

## Seizing Life, episode 53 The Impact of COVID-19 on Epilepsy Research Guest: Mike Coburn (Transcript)

Kelly Cervantes:	<u>00:00</u>	Hi, I'm Kelly Cervantes and this is Seizing Life, a bi-weekly podcast produced by CURE Epilepsy. Today on Seizing Life, I'm happy to welcome Mike Coburn, the executive vice president and chief operating officer of Research!America. Founded in 1989, Research!America advocates for science discovery and innovation to achieve better health for all. The organization urges policymakers to increase funding for the NIH, CDC, FDA, and others at levels that keep pace with scientific opportunity. With the COVID-19 pandemic disrupting life across this country, Mike is here to discuss the pandemic's effect on the scientific community and how it might impact epilepsy research and the epilepsy community at large for years to come.
Kelly Cervantes:	<u>01:06</u>	Mike, thank you so much for joining us today on this incredibly important and timely topic. We have all been, our lives have been drastically affected by COVID-19, the understatement of 2020, I suppose. But what I really want to dive into today is how COVID-19 has really impacted our research partners and what that means for them when their lab is shut down and how that affects the researchers and the research that they're doing. I know that's a very broad question to start with, and we'll dig in a little bit more as we go along, but what has the overarching impact been for the research community?
Mike Coburn:	<u>01:56</u>	Well, Kelly, it's a pleasure to be with you, and I'll have to say that the pandemic has caused an abrupt stall in research, research on every level. As you know, most of government funded or NIH funded research takes place at universities. The universities and other employers have had to adhere to protocol to keep their employees, their staff safe, and so labs have closed. They closed pretty abruptly in March, and labs, depending on where they're located are still at a level of partial operation, full shutdown, and some may be up and running more fully. Again, local mandates dictate how well institutions can rebuild their normalcy. And so, it has stalled research.
Mike Coburn:	<u>02:50</u>	The problem here is that research isn't a start and stop activity. It is a continuum of discovery. And so all of the work that had been done up until March, March 12th or 13th or whatever the day was in March when we were all hugely impacted that that knowledge is left on the bench and not perhaps picked up. There's lost opportunity. You look at the researchers themselves and they've had to leave the environment in which they work in and thrive in, which is the bench side and have been working at home. And you can't do basic science at home.

		There's been a lot of writing, a lot of research and they've used their time optimally to wrap things up that they hadn't been able to do and to plan new research. But, they're not back at it yet and it will take some time.
Kelly Cervantes:	<u>03:45</u>	So what happens to the research that they were doing in the lab? What happens to the animal models that they have been working on?
Mike Coburn:	<u>03:55</u>	Yeah, that's unfortunate. There were emergency policies that were put in place by many institutions to preserve animal models. And so, there was an attempt and NIH has said this as well to provide that emergency status for certain employees to keep the models going. But there was no further research as a matter of trying to preserve the knockout mice or rats or whatever the model might be. And there was the unfortunate need to stop experiments. So they weren't being used in actual experiments, they were just keeping the colonies alive for future use.
Kelly Cervantes:	<u>04:40</u>	And how were researchers salaries affected? Do they still get paid even though they're not doing research?
Mike Coburn:	<u>04:48</u>	Yeah, that's a good question. And fortunately NIH by the way, has been extraordinarily flexible. And most of the university level research is funded by NIH. They've been extraordinarily flexible in terms of working with their grantees. Salaries are continuing to be paid for by the grants. Scientists continue to work hard in terms of writing up a lot of research. There's been just an abundance of new publications, almost a flood of new publications that have come out during this past six months because scientists have shifted from hands-on experiments to data analysis and write up their research. So on that end, there's been great productivity.
Mike Coburn:	<u>05:33</u>	Their salaries have been able to be continued under the grants. However, because their salaries have been able to be continued and their activity has been diverted to other non lab activity, if you will or non experiment activity, there's probably a challenge that money could run out down the road. In other words, they've got to get back restart research, restart their experiments, but the grant has been using money all along and they may run to the end of the road.
Mike Coburn:	<u>06:06</u>	And so important there, Kelly is the need for Congress and this administration to pass in the stimulus bill a robust, a mark for funding, NIH funding to restart research. We as an advocacy organization are asking Congress, and we're asking all of our

