



#WIGWednesdays

June 10, 2020

“COVID-19 Ongoing Impact on Cancer Patients and Survivors & Physically Distanced But Socially Engaged: My Cystic Fibrosis Life”

Featuring:

Lucy Gettman, Executive Director, Women In Government

Michigan State Representative Rebekah Warren – Moderator

Amy Farner, Project Manager, Survey Administration and Analysis, American Cancer Society Cancer Action Network

Emily Schaller, Founder/CEO of Rock CF Foundation

Lucy Gettman: Welcome to [#WIGWednesday](#) everybody, Women In Government’s virtual policy roundtable series delivering timely information to women state legislators across the nation. I’m Lucy Gettman, Executive Director of Women In Government, a nonprofit, nonpartisan organization by and for women state legislators. We’re led by our [Board of Directors](#) who are all sitting women legislatures and they guide our initiatives and our programming throughout the year.

To make this an interactive experience, we’d like to get the conversation started with a pulse poll question: Have you or someone you know experienced a treatment interruption or a health condition as a result of the COVID-19 pandemic? Just answer yes or no.

While we’re doing that, I’m excited to encourage everyone to register for WIG’s first virtual [Summer Summit series](#) starting next Wednesday, June 17th, same time, same day. We have a special guest kicking off our [five-week series](#), the Council of State Governments National Chair, State Representative Joan Ballweg of Wisconsin. In the ongoing weeks of our series, we have additional special guests joining us, including, Arizona Treasurer and former state legislator Kimberly Yee; Shelby Kerns, Executive Director of the National Association of State Budget Officers; and Tennessee State Representative Karen Camper, who is president of N.O.B.E.L. Women, the National Organization of Black Elected Legislators, so be sure to check our [social media accounts](#) and our [website](#) regularly for even more sneak peeks into our speakers and programming.

Right now, I would like to tell you a little bit about our invited moderator for this afternoon's session, but first I want to reveal the results of our pulse poll. So, this is actually disturbing. Fully half of you on the policy roundtable today have either experienced or know somebody who's experienced an interruption of care as a result of the COVID-19 virus. As we know, even one patient who is denied access to needed treatment is one too many.

So, with this in mind, a little bit about Representative Rebekah Warren of Ann Arbor, Michigan, who is invited to moderate our program today. A longtime resident of Ann Arbor, Representative Warren was first elected to the House in 2006, where she represented the 53rd District for four years. She also served two terms as the State Senator for the 18th District. She now proudly represents the 55th District in the House of Representatives and is Vice Chair of the Ways and Means Committee. Over her career, she's been a leader in committees on natural resources, regulatory reform, competitiveness and economic



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development, and international investment. Representative Warren was also a member of a number of other committees and task forces, including the Senate Finance Committee, the Mental Health and Wellness Commission, the Responsible Retirement Reform for Local Committees Task Force, the Health Care Costs and Quality Advisory Committee, the Committee on Human Trafficking, and a Legislative Co-Chair of the Annual “Let’s End Campus Sexual Assault Summit.” She was also appointed to represent Michigan in the prestigious Great Lakes Commission. Representative Warren is a longtime friend and supporter of Women In Government, as a state director for many years, and also just this month coordinated a donation of bleach to those in need, working with Women In Government, the American Chemistry Council and the nonprofit organization Food Gathers in Ann Arbor.

Representative Warren is currently on the floor in the Michigan House of Representatives and will join us as soon as she can, so your spectacular team at Women In Government of Maura LaGue, Laura Blake and Lindsay Eggware will be holding down the fort until she's able to get here.

A couple of housekeeping items: if you have questions or comments during the presentation, please be sure to identify yourself by name and state, and then write them in the chat box. That can be found in the zoom meeting toolbar, probably at the bottom of your screen and make sure you select ‘to everyone’ in the drop-down menu. Please note that all #WIGWednesday presentations will be available on our website within a few days of the event.

So, I have the pleasure of introducing our first speaker this afternoon. Amy Farner, project manager of survey administration and analysis for the [American Cancer Society Cancer Action Network](#) and she's here to speak about COVID-19's ongoing impact on cancer patients and survivors. Amy has spent the last 20 years helping some of the world's leading organizations make better decisions through data. Her work has been published by the New York Times, the Harvard Business Review, The National Journal, Web MD, Reuters and many others. She's currently leading an effort at the American Cancer Society, Cancer Action Network to understand the experiences and opinions of cancer survivors, using the information to drive policy that helps more efficiently prevent, detect, and treat cancer and improve the lives of cancer patients and survivors. Previously, Amy served as a leader in the [Deloitte Consulting Survey Research and Analytics Center](#), driving higher organizational performance through employee surveys for private and public sector organizations. Early in her career Amy spent eight years at [CEB](#), now [Gartner](#), helping define and launch new data-driven human capital projects. After CEB, Amy built an employee engagement solution targeted to hospital and healthcare center employees at the [Advisory Board Company](#). Amy, the virtual microphone is all yours.

Amy Farner: Thanks so much, Lucy and I'd like to thank everyone at Women In Government for inviting me to speak to you all today and I'd like to thank all of you for joining. I am so happy to share with you some of the research that we've been working on at the American Cancer Society Cancer Action Network around the impact of COVID-19 on cancer patients and survivors.



