Barry Munro: Well, welcome everybody to our next installment of our webinar series called SCI: Moving Forward, which is a response to COVID. I can't go really a moment without thanking our generous sponsors, the Craig H. Nielsen Foundation for helping us put this webinar series on and I just want to send kudos out to the Nielsen Foundation, again, for your help. Thank you.

As you know this webinar series is made possible by the North American SCI Consortium, and our mission here is to bring about unified achievements in research, care, and cure and policy by supporting collaborative efforts across the spinal injury continuum. For those of you who don't know about NASCIC, please, I urge you to go on to the website and learn more about this organization and feel free to join as a member, as an individual or if you are a stakeholder with an organization, there's that opportunity or if someone from industry, we'd love to have you on board. Membership is free. It gives you some insight access to information that sometimes the general public doesn't normally get.

Our SCI: Moving Forward webinar series was really a response to the COVID-19 pandemic and how it's affecting the SCI population. We have many materials and archived materials that are connected to each webinar that has been presented to in this link that you have here in front of you. You can go on to that and check the various resources that we made available. The webinars will be archived as this one today is and they will be dubbed in Spanish for our Latinx community to give them an opportunity to better understand what we're doing here.

We have really a plethora of great resources and really would like to encourage everybody to go on board. Remember, NASCIC is a unique opportunity. The reason we stepped forward and wanted to put this webinar series on is that we are uniquely placed in North America to bring together some of the great resources from all the amazing groups and individuals from all corners of the North American continent. That opportunity could not be missed and we thought, if we can share this information, perhaps different parts of the continent can enjoy a different perspective from others and build upon that great knowledge.

We have two more upcoming webinars. One is next week is called it's the SCI Latinx Community, and again, it's a continuation of their previous webinar. That's on July 14, set at a special time at 3:00 PM, Eastern and not our regular 4:00 PM, Eastern Time slot. And then our final webinar will be held on July 21, and it's really a culmination of all the great things that we've learned over the last 10 weeks, and the webinars that we put on called Positive Learnings, and hopefully we can take the lessons learned, as per the categories and even up until the next couple of weeks, what we've learned from the community and how we can again, summarize that, bring that back to you as a community, and that we can learn from our efforts, positive or negative, and great results that have come out of great advocacy and work that's been done by all these great people, and hopefully learn and build upon that going forward.

So today, we're talking about advocacy during COVID-19 and beyond, and I wanted to, as part of our agenda, I'm going to introduce our panelists and then invite their perspectives from the three great organizations: Unite 12 Fight Paralysis, Spinal Cord Injury Ontario, and United Spinal Association. And then we'll open up to some discussion points and have all of our three panelists weigh in and provide their opinions, perspective on the topics.

And of course at the end, as always, we'll have time available for people and all our participants to either via chat or you can come in unmuted and ask questions of our panelists, and feel free to do so. They know what's coming. I got to tell you, these guys are champions in our field. They are true leaders in advocacy and there's a lot that we can learn just by having a conversation, so this is a great time right now. If you want to ask key questions, you have that opportunity.

So, I'd like to introduce all three of our great speakers. We have Peter Athanasopoulos from the spinal Cord Injury Ontario. We have Matthew Rodreick who is the... sorry and Peter is Director of Policy at SCI Ontario. Matt is the executive director of Unite 2 Fight Paralysis, and Kent Keyser is the Public Policy Fellow at United Spinal Association. Three great, great resources, excellent advocates and gentlemen, to say the least.

So for our first presentation, I'd like to invite Matthew to tell us what he's been doing and what United Spinal has doing in within the context of the COVID-19 crisis, but really, you can also extrapolate and go beyond and really talk about what Unite 2 Fight Paralysis is doing in general in terms of advocacy. Take it away, Matt.

Matthew Rodreic...: Thanks, Barry. So, my name is Matthew Rodreick, Executive Director of Unite 2 Fight Paralysis. For those who don't know, we're a grassroots SCI advocacy community organization committed to curing paralysis, specifically for those with chronic injuries. Just to give you a kind of overview, really what drives that mission practically Is that really what we're trying to do is create effective relationships between the SCI community, and the SCI research and clinical community, kind of all the stakeholders involved, excuse me, in that effort.