		advocates, anybody we know to ask Congress to include at least \$26 billion in the stimulus bill to restart research, so that those salaries for the scientists who have been working can be picked up and continued.
Kelly Cervantes:	<u>06:40</u>	As we are recording this particular episode, it's probably worth noting that it is a week before the presidential election and I do believe that Congress has just gone on a bit of a break or Senate has at the very least. So are we hopeful that something like that will be passed that researchers will get that stimulus money that they so desperately need? And what is at risk if they don't?
Mike Coburn:	<u>07:11</u>	Yeah. Again, as you say when this episode is aired, we'll be on the other side of whatever happens on November 3rd. And I think that there's great interest in certainly in the house to pass a bill and to include stimulus for NIH. The Senate has been, when it's not caught up in the political realm that is right now has been very supportive of NIH. The house and the Senate have come together in the past, and we hope that's what will happen past the election. There is optimism that the Congress will include robust stimulus for NIH. The level, we don't know yet, but, dr. Collins, the director of NIH has given the scale that we need to see about 26 billion or more to restart research.
Mike Coburn:	<u>08:04</u>	So it's been caught up in the politics and is so very unfortunate because it's nailbiting. PIs are looking at how do I keep my lab running? Early career researchers are worried about their careers, and these are all impacts of There's the impact of what we're going through with the pandemic and the need to follow public health directives of staying apart and working where you're in your kitchen, I'm in my downstairs room.
Brandon:	<u>08:37</u>	Hi, this is Brandon from CURE Epilepsy. An estimated 3.4 million Americans and 65 million people worldwide currently live with epilepsy. For more than 20 years, CURE Epilepsy has funded cutting edge patient focused research. Learn what you can do to support epilepsy research by going to cureepilepsy.org. Now, back to Seizing Life.
Kelly Cervantes:	<u>09:00</u>	You bring up something that is terrifying, this idea of young researchers and that's something that CURE Epilepsy has been very involved in, in trying to certainly get young researchers into the field of epilepsy research with our Taking Flight award. Is there discouragement among students who had planned to go into research and are now looking in other directions because the landscape is so uncertain?

Mike Coburn:	<u>09:32</u>	We've heard stories of this, and certainly there's been all along the lack of people wanting to go into STEM for various reasons. And so, when they see what's happening right now with the uncertainty and the academic institutions, and young scientists who are postdocs, or just early in their career, I'm not sure where the funding's coming from, there's a great deal of anxiety. And I think that part of this stimulus funding for NIH has to address that to make sure that early career scientists have the opportunity to continue. There's been a freeze on hiring. So, postdocs came out of their doctorate programs. They graduated, they got their diploma, and now their next step is to do the very important step in their career of obtaining a postdoctoral position.
Mike Coburn:	<u>10:22</u>	There's been a freeze at universities, and of course universities are the largest employer of post-docs. There's been a hiring freeze, and so these four scientists come out of school with a PhD in molecular biology, and they're sitting there waiting for the gate to open for postdocs to be able to report to PI labs and begin that process. So, it's a very daunting time, and we're all concerned for young scientists and what the future brings.
Kelly Cervantes:	<u>10:53</u>	Is there anything that organizations like CURE Epilepsy can do to help support these young researchers and help them progress in their careers or even start their careers?
Mike Coburn:	<u>11:08</u>	Yeah, I think the one thing is certainly to message out that CURE and all the other voluntary groups and funders of research are continuing to amass resources to do that. And we've all gone virtual and things work, and we're still working hard to generate the resources to fund research and to get, when research opens to be there to ensure the grants are going to be made and paid. And so, I think just the message to the research community that the voluntary sector is with them and continues to need that talent to further drive discovery. I think that's something that all organizations could do as a signal to researchers is that we're with you and we're not going away. And we're doing our fundraising and we're finding ways to generate dollars to fund research.
Kelly Cervantes:	<u>11:57</u>	Heard, and all the listeners hear that too. [crosstalk 00:12:01]-
Mike Coburn:	<u>12:02</u>	I'm sure. As advocates, that's what we do as advocates.
Kelly Cervantes:	<u>12:07</u>	So I've read that the COVID-19 is going to impact research moving forward for years to come. For a focus like epilepsy that is already underfunded, that's terrifying to think that we could be taking steps back when we're already just clawing at the bit