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So, I think that the next slide will bring us right into some of what I brought to share with you today. Let's go ahead and dive in. I think we've got some really great information to share with you. Let's start by talking about the overview. Why am I here to talk to you today? This story really starts back in March, as so many of our stories related to COVID-19 do.

My role at the American Cancer Society Cancer Action Network is that I run a program called [Survivor Abuse](#). Survivor Abuse was designed as an opportunity for us to engage with a group of cancer patients and survivors over the course of a 12-month period, deploying regular surveys to them to better understand their experiences and their opinions on legislative and advocacy issues that affect our lives. We launched Survivor Abuse in the summer of last year and we've really had some fascinating and really exciting input from the group to help us with so many of the issues that we work on related to access to health care, affordability of health care, how their patient data is protected and handled, how they have access to medicine and care that they need in order to treat their cancer and symptoms and side effects, and so many other things.

We were scheduled to deploy a survey to our Survivor Abuse group in mid-March and as many of you – if not all of you – will recall March was a really crazy month for us here in the United States, as we started to see the cases of COVID-19 increasing significantly. We also started to see many state, local, and federal restrictions put in place to help stem the spread of the disease. We said, “gosh, we absolutely need to understand how this is affecting cancer patients and survivors.”

We were able to quickly put together some survey questions for our Survivor Abuse participants to better understand the impact of this on their lives. When I say very quickly, we took about a week and we really said this is a 24/7 goal for us – to figure out what are the absolutely most critical ways that we need to understand what's going on in this world. How do we best understand the most urgent things that our cancer patients and survivors are experiencing right now?

So, you can see in the first bullet on the slide our survey actually went into the field on March 25. I live in Maryland and our state started shutting things down right around March 12 – I remember because it was my son's birthday so, really, we were very early in the pandemic when we pushed that first survey into the field. It ran for two weeks and we were able to gather responses from just over 1,200 cancer patients and survivors.

As a result of that survey, we immediately said we know there's more we need to understand, we know that we are at the front end of this pandemic and we want to make sure that we are continuing to monitor the most urgent issues that are related to this population in this very unique and very rapidly evolving situation.

So, we immediately began working towards a second and more detailed survey, which we were able to launch on April 30, and it ran through May 14. The goal of this was really twofold. The first was to track



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some of the most urgent and concerning things that we saw in that first survey – to see how those are evolving over time, but also to dig deeper on some of the things that we learned in the first survey that we felt we needed to better understand. Some of those issues that we surfaced, we said, “gosh, we need to know more about what’s going on here.”

In addition to cancer patients and survivors, in the second survey we expanded our scope, a little bit and reached out to a small sample of caregivers and healthcare providers who work with cancer patients and survivors to better understand how the pandemic affects them as members of the cancer community and the subsequent impact this has on our patient and survivor population.

Overall, we received again just over 1,200 responses from cancer patients and survivors, as well as additional input from the caregiver and healthcare provider population and this gives us a strong degree of logistical reliability to the results that we received.

So, with all of that background, why don't we go ahead and dive in. We can take a look at the next slide, which tells us a little bit about the cancer patients and survivors who are represented in our survey. You can see on the left that we've plotted out the most common cancer types here and you'll note that we have just over 50% of our respondents were breast cancer survivors, as well as representation from Leukemia and Lymphoma survivors, lung cancer survivors, colorectal cancer survivors, uterine cervical and ovarian cancers; these aren't the only types of cancers that are represented, but these are some of the more common ones that we did see in the population.

Now, when we compare these two incidence rates on an annual basis for each of these cancers, we do see that we are a little bit higher on breast cancer survivors than on other types of cancer survivors, but not dramatically. This is not uncommon. When we reach out to cancer patients and survivors, we find that the breast cancer community does tend to be very engaged and very active, so we often do have very strong participation among those, but we were heartened to see that our representation of other types of cancers is not terribly far off from the incidence rates for those cancers, which tells us that we do have that representation that we'd like to see to make sure that we are able to tell the story of a diverse and robust set of cancer patients and survivors.

Another one of the important demographics that we did collect in the survey – we wanted to look at how these individuals source their health insurance, because this very much does affect the way that they're able to access care overall, but particularly in light of the economic upheaval that we're seeing as a result of the COVID-19 pandemic.

Just over half of our respondents told us that they have health care that's provided through their employer – either their own employer or a spouse or family member’s employer and that absolutely is important for us to be aware of, particularly given some of the job loss and unemployment that we're seeing as a result of the pandemic. Around a quarter of our respondents have Medicare – this is a little



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bit higher than the national rates of Medicare coverage, but again, is not surprising when we consider the age demographics of cancer patients and survivors. This is something that we do typically see. We also do have representation from participants who have privately purchased a health insurance, for example through an exchange, those who are on Medicaid, as well as those who have other types of insurance, which is military health insurance, or Indian health insurance, as well as those who are uninsured.