We do that by hosting an annual symposium called Working To Walk, where we convene many of the stakeholders in that effort, research, clinicians, funders, governments, and very well-populated by the SCI community. This year, it's actually going virtual, that's one response to COVID. For us, we didn't think that even by October, it would be prudent for us to ask our community to travel, so we'll be having a virtual symposium this year.

We also do that with our Cure Cast podcast. Similarly, having conversations between us as representing the SCI community and researchers, clinicians, advocates. We also have the Science Advisory Board, which really is working to create relationships between small and mid-sized SCI foundations and the research labs that they're seeking to fund.

Probably one of our most practical approaches and one that's been maybe hit the hardest by COVID is our Cure Advocacy Network, which is an effort where we guide SCI community members in various States in the United States to pass research funding bills for spinal cord injury research, and very specifically, it's not really so much about the money, which is sort of the easy thing to promote, but it's really about again, creating relationships between the research community and the SCI community and we do that by creating advisory boards that are local SCI community members, local researchers, local clinicians to prioritize and fund research projects within the State.

We also look, we also recognize in a lot of ways that we have system issues at play in this effort to accelerate curative treatments, so we have a few kind of strategic key projects. One of them is developing, helping to develop an activity-based therapy association, which has recently just initiated a study to prove the effect of the benefit of exercise in the SCI population. Second one is we do quarterly neuro modulation conference calls with many of the scientists working in human beings to really strategize, encourage collaboration, and in many ways to focus on the strategies being used in the lab and in human studies towards translation to clinical products. Things that would be relevant to people in the community. And the last one I can't say much about, but it's a very new project, convening a group of scientists from across many disciplines and advocates looking at really the pathway of discovery science to treatment innovation.

Lastly, kind of in all of that, I know we'll talk about this a little bit later, but I just wanted to have a quick word that we talk at Unite 2 Fight Paralysis quite a bit about the subtle differences between advocacy and activism. Advocacy is kind of this notion of coming in between the players advocating for a particular direction. Activism is a little more of an intervention per se, where maybe the difference in simple terms, I used to coach soccer of several years when my kids were younger and it's kind of like the difference between helping the team to play together to win a game and turning to a player or helping the team to understand that maybe Johnny or Louise or Muhammad Mustafa, whose kids I've coached are probably not best suited to play goalie.

And you have to change them to midfield in order to seriously win and maybe that's a metaphor. I hope that works for understanding a little bit of the difference between advocacy and activism, which we are constantly talking about and deciding, when do we just hold hands together and point in the right direction and when do we say no, we have to change something in order for all of us to win. That's about it. Thanks.

Barry Munro: Thank you, Matt. Next, I'd like to invite Peter to speak. Peter, take it away.

Peter Athanasop...: Great. Yeah. I'm Peter, and I work for Spinal Cord Injury Ontario, which is a Federation of Spinal Cord Injury Associations that are across the entire province, that touch every corner of our country, and we provide services, supports and advocacy in many different ways depending on the organization across Canada. We are going to be celebrating 75 years of our existence this year.

And our organization was founded by World War II veterans from the Second World War, who came together and decided that they no longer wanted to be institutionalized in their own communities. They wanted to live in the community and thrive and do what they want to do, and live the life they choose in a fully inclusive Canada. And we've been riding that mission for 75 years, providing peer support, system navigation, and advocacy around addressing and resolving systemic barriers that impact the quality of life of people with spinal cord injuries.

We also are highly connected through our networks with research. We believe that good evidence results to good policy change, so we have built very strong foundations across our country and through associated partners and organizations, in the belief of our philosophy that if you put people with spinal cord injury policymakers, service providers and researchers, all in the same room navigating one goal that that will give us the best opportunity, as Matt suggested, to win. So, that's been our philosophy in terms of an organization and our networks and partners.

COVID, when it hit, it redirected a lot of what we do on a day-to-day basis, to support our community, to keep them safe and healthy during the pandemic. We rallied as a community across the country, we united into regular communications, examined different evidence and really looked at the strength of each other's organizations and what they can provide. We had a goal that no person with a spinal cord injury will go positive, even though that was a really ambitious goal, we relatively have kept the numbers significantly low for our population. We have had people with spinal cord injuries that have contracted COVID, but really, really, really small numbers and we're proud of that.

