasma, and how, if I were to be one of the first survivors, that I would have the opportunity to possibly save lives by donating my plasma, by partnering with science, by engaging in every trial and study that was available. And if I had that power, imagine what a coalition of people could do.

Diana Berrent:

When I came out of isolation, New York was on fire, April 2nd or so. And I received the first antibody test in America, I was one of the first plasma donors, and I started Survivor Corps in a way to connect patients with science and collect plasma, and neutralize what I was afraid was going to become a free market where there would be competition among plasma collectors, and in order to neutralize that market, we needed collaboration. So that was the start of Survivor Corps on March 24th of 2020, I started it with the mission of mobilizing an army of survivors to donate plasma and support science.

Adrian Hernandez:

Natalie and Nick, tell us about how you all got involved.

Natalie Lambert:

Well before the pandemic really hit, the type of research that I've always done is to try to understand patient's experiences with a disease. And the way that I often do that is by going online, to online health communities, where people talk with other patients, and it's a great way of capturing data about the problems patients are facing, and to understand what they really need, and what they're really thinking.

So, when I started to hear on the news about COVID, and it's starting to spread around the world, I was online obsessively trying to read patients firsthand experiences with the disease.

Natalie Lambert:

And it was immediately obvious that the symptoms that they were reporting, for many people, they were not going away. They were having really unusual things you wouldn't expect from a more flu-like virus, to having heart problems, crushing headaches that would last for months, and I just knew that we had to start researching this. We had to learn from patients as quickly as possible because it would take a lot longer to do things like clinical studies. So I found Survivor Corps, which was very quickly the largest and just most informative and wonderful place for people who had COVID to meet online. And I emailed all the admins that I could until they finally put me in touch with Diana, and we've been working together to do COVID research ever since.

Adrian Hernandez:

Terrific. And Nick, when did you get involved?

Nick Guthe:

I got involved about three and a half weeks after my wife committed suicide in our house, after a 13 month battle with long COVID that left her completely in excruciating 24 hour a day pain, and the inability to sleep anymore. I was in a tail spin, but I did manage to send her obituary into the Hollywood Trades, she had been a screenwriter. To my surprise, her obituary went viral within an hour, around the world, and Diana at Survivor Corps read it and tweeted about it. And as I was going through my wife's phone, she had a Twitter account, I saw Diana, I saw her tweet and I remembered my wife mentioning Diana several times, and Survivor Corps, in the last six months of her life, and that she was very impressed by them. And I thought I would just reach back out to Diana. She responded to me, I sort of said, "I'm here to help, hopefully prevent this from happening to somebody else." And we'd been working together ever since.

Adrian Hernandez:

Well, thanks for sharing how you all came together. Maybe the next question, I'd like to go through you all, you all were really pioneers in bringing together people who have the lived experience of, unfortunately, having COVID, people who've cared for loved ones who had COVID and have had major problems, and researchers who are really motivated to try to get answers together. Tell us a little more about what you all learned in creating Survivor Corps and building it out. It's a, I'll say, an important model, and what did you learn from doing it this way?

Diana Berrent:

This is Diana, I'll take that, for the first stab at it, at least. We have, from the beginning, been the bridge between what's actually happening on the ground and the policies that are being made. And unfortunately, from the beginning of this pandemic, there has been a chasm between real-world evidence and the policies that are in effect, that we are living by. And I felt that, Natalie and I together had the ability to close that gap. When people were doing fever scans all over the place, I mean, that was medical theater. We put out a paper last October, maybe, Natalie? When was it? That said what percentage of symptomatic, what was it, symptomatic people who were actually contagious? What percentage of them actually had a fever? And that's when we were talking about once they're symptomatic, it was something like 7%, which just showed that we were using yesterday's tools to try to solve today's problems.

Diana Berrent:

And we have been the canary in the COVID coal mine from the beginning because of that. And what we did as a result was we redefined what it means to be a citizen scientist, and we have redefined it as citizen scientist collaboration. So we have studies going on with the top researchers in the world that is based on our Facebook polling data. We started a study at Yale with Dr. Krumholz, on these neurological issues, the same things that led Nick's wife to take her own life. You cannot watch those videos and not be moved to do something about it. And when Dr. Krumholz said, "If you can find me 20 patients, I will run a study," we had a cohort of 150 patients for him within 24 hours.

Diana Berrent:

And so, the IRB should be coming in any day, and instead of having to wait, we will have that cohort ready to go, because while Yale can't recruit while they're waiting for an IRB, we can. And so we have that cohort ready to go, and this is science at warp speed, and I use those words intentionally. This is a new model of cooperation, and through it, it has to be done in a way where scientists are not taken off of their pedestal, but they are brought down to eye level, and they treat patients with respect. People are not subjects, they're not rats, they are people, and you have to bring them along for the ride, let them be involved. Don't use them, but engage with them, and let them learn along with the scientists, because never has a population of lay people been so interested in science.

Diana Berrent:

And in the long run, what we'll get out of that, is rebuilding trust in the scientific method, and hopefully we will regain trust if this, God forbid, ever happens again, we won't have the kind of vaccine hesitancy because the more engagement we have with science and the more transparency there is, the more trust we will get.