		to try and get the research produced to make a difference. What does that impact look like for the clinicians and for the patients?
Mike Coburn:	<u>12:45</u>	Yeah, I think it's certainly a little bit unknown Kelly. There's going to be, when research restarts the need for people to start up what they were doing. But so much of what's on the mind of curious scientists is what's the next place to go to find an answer? And so, I think that, A, ensuring the research community, the CURE and other organizations are going to fund this type of research is really, really important. I mean, we have to understand that, probably a lot of that epilepsy research that was moving forward got stalled and it will be restarted. But then there's the other, everybody that comes into the field of epilepsy research comes in with an idea. And, if we don't get the young scientists into the labs, we don't get post-docs into the labs, those new ideas won't germinate. And that's really a fear.
Mike Coburn:	<u>13:38</u>	I think that epilepsy like other organizations, the epilepsy population community has to be loud and demanding to get the resources that are needed for epilepsy. You do a great job. The movement that advocates for epilepsy does a great job at getting the attention, heightening the priority of epilepsy research. And I think it's going to be even more important for the community to be visible, to be vocal, to be demanding of policymakers. There'll be a new Congress and there'll be new people in Congress. And, there's important work to be done for epilepsy advocacy to make it a priority to find the resources to build champions in Congress.
Mike Coburn:	<u>14:28</u>	And I know there are champions for epilepsy in Congress, but there'll be a need to develop new friends. And, with this administration, if there's a change in administrations, we may see more positive outlook for science, if you will, science is so important, evidence and science. And so, there's been disruption in I think the enthusiasm for science, if you will.
Kelly Cervantes:	<u>14:57</u>	We talk about COVID and potential treatments or vaccines. And we hear a lot about the FDA and getting these treatments or vaccines pushed through the FDA. How does that impact potential epilepsy treatments? What is going on in the FDA when it comes to all of the other diseases that are trying to work with the FDA?
Mike Coburn:	<u>15:21</u>	And that's a great question, Kelly. First and foremost, the FDA has pledged the importance of transparency and working with the research community on COVID vaccines and therapeutics. They've also said that the important work that they're doing on

		the approval process of other drugs in the pipeline and other therapeutics in the pipeline has to continue. But one of the challenges the FDA faces is it's woefully understaffed, and that's a matter of funding, congressional funding for the FDA. Many of the commissioners have said quite frankly, the number one challenge at the FDA is workforce development, that there needs to be funding that allows the FDA to bring in additional resources to help marshal the new therapeutics products or what have you through the approval steps.
Mike Coburn:	<u>16:15</u>	So they've committed to stay focused on moving things forward, but there's always a breaking point when you have so much air in the balloon and the balloon can't hold it anymore. And, I think it is a real challenge. So again, it gets back to making sure the FDA is properly funded by Congress, has the resources to really get the job done. I can't say that there won't be some slowdown in evaluation, but the FDA leadership has pledged to keep doing their mission. And I hope that they can, and I hope that we do see some terrific leadership out of the FDA in terms of what will face all of us in this pandemic, but also the need to move new therapeutics through the approval pipeline.
Kelly Cervantes:	<u>17:08</u>	Yeah, absolutely. And, hearing you loud and clear that I think we all have to be more vocal than perhaps we have been in the past or ever with our elected officials and representatives. We have also heard that the pandemic is disproportionately affecting female researchers. Why?
Mike Coburn:	<u>17:35</u>	Yeah, I think you're right. And I asked my colleagues, I said, I've heard this too, but tell me what is the issue here? The issue is really what a lot of females in the workplace are seeing is that families are now schooling children at home, they're caregivers, they're educators and they're career people. So, unfortunately, the balance is tipped where apparently more of the productivity right now through publishing, if you will, writing papers, writing manuscripts is more on the male side, and it's way overshadowed the ability for female scientists to keep up.
Mike Coburn:	<u>18:21</u>	And I think part of that is just what we're seeing in the workplace, the inequalities in the workplace that we're challenged with. And I think that this pandemic has brought that to the front. Colleagues that I work with that are home with their children, educating them, making sure Zoom works, making sure they're where they're going and trying to do Zoom calls with us and do all that we do, I just don't know how they can do it. So, and science is not immune, it is true, more of the productivity during this pandemic has been tilted toward the