So, similar to what Matthew was describing, we look at the active advocacy component where we're utilizing different strengths and levers to engage the government and then in terms of activism, we believe in strength in numbers. We have the ability to mobilize our community across the country virtually as well as provincially in a very systematic way where our voices cannot be ignored and we use that method when we really need to, when we're being ignored. But more importantly, what we try to do is create partnerships, so all parties can be educated, including government to see the solution to what we're trying to achieve. And that's me.

Barry Munro: Thanks, Pete. And last but not least, I invite Kent Keyser, Public Policy Fellow from United Spinal Association to come on board. Kent, let us know what you're doing at United Spinal.

Kent Keyser: All right. Well, thanks, Barry, and thanks to the consortium for this panel. It's very timely on a very topical issue and it’s coming also on the heels of our National Independence celebration, so our two countries have both exclaimed our national identities and I'd like to sort of begin the kickoff of the conversation in that framework.

This last past weekend, I was reminded of just how deeply the roots of advocacy, yes, advocacy, run throughout the foundation. This great continuing experiment of ours in the States, testing whether we the people can truly govern ourselves. Saturday, Spanish American Chef José Andrés, who became a U.S. citizen in 2013, spoke at Monticello, Thomas Jefferson's home and he laid down a couple of principles on the line that I thought framed today's conversation on advocacy, pretty darn well.

First, he said, "What makes you and me with American is not our birth certificate or our passport, it's our actions and our values and our contribution to society." Chef Andre said that he found his voice for freedom when he founded his nonprofit, that now has served some 20 million meals to those in need throughout the world, so that's his idea of advocacy and activism. But his second principle was the real kicker, that speaking up, speaking out, that contributing to society was not just our right as Americans and as Americans, advocacy is our duty. And I think Canadians can say the same thing. As he put it, you cannot be silent, if you want to be a true American citizen and he didn't even know that we were meeting today. So to each of you, that's our rallying cry today and tomorrow, do your duty, do your duty and advocate for the greater good.

For one thing, it's no secret that COVID affects everybody. Our community recognizes that even if some others don't. My organization, United Spinal Association, has heard from our members loudly and clearly that living with an SCI or a spinal disorder, while COVID is lurking everywhere... hold on just a minute, I'll get my Power Point. I made notes and I'm trying to turn pages... presents challenges that are bigger than one person, one family or even one community can handle.

And that's where those of us in advocacy, we policy, and that's where the advocacy team at United Spinal goes to work on your behalf. Among the biggest concerns we've heard are shortages with supplies and equipment, the need to increase home and community-based services supports like personal care assistance especially problems with hiring and maintaining enough of a team to cover all our needs. Believe me, United Spinal gets it. We exist to enhance the quality of life of all people living with spinal cord injuries and disorders, including veterans and providing support and information the loved ones, care providers and professionals.

United Spinal membership is also free, and you can sign up today at unitedspinal.org. And I'm sure most of you are already members. I'm sure we'll touch upon many challenges our community faces in today's discussion, but we at United Spinal also believe that COVID presents some tremendous opportunities to advance our community research efforts. Let me touch on three rather quickly.

We've been making these points to federal policymakers and welcome your voices as well. There is certainly strength in numbers and the more voices we have singing from the same hymnal, the louder the voice for change will become. Most recently, we made these points to NINDS at NIH, the National Institutes of Health at the National Institutes of Neurological Disorders and Stroke. Just recently, NINDS asked for comments on areas of health disparities and inequities in neurological disease and/or care in the United States across the lifespan of everyone.

In other words, they want to know what's wrong in our world today and tomorrow? Well, first, we suggested that in light of COVID, NINDS should, in various phrase, seize the moment and rigorously address the life and death dynamics, both the increased health threat wise as well as the healthcare delivery silver linings. We equated this dual approach as every bit essential to our community, as is the development of a vaccine for all of us.

Second, as every good researcher knows, we need data points. We called on NINDS to survey our community immediately and/or immediately for them, means some time from now, but get started now, analyzing the needs and urging expedited research to fill those needs. The lessons NINDS can glean from COVID can not only serve as a long range model for healthcare delivery in whatever our communities need normal environment entails, they can be extrapolated by NINDS's institutional partners to serve the greater general population.