So, let's go ahead and take a look at what we learned from these participants. One of the first things we asked about, which we show on our next slide is what types of challenges are they experiencing in obtaining healthcare? You can see at the top in the very dark blue bar there, we looked across all different types of healthcare and asked, to what extent our cancer patients and survivors were having some type of impact to their health care. You can see here that 87% - so really a very, very large proportion – said that there had been some impact or change to their healthcare as a result of the COVID-19 pandemic. This is a big number and it's a very substantial increase over what we saw in our initial large survey, where only 51% told us that they experienced a change to their health care, and that those changes, affect all different types of health care.

So, in this survey we actually broke it down to ask to what extent they were seeing changes, disruptions, delays, or other types of impacts to regular and preventive care that's directly related to their cancer or care that's related to other chronic conditions, if they exist.

You can see that 80% -- 8 in 10 – of our respondents told us that their regular preventive care has been impacted. This was something that – well, it's certainly a large number, and it is concerning. Unfortunately, it's not incredibly surprising, even when we look outside of the cancer patient and survivor population. How many of us within our own household have missed a checkup or have delayed something that we may have otherwise done or even, for example, scheduled a health care service to be provided by telemedicine, rather than in a doctor's office.

Certainly, where we see the impact to our own care that's where we start to see some of the particularly unique impact for cancer patients and survivors. I also want to note that regular and preventive care is particularly important for cancer patients and survivors, because often, that can be the first step in identifying complications or occurrences that they may be having as a result of their cancer.

Now, as I said, that healthcare impact includes a large set of changes and things that may be really concerning, like if I cancel the visit, or a provider canceled a visit, but it also includes things like receiving care via telemedicine, rather than in person.

We wanted to kind of drill down a little bit and say, “well, what are the things that we are more concerned about?” Such as, healthcare being delayed. What we found was that even when we strip out



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some of the potentially less concerning types of changes, we still are seeing very dramatic rates of impact to healthcare.

So, 78% of our respondents told us that they had some type of healthcare delayed across those three categories, which is an increase from 24% in the survey that was deployed only a month earlier. So, we're really seeing just tremendous increases in the extent to which healthcare is being disrupted.

I was very interested in the poll that we started off with today where we said that just amongst this population, half of us were seeing changes to our health care, where we have cancer patients and survivors who have more frequent interactions with the healthcare system, but also where some of those interactions may certainly be particularly critical. It's certainly concerning that we are seeing these types of delays.

Why don't we go ahead and move on to the next slide? Thinking about the delays that specifically impact our cancer patients and survivors, I just want to pause for a minute and talk about, who are we looking at here? We are looking at cancer patients who are in active treatment, but we also included in our population cancer survivors who may be done with their active treatment or on some type of maintenance program to monitor for or prevent the return of their cancer.

We wanted to drill down into those participants who specifically are still in active treatment for their cancer because we know that they are at particular risk from changes to their health care. When we looked only at participants who are in active treatment for their cancer, 79% of them told us that their health care had been delayed in some way, so that is right around the same percentages as those who are in the overall population. Nearly 8 in 10 people told us that “I'm in active treatment for my cancer and that's been delayed as a result of the COVID-19 pandemic.”

Now, the light blue bar underneath that that large dark blue bar is showing what we saw in our earlier survey. So, there we saw that only 27% of respondents who are in active treatment for their cancer had healthcare delays. So again, a really, really substantial increase from that time to now, this was looking at all different types of healthcare – as we said, we looked at preventive care, we looked at care for their cancer, which may include a visit with their oncologist, but it also may include active anti-cancer therapies and that's something that we were particularly interested in.

In the second set of blue bars under here we asked to what extent are patients who are in active treatment for their cancer we're seeing their cancer therapies delayed. These are ongoing therapies such as chemotherapy, radiation, hormone therapy – which are often administered in a physician's office or in an infusion center – require leaving their home. In this survey, the most recent one, 17% of patients who are in active treatment for their cancer told us that cancer therapy had been delayed as a result of COVID-19 – that's really a concerning number, one in five, nearly, told us that – and it is an



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increase of over 8% who told us that they had experience delays in the active treatment of their cancer or their anti-cancer therapies in April of 2020.

We also wanted to look into how long these delays last. So, is this simply my doctor's office is taking a short period of time to determine how they're going to handle new social distancing requirements or is this something that is more long term. Among those who had experienced delays to their health care – again, this is active patients in active treatment for their cancer – more than a quarter told us that their cancer care had been delayed by more than two weeks. So, these are not simply short, a day or two delays. In fact, 19% of them told us that their cancer care had been delayed and they do not know when that care will be rescheduled, which adds a degree of uncertainty – that's absolutely a concern to us at the American Cancer Society Cancer Action Network.

Now, I know that we've got the opportunity to ask questions in the chat. So, to the extent that there are questions, please do feel free to go ahead and enter them in the chat. In the meantime, I am going to go ahead and keep us moving forward and of course, we'll have opportunity for questions at the end.

We've talked a little bit about the impact on cancer patients and survivors being able to access and get to their health care, but we also know that there is a substantial impact on the financial ability to afford health care as well. I think that all of us are well aware of the unemployment numbers as well as the number of businesses that are laying off employees or are shuttering for the duration of social distancing or are required to close down. So, absolutely we want to know what both businesses and households are feeling the financial impact from the pandemic.