Adrian Hernandez:

So you all have been really putting together citizens on the ground with scientists around the ecosystem to get to the best answers for people, understanding the long term impact of COVID-19. But also, some of the barriers that may exist for getting new therapies. Monoclonal antibodies is an example of that, where people don't have as much access, and there has been evidence around this, and then also the uncertainty of what may be able to be prevented for long-term COVID. So, Natalie, from a researcher perspective, how has it been working together with all these citizens and patients and caregivers in this program, for bringing science and trust together?

Natalie Lambert:

Well, it's been one of the greatest honors of my life because I developed a survey, and Diana and everyone at Survivor Corps really helped me to make the questions, really fantastic questions. But, we had well over 5,000 long haulers take a survey that could have taken each of them two hours or more, it was extremely detailed. We're analyzing new data from it continuously.

Natalie Lambert:

And these are people that when you read their stories, and what they've posted in the Facebook group, are incredibly ill, and are facing so much uncertainty. Many of them unable to keep their jobs, even their family members may not understand what they're going through. And if a researcher hasn't worked directly with patients or survivors in this way before, I just want to say that people who are suffering and yet so willing to give of their time, it's really our duty as researchers to go there and meet them, where they are, and to work with them, and to really collaborate in the way that Diana has described, because the things that we've been able to learn, in just over a year, have really helped define the symptoms that are long COVID, and to start to define the way that COVID impacts people, and their health, and their jobs, and their lives.

Natalie Lambert:

So I guess the experience for me has been that, I'm a researcher, but I'm reaching out to people who are at the worst point of their lives and yet they're still willing to give so much to get answers. And I think that this is the model that not only will help us do better science and faster, but it's an ethical model for doing research. So that, like Diana said, we're bringing the participants along with us and we're working together.

Diana Berrent:

Can I add one piece on that?

Adrian Hernandez:

Sure.

Diana Berrent:

I think that one thing that's really important to remember, and has been lost in the narrative of this pandemic, is that this is the first time in modern medical history, so far as I know, I'm no medical historian, but, where we have completely cut out the general practitioner from the medical landscape, and we've relied from day one on the emergency room as our first line of medical defense. And what ended up happening, as a result, is all of our studies, all medical studies, all of our data, was only based on hospitalized patients who were a small subset of the general population who had had COVID, and had a very different disease trajectory because they received therapeutics that the rest of us didn't. And so by extrapolating data based on hospitalized patients and applying it to the population at large, there were mistakes being made. And that's why we needed to bring the voice of the 95% of people, or whatever it is, who were not hospitalized, and tracking their experiences, and tracking them retrospectively and prospectively.

Adrian Hernandez:

Agreed. There was a lot of attention going from the inpatient environments in the ER, but not the other 80% that was having COVID. Let me turn to Nick to ask, based on the experience for over a year, we're in a fourth surge. What's going to be really important going forward in terms of how we bring, or develop answers, for patients and their families related to COVID-19? Nick, what needs to happen?

Nick Guthe:

Well, I mean, what really needs to happen first is the NIH needs to release those funds it's sitting on so that actual real research can begin. And the secondary reason for that is a psychological one, people who are suffering from long COVID right now need hope. They really need to feel like there is some sort of a plan on the horizon that's going to help them deal with these symptoms, and also deal with all of the other issues they're dealing with, like not being able to sleep. The latest White House initiative on disability for long COVID was very, very positive, but there's a lot of other things that have to happen.

Nick Guthe:

We also have to start dealing with the issues of the blood supply, specifically regarding organ donation. My wife was an organ donor, and I fought tooth and nail against having her long COVID organs donated, because the State took over and didn't even want to admit she had COVID, and her organs are in somebody else. We need to start treating it like we did with AIDS in the 1980s, making sure the organ supply is clean. We need to rethink pain and sleep management for people who can't sleep right now, which if you can't sleep, you can't heal.

Nick Guthe:

We are going to have a surge in suicides, and I can tell you this because I hear every single day from people who are at the point where my wife was, where they're desperate, they can't sleep, they don't know what to do, their doctors are gaslighting them. I mean, those are the things that have to happen, but it has to start with giving people hope. And doctors really need to understand, when they meet with a COVID patient, they are breaking the Hippocratic oath by not giving that person hope when they first meet with them. They are literally sending them down a path to depression and potentially suicide.

Adrian Hernandez:

Well, Nick, thanks for those insights. And so, I want to go ahead and summarize here what I've learned today, and also from you all on our Collaboratory Grand Rounds is that we are in unprecedented times, it's really important to come together with patients, patient community, caregivers, researchers, to address COVID-19 together, and really be informed by the experiences that people have had, and have observed, and recognize that there is humility that we have to have around science. We don't necessarily know everything, and we don't necessarily know all the long term implications around COVID-19, so having groups come together will be really critical for that. So, thanks everyone for spending time with us on this podcast, and please join us for our next podcast as we continue to highlight important changes in the research world.

Speaker 5:

Thanks for joining today's the NIH Collaboratory Grand Rounds podcast. Let us know what you think by rating this interview on our website. And we hope to see you again on our next Grand Rounds, Fridays at 1:00 PM Eastern Time.