And finally, we threw technology into the solution, offering that creating accessible healthcare options through technological advances in Telehealth and in transportation alternatives can provide better health and functional outcomes for all Americans, whether it is for people with disabilities, integrating a growing senior population serving all manner of needs of the consumer. And we put a fine point on Telehealth. We're reminded them that somehow the barriers even the technological ones that we in the disability community repeatedly have been told made Telehealth difficult to deliver, if not impossible, had now been removed and then miraculously, overnight, Telehealth had been implemented across the country.

But, and this is a but, there's no guarantee this extension of Telehealth care will continue on a permanent basis, which Barry mentioned early on. NINDS must immediately, we said, engages majoring how helpful Telehealth is to demonstrate some proof to the policymakers for it. And that's where I'll leave it.

Barry Munro: Well, thank you, Kent, that's great. And gentlemen, that was an excellent overview of what you're doing right now. So, I thought what we can do is I'm going to start tossing up a few topics and then I'll invite you on in separately, but then I'll allow sort of an open forum to have you jump in and do what you do and advocate your position because that's what you do.

So, the first topic I wanted to bring out was, what best practices and processes have been used. So, why I'm asking this, it's really more specifically to, if you can identify even a couple of specific tactics that you use to accomplish some of the great things that you just spoke of. I'd love to hear about that. So Matt, looking at what you've done, how you've responded and again, in the context of the times, and the mandate of United Spinal, is there anything in particular that you can say that you did differently or continued to do that helped you through in the organization through the crisis and achieve your goals?

Matthew Rodreic...: Well, first off, Unite 2 Fight Paralysis. I think you referred to this as United Spinal, just to clarify.

Barry Munro: Oh, sorry.

Matthew Rodreic...: I think, really two things. One of them is we acted pretty quickly in the recognition of how broadly COVID was affecting and likely to affect almost everything that we do. So, obviously, I mentioned earlier, our annual symposium, which is an in-person meeting, it was planned for Salt Lake City, also, our legislative efforts in multiple states have been affected, both in existing programs, but in programs that we're looking to pass in Wisconsin and Texas and Colorado.

So, we really quickly as a staff pivoted our activities to reflect that and craft an amendment to our strategic plan that reflected those changes. And so I really credit our staff within a pretty short period of time and our board to recognize and support that, that we were able to protect each of these initiatives, pivot them to things that wouldn't require in-person stuff or alter some of what we do, so that's one thing.

And then I think the second thing is recognizing in particular that our mission is to accelerate curative treatments, which I applaud, like Kent, what you just described, I'm grateful for the work that you all do and do not see it in any way, so in a sense, different from what we do. It's all along the continuum of improving the quality of life for people with spinal cord injury, but in recognition of that, we also had to react to recognize that both our political successes over the last few years could be in danger due to funding issues and recession and deficit State by State and even Federal deficit. And so we have crafted a strategy looking at the sessions in the fall and into the spring of next year to really protect our funding mechanisms, and also a way to navigate how do we go to a legislature that's reeling from COVID and, and make a case for funding research that ultimately in our opinion, would reduce the risk of our population. [crosstalk 00:25:37]

Barry Munro: Thanks. I'm interested to hear more about that. We'll get into that one just to further down in the questions. Peter, I'm interested to hear about how you kept as an organization which has done a remarkable job of making sure there was less to no positive results of COVID-19 in our community in Ontario. Was there anything particularly you did differently in terms of the best practice and tactic?

Peter Athanasop...: Sorry, I was on mute. Our fundamental best practice as an organization is to ensure that our community is united together. So we quickly were in the process of researching and developing an app called VIP for SCI, where while we would never replace our face-to-face services, we always wanted a mechanism where when people were not able to be face-to-face, we can have a comprehensive holistic ability to utilize our services with our clients through virtual supports. So, while VIP for SCI was not ready for launch into production, until probably April, we've made the immediate investment to launch it in 20 days.

So, we successfully were able to not create a big interruption in terms of our services and continue the goals and purposes of why people were connected with us to continue. And we also connected with our corporate partners and our corporate donors, and requested some social responsibility in ensuring that our community stayed safe. And we work towards a fundraiser called Safe at Home, where people were donating funds to support equipment, medical supplies, as well as other mechanisms for enhancing independence during COVID-19. So, we were able to raise some funds to give back to our community in light of the challenges.