We wanted to understand how this is affecting cancer patients and survivors' ability to pay for care. So, we asked them some very specific questions about some of the different ways that the pandemic may be affecting their personal finances and we asked it very specific to their ability to pay for health care. This is not simply, “did you experience this effect?” but it's “did you experience this effect and is it affecting your ability to pay for your health care?”

What we found, is across the laundry list of different types of financial impacts that we asked about nearly half of respondents in the most recent survey told us that they had experienced at least one financial impact that affected their ability to pay for care. That's up from 38% in the previous survey. The most common types of impacts that we're seeing are they or a member of their household have had work hours reduced. We're seeing that folks are telling us that they have reduced investment values which affects their ability to pay for care. Again, this may affect many of our retired or close to retired cancer patients and survivors as they look at their 401k or other type of retirement plan balances, but also may affect cancer patients and survivors who are relying on investments or savings to pay for their care. We also did see that 8% of our respondents told us that they or a member of their household had lost a job and that job loss affected their ability to pay for care.



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Now, when we look at things like work hours being reduced and job loss, again, those are concerning because less money coming in absolutely affects the resources available to pay for care, but also we now affects their ability to access health insurance, where 55% of our respondents told us that they do have an employer sponsored health care plan. So, we absolutely are concerned about both aspects of that – do they have the money to pay for the out of pocket expenses of care? But also, are they able to sustain health insurance that allows them to afford care as well? I want to drill down on that health insurance issue.

Let's take a look at the next slide. Independently of what experiences they had in terms of their own financial changes to date, we also know that a lot of individuals are experiencing anxiety about the financial impacts – perhaps they haven't lost a job just yet, but are worried that someone in their household may or worry about the economy and its effect on their family business or so many other things.

We did ask, independent of what you've experienced so far, to what extent do you agree or disagree with the statement: I am worried about losing health insurance because of the COVID-19 pandemic and its effects on the economy and my finances. Nearly a quarter of our respondents agreed or strongly agreed with that statement. We saw, not surprisingly, that the concern was particularly strong among individuals who had privately purchased health insurance or employer provided health insurance, which really reinforces some of the concerns that we noted on the previous slide.

Now, obviously being able to afford health care is absolutely important, but we also are concerned about how cancer patients and survivors are able to afford basic household expenses in light of the pandemic as well. So if we go ahead to the next slide, we asked a similar type of statement again, independent of the financial impact that they may have experienced today we asked, to what extent do you agree or strongly agree with the statement: I'm worried that the financial impact of COVID-19 will make it hard for me to afford basic household expenses such as rent or mortgage, utilities, and food. Nearly a third, 32%, of our respondents agreed or strongly agreed with that statement. Not surprisingly, that degree of agreement was very strongly correlated with income, with the lowest income respondents – those whose household income was \$30,000 or less – most commonly expressing this concern; more than half of them telling us this was a concern.

Now, affording those basic household expenses is always important, but it becomes particularly important when we're being asked to shelter in place in order to protect our health. I don't know how many of you did massive grocery orders in preparation for shelter in place – I know I did. I absolutely needed to bring more into my home in order to keep my family at home and make sure that we were not out exposing ourselves to potential COVID-19 infection. This is an even greater concern for cancer patients and survivors who may be more vulnerable to the infection or to complication from the disease. So absolutely something that we wanted to press on.



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So why don't we go ahead and take a look at the next slide? We asked them how difficult it was for them to find and afford different types of supplies that they might need in order to safely shelter in place and not go out during the pandemic. You can see the dark blue bar on this chart is telling us what percent of respondents told us it was difficult to find certain supplies and the light blue bar is telling us what percentage of respondents told us it was difficult to afford those supplies.

So 40% of respondents told us it was difficult to find food, and we specified with food that we were looking at a healthy variety, and again in my own experience I saw something get ripped out of my cart for an online shopping order or if you went to the grocery store and saw the absolutely white bare shelves of meat or vegetables and produce. There is difficulty finding a healthy variety of foods, which again, is an important thing for cancer patients and survivors to access in order to maintain their health. 19% told us it was difficult to afford that food. 81% told us that it was difficult to find household supplies, which includes things like disinfecting cleaners, paper products, hand sanitizers, and soaps. And again, I'm thinking back to when many of us saw it ourselves in person or in pictures online, those white bare shelves, no Clorox wipes to be found, even sometimes no hand soap to be found.

And then we also asked about protective equipment such as masks and gloves – 70% of our respondents told us they had difficulty finding it and 29% told us they had difficulty affording it. Again, these are things that can prevent the spread of COVID-19.

These also may be supplies that are necessary for health care that cancer patients and survivors are regularly accessing or administering, so if you have a family member who's administering medication by a shot or if you need a mask in order to protect you, because your immune system is compromised. These are things that are important for protection from COVID-19, but also may be a part of the daily life of cancer patients and survivors.

We've talked a little bit about difficulties accessing healthcare. We've also talked about difficulties affording healthcare. One of the things that came out very, very strongly in our first survey that we wanted to go a little bit deeper on here is the effect of the COVID-19 pandemic on the well-being of cancer patients and survivors.