		males and females have fallen behind if you will. And that of course has some implications for careers.
Mike Coburn:	<u>19:05</u>	Like it or not careers in academia are based somewhat on productivity. And you go through the tenure process based on what you've been able to do and contribute to the body of knowledge and certainly science. So there are some implications beyond just how many papers you can get out during the pandemic, but what does this do for my career? To our male colleagues, maybe we just say, pick up some of the slack. They're the dudes.
Kelly Cervantes:	<u>19:38</u>	I hope my husband is listening to you say that as I listen to my son on his Zoom call upstairs stomping around in his room. So we talked a little bit about researchers are starting to return to the labs. What does that actually look like for them? Because I can't imagine that I mean, there's no complete return to normal here. So, what are the new protocols that are in place? How are people getting back into the labs at this point?
Mike Coburn:	<u>20:14</u>	Once you've seen one lab, you've seen one lab, and once you've been to one university, you've been to one university and they're all very different. They're all driven by university [inaudible 00:20:23]. If we're in a university setting, the protocols that have been developed there, I know firsthand that there are universities that require significant levels of testing, not every day, but a couple of times a week, if you're going into the lab. Lab space has been reorganized so that workspaces are further apart. And there can be, obviously there's a demand for PPE for clinical workers. There's also the possibility there could be a shortage for labs. So labs getting resupplied is very important.
Mike Coburn:	<u>20:58</u>	But again, getting back to the lab is all dependent on a number of trickle down activities starting from the state, the local municipality, the university community itself, and then leadership of the departments. So I think we're starting to see, as I said, in some areas a portion of the lab staff coming back. Here in the district of Columbia, we're still in a phase two status. So, remote working is still what is expected in the district of Columbia and in Maryland. Even at NIH, everybody at NIH except for emergency employees deemed to be there for reasons to take care of animal communities and what have you, we're still all in a remote work situation because that's what our governments have asked us to do. But again, it will change as this pandemic goes through this curve that it's at, it will dictate how much longer we stay in this mode.

Kelly Cervantes:	<u>22:02</u>	Is there anything that we can learn from this experience moving forward? There's all of these talks about winter being incredibly difficult in terms of the pandemic and many people perhaps needing to quarantine again. And so how do we prepare for the future? Are there things that government, that researchers, that organizations like CURE Epilepsy can be doing now to better prepare for the future?
Mike Coburn:	<u>22:31</u>	I think that the workforce in the next period of time is probably going to be different. There are research organizations talking about shifts, working shifts around the clock so that workers are able to get into the labs, use lab equipment and do it when there aren't a lot of other people there. Well, if you talk to postdocs, they all say they work very long shifts as it is, but that is perhaps a workplace norm that could change for a period of time, that people will be able to do some of this work on shifts, where there are fewer people to interact with and protect themselves.
Mike Coburn:	<u>23:09</u>	I think also in terms of governments and institutions, whether it be private sector or public sector, making sure that the employees have the safe and secure environment, that all protocols are followed and public health precautions are taken to give people that confidence, they can be in a workplace that's safe, including the, as we talked about the importance of supplies and equipment, but also the environment that they're in. And then in terms of organizations like CURE and other organizations that are working closely with the research community, I think it's just important for them to know that you haven't forgotten about them, that you're there, you're fully committed to funding innovative high-impact research to find and drive new treatments and cures for epilepsy.
Mike Coburn:	<u>24:01</u>	That's important for them to hear that you haven't gone away. That this army of volunteers who do all sorts of activities and now becoming very good at virtual activities are continuing to muster resources to support the research community. It's so important that they hear that that's ongoing. And I think that it'll be very appreciated by the researchers, by the scientists to hear that signal of, it's this cliche that we always hear, we're in this together, but yeah, we are and we're alongside the scientists.
Mike Coburn:	<u>24:36</u>	Research!America was founded a little bit more than 30 years ago for the very reason that we're talking about is to put a higher priority on research. And we do advocacy all day every day and are delighted to partner with the patient community, the economic community, our friends in the industry, to really

		be one voice, to really ask for research for health to be among the top priorities of the nation. So we look forward to working alongside you as we go through this together.
Kelly Cervantes:	<u>25:07</u>	Mike, thank you so much for joining us today. Thank you for sharing your incredible expertise, for giving us a crash course in COVID pandemic research, government, all of it. And thank you for fighting for all of us as well.
Mike Coburn:	<u>25:26</u>	It's been a pleasure.
Kelly Cervantes:	<u>25:30</u>	Thank you, Mike, for sharing your insights with us today and for your advocacy and efforts to support the research community. For more than 20 years, CURE Epilepsy has understood the value of research to the 3.4 million Americans and 65 million people worldwide who are affected by epilepsy. Now more than ever, it's vital that we raise our voices and strengthen our efforts in support of epilepsy research. Too many people are impacted by epilepsy, too many people need new medicines and therapies, and we've made too much progress to be deterred from our goal, a world without epilepsy. To help us support epilepsy research, and continue to pursue our goal, please visit cureepilepsy.org/donate. Your support and generosity are greatly appreciated. Thank you.
Brandon:	<u>26:36</u>	The opinions expressed in this podcast do not necessarily reflect the views of CURE. The information contained here is provided for general only, and does not offer medical advice or recommendations. Individuals should not rely on this information as a substitute for consultations with qualified healthcare professionals who are familiar with individual medical conditions and needs. CURE strongly recommends that care and treatment decisions related to epilepsy and any other medical condition be made in consultation with a patient's physician or other qualified healthcare professionals who are familiar with the individual's specific health situation.