And then we just, as an organization with multiple networks, we created mechanisms where we can all stay together and talk about challenges and built small working groups around how challenges were identified on how to tackle them. We also developed a YouTube channel where we identified certain challenges where people would have with not being able to leave their homes and not being able to access regular supplies or assistive devices and stuff and clinicians started building videos to support. Our research community started giving out funds for specific research targeting COVID-19. Practice Institute led that charge in providing some one-time funding around things that we needed evidence for to go back to our governments and change.

And our government, I have to say, was quite reactive. We didn't do the traditional approach of writing a letter and setting up a meeting and so on and so forth. We got ourselves on the committees that matter that had influence, and we just inserted our voice and demanding certain things and we were able to get expedited approvals for assistive devices, we've got physician billing support, we got funding for transportation services for people who couldn't leave their home. So, overall, we did okay, in terms of re-jigging a new reality for a short period of time and ensuring people were safe.

Barry Munro: Well, thanks, Pete. I think you're being modest. You guys did an excellent job. I have to declare my conflict, I live in Ontario and I've seen firsthand some of the great work that you've done there, Peter in SCI Ontario, thank you.

Kent, I'd like to ask you, specifically you've identified two great things working with NINDS and working on building up the Telehealth opportunity. How did you do that? Really more about tactics and what was your way of making change that way?

Kent Keyser: Well, we are constantly on the lookout for opportunities to impact federal agencies and luckily, they often, at least in our community, ask our opinion. And if I could just say a word about that, it doesn't always have to be an organization that makes the response on behalf of the community. In fact, one of the most valuable things that policymakers and federal agencies that you mentioned is they bring this up constantly, they want to hear from actual individual stakeholders, from people who are directly personally affected by federal policy or the lack thereof.

And so, me as a "professional advocate," meaning I get paid, right? And taking it back still, when I submit comments for me personally about a policy issue and I'll have an agency representative come up to me and say, "Good comments or I've got a question to ask you about your comments." And I said, "United Spinal?" They say, "No, no, your comments." So that the fact that they took the time not only to read them, but recall them is quite extraordinary and that's a lesson for all of us, I think that individuals can have equal impact.

And as I mentioned earlier, the stronger that course is, the stronger your position is in the eyes and memories of federal policymakers and that works for our good friends, the bureaucrats and agencies as well as members of the legislatures and executive officials, too, so that that three branch effort is one that's important to keep in mind. And to their point, United Spinal's strength really is our network that Peter mentioned in network. Our network of 52 chapters across the country have wonderful, strong, fully informed, enthusiastic leaders that help us on the federal level, but also back in their States, their local communities.

And that's really been a strength of the United Spinals and how we've impacted agency, but looking for those opportunities to comment, always responding even if you repeat and we do that quite often, to make the point even stronger, previous points, we do it. We seldom miss an opportunity to raise our voice.

And I just wanted to refer back to your earlier question, Barry, and point out that as our President and the CEO Jim Wiseman said early on in the COVID crisis, "Heck, people with disabilities have been in touch remotely for years, decades, so we know how to do this." And he's right and it was an easy plug in for us at United Spinal.

Barry Munro: Well, that's great. And gentlemen, that brings us to the next topic and I'm hearing the themes about the power of the people and what we can do, united and working together and kind of one piece. One thing I've heard over and over again in talking to all three of you and your organization representatives is that this crisis has somehow awakened our community, that actually, we're getting more input now for obvious reasons and people that are in crisis, reaching out back into their community, which is kind of a double-edged sword, but it's an interesting opportunity, in fact that we're being kind of somewhat reintroduced to the community, be it the individual members and the organization.

So, Matt, I'm going to ask you, how is the crisis and in the awakening of the community and its response, how does that work with United, sorry, I'm only a board member. I mean, Unite 2 Fight Paralysis, sorry about that. For Unite 2 Fight Paralysis, how is that awakening or have you noticed that, maybe I'm being presumptive here, but?

Matthew Rodreic...: Yeah. It's hard to distinguish where that's coming from, honestly. I mean, I do see it a little bit in the SCI community. I see it quite a bit in the research community. In the SCI community I think there is. Kind of as Kent says, I did sense of sort of swell of like, we're a professional shelter-at-home folks. I don't have an injury, myself, my son has an injury and my son was a good example of someone who was on strict quarantine and still actually, for the most part is on strict quarantine and was pretty frustrated by it because he was headed out on tour of the country.