In our first survey, we had an open-ended question. We basically wanted to just open the floor to our participants and allow them to tell us what their experience is and tell us what they are experiencing in this pandemic. One of the strongest messages that came out of that was that they were experiencing record high levels of anxiety and in some cases even reported that they were experiencing depression and there were a lot of different causes for this.

In many cases, they were saying “I'm concerned because I'm afraid I'm going to contract this illness and because of my cancer I'm at a higher risk of complication.” They also expressed concerns because they felt isolated, they say “gosh, I'm at home and I don't want to go out because I don't want to get ill and so



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I'm just at home alone all the time and that's affecting me.” Or “I have to go to a doctor's office by myself, because my facility has put policies in place to prevent the transmission of COVID-19 and now I'm afraid that I'm going to have to get bad news about my cancer, and I won't have a caregiver or a support person there to help me.” So, lots of different reasons why cancer patients and survivors were expressing concerns about well-being in this pandemic.

We asked a series of questions related to this. Overall, 48%, nearly half, of our respondents said that the experience of being a cancer survivor during this pandemic is having a moderate, or a major effect on their overall well-being. We dug into some of those reasons.

70% of our respondents told us that they will worry that going to medical facilities is going to give them a higher likelihood of being exposed to COVID-19, so certainly concerns about their own ability to access care, not just “can I get there, but can I safely get the care that I need.” Two thirds of respondents told us that as a cancer survivor, they're worried that it will be harder for them to stay safe when social distancing policies relax in their area. As we are starting to see those relaxations in so many areas that's absolutely a concern as well. Nearly 40% told us that they're worried about having to go to a doctor's appointment or get test results without a caregiver and that concern is actually something that we heard echoed even more strongly from the response of the caregiver respondents who we spoke to as part of this offer. The caregiver said, “I'm worried about my loved one having to go to doctor's appointments alone without support.” Finally, one in five told us that they're concerned that their cancer could be growing or returning due to the delays or disruptions in their care as a result of COVID-19, so that's absolutely a concern.

This is where, I think, the context from healthcare providers becomes very interesting. Again, looking at the caregivers and the health care providers we saw that concern echoed even more strongly where providers said, “I am worried that my patients will have cancers that are detected at a later stage or not treated in a timely manner, because of this pandemic.” So obviously, a lot of concerns around access to care, as well as around the ability to afford care, and then finally on the overall well-being and mental health impact of the pandemic.

I think I saw a question pop up in the chat. So perhaps we can go ahead and move to the question and answer section now.

I see in the chat a question from Cindy, “do we know what the financial impacts on the cancer treatment providers were and will it jeopardize them coming back to provide treatments?” Yes, this is something that we did see in the conversations that we had with health care providers. We asked to what extent they were seeing fewer patients as a result of the pandemic and many of them told us that they are in fact seeing either fewer patients or, in some cases, no patients, because of the pandemic. Now this



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spanned all different types of health care providers, depending on the type of care, they're providing obviously, different types of impacts.

What we also saw as we asked, to what extent they were either furloughing or laying off office staff and providers and more than half of those that we spoke to did tell us that they were experiencing those types of workforce challenges where they were having to reduce headcount and they expressed a great deal of concern about the ongoing financial viability of their practices as a result of these all of these challenges.

Laura Blake: Hey, thank you so much. This is Laura Blake, I'm outreach and development manager here at Women In Government. We do have a little bit of time for Q&A from the audience. Thank you, Representative Ryu from Washington State for your question. If anyone else has any questions, please feel free to write them in the chat box or text them to me. I'm just going to quickly jump in with: Have you seen any concerns expressed by cancer survivors and patients that are unique to the COVID-19 pandemic?

Amy Farner: Yeah. I think that so many of these concerns are unique to the COVID-19 pandemic. That's the challenge that we are absolutely in uncharted waters. I think one of the things that is most unique about what we're seeing in this pandemic is the degree of uncertainty. We talked a little bit about the difficulties accessing healthcare, delays, cancellations, and changes to care.

We asked in a survey who proposed the change to your care – did you propose the change, did your provider propose a change, or was it a joint decision that you made? And then based on who proposed it, we asked questions about what the driving force behind that was. What we found was that in many cases the patient's themselves were proposing changes to care and the number one reason why they were proposing those changes as they said, “I don't know if I should do this, I don't know if it's safe for me to get this care.”

So that degree of uncertainty is absolutely something that creates challenges for them in being able to chart the most effective course to treat their cancer, but it also creates so many of those mental health and anxiety issues that we've mentioned as well.

Laura Blake: Gotcha. We have time for just one more question. What can state legislators do specifically to make sure that cancer survivors and patients have the healthcare access that they need, especially during the pandemic?

Amy Farner: Yeah, absolutely. There are so many things that we can do to help support cancer patients and survivors. One of the things is making sure that there's access to affordable health insurance for all cancer patients and survivors. Where we are seeing job loss, where we're seeing people losing access to



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health care due to reductions in hours, being able to enroll in health insurance through the state exchange or having access to fully funded Medicaid programs is absolutely important.

We're also thinking about things like [Cobra](#), which is important as well. In many states we're seeing a special enrollment period opening for Affordable Care Act exchanges, so that perhaps those who are worried that they don't have sufficient health insurance right now are able to change their plan or are able to make sure that their plan will cover them if they have concerns that they may, in the future, lose access to their health insurance.

Laura Blake: Well, thank you so much. I'm going to turn it over to Lucy to introduce our next speaker, but Amy, thank you so much for being here. This has been a wonderful presentation.

Amy Farner: Great. Thank you, Laura. I enjoyed it.

Lucy Gettman: Amy, this is Lucy, I echo Laura's thanks to you for providing your cutting-edge information for those of us around the virtual policy roundtable today. But don't go anywhere! We have a double feature this afternoon.

I'm delighted to introduce another great presentation today, titled “Physically Distanced but Socially Engaged: My Cystic Fibrosis Life” featuring Emily Schaller. Emily Schaller, 38, is a heroine with one goal in mind: to rock CF. Equal parts spark, wit, and humor, Emily is claiming her victories against cystic fibrosis, having launched the [Rock CF Foundation](#) in 2007 to heighten public awareness and raise funds to increase the quality of life for everyone with CF. Emily created and manages an internationally acclaimed line of merchandise to help fulfill the mission of Rock CF and today Emily's battle against this deadly genetic disease is printed in Runners World, Forbes, the Atlantic, and Spin-Off Magazines, The New York Times, The Washington Post, USA Today, NPR, and is posted on competitor.com, shape.com, the Associated Press, and various cystic fibrosis focused educational websites. So, Emily, you get around! She's a super teacher and a speaker addressing parents, patients, and audiences about the effects of cystic fibrosis, and the ever changing and improving treatments being made. Through Emily's humor and personal experience, she inspires the masses to transform their lives with exercise and diet and goal setting. Emily, welcome to #WIGWednesday, the podium is all yours.

Emily Schaller: Oh, wow, the podium in my kitchen. Thank you, Lucy. Big shout out to Amy, awesome job on collecting all that data, it's very impressive stuff and really when you were speaking it had me thinking of all the parallels with the cystic fibrosis community as well so, awesome. Very cool to see.

So, I'm going to fill you in a little bit about my life with cystic fibrosis and how this social distancing isn't so new to me and the CF community. I did cut my hair for you guys today. This is my fourth quarantine haircut I've done myself, so it doesn't look so great but bear with me. I was diagnosed with cystic fibrosis in 1983 when I was 18 months old. It's a genetic condition that causes super thick and sticky mucus to



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build up in our lungs and digestive system and pancreas. The problem with having that mucus in our pancreas and digestive system is makes it really hard to absorb the nutrients from our food and gain weight and thrive, and the bigger issue with the thick mucus in our lungs, is it traps bacteria which becomes a very important part of my talk here in a little bit.

I had a pretty healthy childhood – no family history with CF, but my mom and dad knew something wasn't quite right – I was small and for the first few months of my life I just wasn't thriving how my two older brothers were. I wasn't gaining weight. My dad was the diaper changer in the family, and we were ripping through those cloth diapers like nobody's business. So, they reported that to my pediatrician. They tested me for CF, and it came back negative. So, my parent's kind of felt defeated and wondered what was wrong with their baby, so months and months went on and these digestive issues and failure to thrive diagnosis was given to me and then I started to develop some upper respiratory tract infections, quite often. Finally, at 18 months they decided to test me again at a CF care center down in Detroit and I was diagnosed with CF.

Prognosis at the time, in 1983, was not amazing. I think the median age of survival was around 18 or so and they told my parents I probably wouldn't live long enough to graduate from high school. That's the case back then because we didn't have treatments like we have today. They were literally digestive enzymes that they gave my parents to start with me and vitamins. So, from diagnosis, until now, I've been taking these digestive enzymes that help absorb the nutrients in the food I eat so I can thrive and grow and become a little bit healthier. Then my parents were told they would have to beat me and – not like that, but more so as chest physical therapy to help break up the mucus in my lungs. So, they would lay me down on their legs or on pillows and pound my chest, and my back, and my sides seven times a day for a while. And those were the treatments I had: chest PT, vitamins, and enzymes for the first, probably, 13 years of my life.

Fast forward to now and we have some pretty awesome treatments that are even treating the underlying cause of CF, which I'd be happy to discuss at another time with you guys, but I had a very healthy childhood, I was an active kid keeping up with my brothers and they even sent me to this camp, a cystic fibrosis camp where there would be hundreds of us with CF, probably starting around age six up until some of the counselors in their 20s or 30s had CF – we all get together once a year. It was this really awesome time to go through, and kind of relate and go through CF together. There's only 30,000 people in the US with CF. It's a rare disease and you don't really know that many people with it. So, going to camp and being able to hang out and party and see your friends once a year was kind of awesome.

It was awesome until about 1989 when they discovered that we were in fact killing each other. The way that was happening was that really thick mucus that I mentioned that's in our lungs traps bacteria, right? And the bacteria can turn into lung infections over time and loss of lung function. What it also



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does, is it holds on to some bacteria and then it's able to pass to other people with CF, so they found that we were passing and exchanging these deadly bugs to each other, so they decided, they we're passing a couple different bugs, one which was very, very harmful to people with CF, especially at the time.