So, I think part of that was people looking to one another and looking to their community in a multitude of different ways, so I did sense that. But also, as I mentioned, I sensed in the research community, we did a couple of podcasts and a couple of blog posts as we surveyed the research community that many labs were shut down or severely restricted and there was a sense of a for a period of time, like a sort of frustration and even a little bit of fear projects that were underway that folks were concerned about.

But then there seemed to be a period of time where people were starting to ask questions about how we do the things we do and the priorities that we have and the assumptions that we make, and that provided a real opportunity for us, I felt like to connect with a lot of folks in the research community and sort of poke at some of those questions, because that's kind of our bailiwick. That's what we've been doing all along, but there was a little more receptivity, in my estimation, as a response to COVID.

Barry Munro: Excellent. And, Peter, we've had conversations offline, and you said, I think you've mentioned that there has been some type of, I'm not sure of awakening but increased contact with your members. Maybe you can explain that a little bit to us.

Peter Athanasop...: Yeah. So to put this as simple as possible, I think COVID pissed off our community and I say pissed off our community because when it initially hit in the month of March and people were losing their jobs, and there was all these relief fundings that were shared among multiple groups, people with disabilities in our country were left out of the conversation, not even acknowledged as a vulnerable group within COVID-19. And early on, initially, our advocacy was to simply get acknowledged on public television, because our Prime ministers and our Premiers were doing press conferences on a daily basis and started describing all these hardships and all these concerns, and people with disabilities were not hardly mentioned once.

And when they were mentioned, it was mentioned as an afterthought and others not simply identifying people with disabilities as a priority in any which way or form. So, I think what has happened in our communities is people started paying more attention and their frustration and the time on their hands from being at home and limited to social interaction, limited to outside got them searching the web, they're asking questions, wanting to be a part of conversations, and wanting to connect with decision-makers.

One of the things that SCI Ontario has done for multiple years is create a team of activists across every MPP across our province. So, we have the ability to deploy all our activists across all 124 writings in less than 24 hours, right? So, that mechanism that we use where we can go locally and connect with the decision-makers of Parliament in that region, all at the same time, all at once is a very powerful mechanism to demonstrate to the government that we're serious, and that we're mobilized and that we expect action and that we're a significant part of this population and we're a priority.

And people started feeling that because they were left out and demanding that because they were left out, and I think that's the opportunity that was created for us in COVID that we can leverage as strengths moving forward.

Matthew Rodreic...: Peter, do you also think that all the complaining that was going on in social media about shelter-at-home stuff, I sensed that in the lot of the community folks that I know that there was a sort of like, "Shut up, shut up about your complaint, that your shelter-at-home or you guys stay at home." Like back to Kent's comment, like we've been doing this for a long time.

Peter Athanasop...: Yeah.

Matthew Rodreic...: I mean, I started to hear that a lot. I wondered, too, if that fed it as well.

Peter Athanasop...: There was some of that, but I think the challenge with our country is that there was like the pandemic reduced our SCI population to really critical poverty levels, like really critical poverty levels, life-threatening poverty levels, and people took that very serious. I think like for an example, for people that were unable to work, they were giving a $2,000 monthly relief for individuals who weren't even work while our social assistance is only $1,000 a month. So they were expecting people to live off half of what they called the average monthly relief for the rest of the general population. And I think that really sparked the inequality for people.

Barry Munro: Thanks, Pete. Kent, I know I've had several conversations with people from United Spinal and, and I keep hearing also the same thing that in the activities that you've been doing with your organization, there has been a type of an awakening. Can you maybe expand on that?

Kent Keyser: Sure. I'm just referring to Matt and Peter's comments. I'd say it's been a mixed bag with United Spinal, but one thing I'd like to highlight in terms of awakening is the foundational corporate support that has been a sort of a lifeline for us and leading the pack was the Nielsen Foundation who gave some major contribution to assist people with exactly the type problems Peter was describing, lifeline access to food or transportation services that were needed to groceries, medical supplies, that kind of thing. So hats off to them for coming to aid at a critical juncture.