When they realized that we were passing these bugs to each other, they thought, okay, let's separate the camps, right.? We'll have a non-bad bug week and then a people with the bad bug together on the second part of the week. Sounds great, right? It's kind of what we're doing now with COVID, right? So, I think they did that one or two years and then just decided, look, there's no way to detect who actually has the bad bug and who doesn't, and we were still passing the bugs to each other, so they closed the camps. They said no more hanging out with each other.

From those early 90s that evolved through the 2000s, up until about 2013 or so, when we had these really strict guidelines placed on us, for example, at a CF event there can be only one person with CF allowed at the whole event, especially if it's indoors, because we could possibly infect each other.

We go to the CF care teams and CF clinics three to four times a year to measure lung function and to generally see how we're doing and when we do that now we have to mask up and wait in different parts of the waiting room. When we show up for our CF appointments, they take us right back into the waiting room just so we don't interact with each other. I know this is all sounding eerily familiar to you guys with what we've been going through the last few months, but this whole isolation and physically distanced lifestyle, is what we've been dealing with for a few decades now.

When COVID really started happening, the CF community kind of looked at each other and were like, wow, this is what we've been doing for a while, like we've been masking up to go to clinics. If, by chance, we were at an event or a venue with somebody else with CF we would be masked up and required to stay six feet apart. I've been to several functions for CF in the past decade or so, when these strict guidelines have come out and it can be isolating and I know Amy mentioned isolation with cancer patients being brought into their homes because they're scared to go out and the people in this community also scared to go out during this time, but we really have kind of been taking it to the next level for decades.

There's a movie called [Five Feet Apart](#), and I'm sure some of you have seen it and some of you looking for a quarantine movie to watch, maybe checked it out. It goes through the life of a few people with CF and how they have to be physically six feet apart, but they take the extra one foot to be together, because they're in love. It's kind of cheesy, but they do a great job laying that out – the whole physically distanced, six feet apart thing.

So we've been doing this for decades and the biggest thing we've gotten good at as individuals with CF and CF organizations is doing this advocacy work from afar, or having these zoom sessions or like if I'm



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speaking at a CF education day around the country for a hospital in one of these events where the CF families come together and the CF doctors speak and the nutritionists and then I'll get up and speak or one of my friends with CF would get up and speak and share their experience about living with CF. Everyone else with CF has to zoom in, or Skype in, or whatever the platform is to watch this, because we're not allowed to be together. So really interesting but still very powerful and it's how with Rock CF, my nonprofit here based in Detroit, it's how we've been doing things.

I'm in several advocacy groups with other CF organizations that have somebody else with CF leading the group or somebody's kid has CF and they're leading the group and we can't get together and hang out and discuss these things. So, one person with CF will travel across the country to the meeting, but everyone else in our group, those with CF have to Skype in, or zoom in. So, it's an interesting life, not new to us, but really hits home with where we all are right now in this COVID world, but I think we're getting good at adapting like we are today. We're all together on this zoom call learning from each other, which is very cool.

One of the big things, I know Amy mentioned, with the cancer patients is these high rates of anxiety and depression which comes along with chronic illness to begin with, but when you're isolated as you are with CF for a lot of the time, unless we can interact through media, being alone is scary and it does, bring up anxieties, throwing in on top of that, the chance that we could possibly be exposed to this virus. So, it's been a whirlwind for all of us, I think, and especially me, having CF and on top of that, leading an organization with CF.

So, I'm now 38 years old and the healthiest I've ever been thanks to these developments in CF medications, but I'm still scared, every day throughout this thing worried about my health and me possibly spreading this virus to my friends. We have halted all of our Rock CF events and they're all virtual which has been tough, but we're still making it happen. A bunch of online support groups have popped up in the past couple of weeks. I know I've never been on so many zoom calls and it's really nice to be able to just talk to people when we're all going through this and just kind of see people.

I have friends that messaged me every single day, like, how are you adapting with Michigan slowly reopening, are you going out, are you having friends over and we're all kind of working through this together, which is really special. And it's really something that you can only do through these zoom platforms or text or FaceTime, which is really cool. Probably the best part about technology, I think, is the way that we can connect with each other in these in these times.

So yeah, I mean, social distancing, I guess, social distancing – I don't know if it's the right word. We're really physically distanced, but we can still socially engage, we can still write comments and letters to our legislators for health care for people with CF and other rare diseases to make sure that people with CF don't go without a ventilator if we were to get COVID and go in, making sure we have access to



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health care and the health care we need, things that Amy discussed really are magnified and echoed in the CF community as well.

So, we're still working on things, even though we're home and isolated, we're still advocating for health care, health coverage, things that are popping up in different states from my friends with CF, we're writing letters and calling legislators to make sure that we're not quiet. We don't stay quiet here in the CF community, we're a lot of big advocates with a big voice and the best thing for us right now is to stay physically distance, but we're always going to be fighting as one voice, virtually, one day, all of us together, but still probably only people with CF will remain a six feet apart.

That's, I guess, the message today, is we're all told to stay six feet apart in general, right now, but for people will see CF, I think, for a very long time, we will still need to be six feet apart from each other.

So, I know I ended that kind of quickly, but I'd be willing to take some questions if you have any about CF or how we're managing in the social distanced world.

Laura Blake: Great. Thank you so much, Emily. If anybody has any questions again, friendly reminder, please type it in the zoom chat box and select 'to everyone.' I'm going to kick it off right now by asking you how can state legislators best support parents and families who are caring for children with CF?

Emily Schaller: I think CF is a very isolating disease, it's a very expensive disease, our treatments are, thankfully, nowadays with advancements in medicines, our treatments are mostly done at home, so hours of therapies to breathe in, to kill the mucus or to kill the bacteria in our mucus, now instead of my parents having to pound my chest and my back, my sides, I have a vest that I put on that fills with air and it does it for me.

These things are awesome and convenient, but they're pricey. So, making sure that we have proper access to care, I think, that's the biggest thing with poor outcomes for people with CF, is not having that access to care, and in remote states, where the CF population is small, say out west or in the Dakotas, some of these patients have to travel very far distances to get to a CF care center and it's very important for people with CF to be at that care center because that's where the experts are for CF.

So thinking about telemedicine and how that plays into an insurance plan or a Medicaid or a Medicare plan is very important, not just in remote states, but really now, because I mean I've had one or two, e-visits with my doctor, because we're not going to the hospitals right now, so I think listening to CF families and patients is really big. I know we do a good job of reaching out to you guys, but if you ever want to know more about CF or the rare disease community, we're here to talk.



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Laura Blake: Thank you, and just kind of building off of that, what do you think are some of the best ways for legislators to connect with patient advocates and to connect with members of the CF community if they want to learn more and do more for your community?

Emily Schaller: That's awesome. So, I'm part of a group called the [Cystic Fibrosis Engagement Network](#) and it's my nonprofit, Rock CF, along with the [Boomer Esiason Foundation](#), [Emily's Entourage](#) and I think six or so other CF organizations that are founded and led by CF patients or parents. So really, really powerful families who are in the fight together. The CFEN is a really great resource. And we're all across the country from California to New York, from Florida to Detroit, so we're very active and open to discussion. Also, of course, the [CF Foundation](#), which is a national organization is a great resource.

Laura Blake: Gotcha, gotcha. Do you think there are any other populations aside from the CF community with rare diseases that are particularly vulnerable that could use some additional outreach during this time?

Emily Schaller: Yeah, I mean the hemophilia population. I have some parallels with CF in the rare disease world. Also, I know in Michigan, [Michigan Special Health Care](#), which is a service for people with CF that covers medications and all CF care beyond what insurance covers is a huge resource for the CF community and also the hemophilia patients because it's a lifelong program. So, we're kind of grouped in with those guys with this sickle cell, especially at this time is pretty important to pay attention to, but yeah, I think there's smaller rare diseases that we can kind of get grouped in with because we're – not left behind, but we're not the main focus like some other larger disease populations are.

Laura Blake: I want to just keep asking you all the questions, but unfortunately, I know that I have to be mindful of the time, so Emily, do you have any last closing thoughts that you want to share with everybody?

Emily Schaller: Yeah, I think as we begin to reopen – and this has just been on my mind for weeks now, as I see parts of the country reopening, we still need to be mindful of the vulnerable populations, whether it's cancer or CF, diabetes, other high risk populations are still going to be high risk, even though we're reopening so just proper precautions still in place and yeah, just looking out for each other. I think that's what we're here on earth to do, is take care of each other and make sure we respect others and keep them healthy.

Laura Blake: Oh, well thank you so much, Amy and Emily. These have been great presentations and I'm going to turn it back over to Lucy to close us out.

Lucy Gettman: Great, Emily, thank you so much for being with us this afternoon, for being candid, for being authentic, for being energized, and just being so present with us, thank you, and the show's not over, folks.



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I also want to thank Michigan Representative Rebekah Warren, who is doing what legislators should be doing right now, which is on the floor, working on good policy for citizens, so, we hope she'll be able to join us on another occasion. I also want you to know about next week's exciting options coming up, June 17th is our very first WIG Summer Summit Series. Our [first program](#) consists of content on sickle cell disease and shaping a better future for patients. It'll be moderated by New York State Assembly Woman Alicia Hyndman and we'll have our featured speaker, Dr. Tartiana Brown, MD, [Senior Palliative and Hospice Foundation Physician](#) at [Metropolitan Jewish Healthcare Service](#). Following sickle cell disease, we have a session on helping your constituents access their medicines – certainly resonates with our conversation today – and our featured speakers include Ellen Cappellino and Stephanie Odutola from [AstraZeneca](#).

In addition, we will be pushing out additional information about upcoming programs, so we hope you will attend the WIG Summer Summit – registration is easy, just go to our website www.womeningovernment.org, click on 'upcoming events' and there's an easy link to register and additional resources are also available on our website 24/7.

So, thank you all for joining us today. Stay, safe. Join us again next Wednesday and continue engaging with Women In Government. Thank you.

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