But again, I go back to the ability for us to remotely connect with people and I said it was a mixed bag at the beginning. I think that there was some frustration, and Matt mentioned that, "Hey, we know how to do this. It's not bad being quarantined. You can live like this. I mean, come on, get real. That's not the worst thing that can happen to you in life. You have access to electricity, you have access to food, you may not have access to toilet paper." But now that [inaudible 00:43:13] is over with, but I mean, it wasn't like we were in the middle of a hurricane. It wasn't like devastated Puerto Rico. I mean, life can be far, far worse off and people need to reconcile with it.

So there was a little bit of that resentment that I heard from fellow members, but I think it was Matt who mentioned the swell of interests from researchers, and I think that that's true that we did get some acknowledgement from not only researchers, but policymakers who said, "What can we do? What do you need? Tell us what's happening in your community?" And we heard that from Capitol Hill to be frankly and so that was rather rewarding.

Barry Munro: Thanks, Kent. I'm going to skip over the next topic and come back to it maybe move to discussion topic number four and I think it started out with Matt, you briefly spoke to this, but I'd like to go back to this and you've all spoke to it.

As we know, in both countries, we've seen significant government dollars from either the Federal level or the State Provincial level being injected back into the community, sorry, into the populace. I wouldn't say the community, that's a bit of an asterisk there. But unprecedented numbers, a huge percentage of GOP. And so, going forward as we start to crawl out of this at some point, there are concerns from everybody, but I'm wondering what your concerns are as how did the economics of the pandemic impact funding with your respective priorities?

So I send it to you first, Matt, how do you See the economic impact of the pandemic affecting Unite 2 Fight Paralysis and your agenda on research?

Matthew Rodreic...: Well, I mean, aside from the impact for us as an organization that relies heavily on donations and both individual and corporate, I mean, certainly there's concern about that, but I think more of a concern for us is with regards to legislators. We've had really good success in the last several years that totals up to, let's see $6, $9, $11, a little over $12 million towards research, actually over $13 million towards SCI research specifically. And really importantly, as I mentioned at the outset, this mechanism for people from the SCI community to sit at the same table with researchers and clinicians and policymakers to direct research and we've had success from that, in some of the funds, things that we funded, that have delivered human clinical trials, even with interventions that have not been seen before.

And so one of our primary concerns is are we going to lose some of that funding, as budgets get shredded as a response to COVID and the deficit? So, as I mentioned, that's why we quickly crafted some strategy to address that, because we have really good support in the areas where we have those funding mechanisms existing and then we look also at the challenges of States where we're working to pass an effort. We're a little we're a little fearful of we're just going to get kicked right out the door when we ask about spending more money or earmarking money, even though what we're asking at State level budgets is pocket change, there's going to be mobs of people fighting over that pocket change.

So that's a really critical piece for us, but then we also wonder about the effect of this at the federal level for federal research projects, and how that may or may not affect some of the projects that we are watching closely. And that's not even withstanding some of the private efforts of companies that are moving into human clinical trials or doing clinical trials or have FDA approval to clinical trials. What's the landscape going to look like for venture capital, Angel capital, given the effects of COVID?

Barry Munro: Next, Peter.

Peter Athanasop...: Yeah.

Barry Munro: How is the SCI Ontario in your endeavors?

Peter Athanasop...: Well, I think I share the same concerns as Matt does. Organizationally, we've had to cancel some of, a lot of our in-person events and we've pivoted and created different events that are more virtual now and we're leaning on our volunteers to be creative and to do some fun stuff. We just launched another fundraiser called rolling through the barriers where people it's a video campaign where people are demonstrating a barrier and how they want to smash through it, as an example. But yeah, of course, we're concerned from an organizational perspective, and I think we'll do okay, but more importantly, as Matthew alluded to is, what does the future hold for future investments and future supports as the SCI community is so small.

But what I think also is happening is I think this pandemic has also exposed the substandard and the critical challenges in some of the sectors of how things have been operating. I'm sure a lot of people have heard about some of the challenges that Canada and specifically Ontario has had around long-term care facilities and the inadequate supports that have been provided there and as the direct cause of multiple deaths as well as attendant services has been a challenge where we don't have enough PSWs or personal aides to go around to support people individually and people were supporting people in multiple sites and became at risk.

So, I think we've requested a lot of commissions to evaluate and we were successful in our province to doing a commissioned evaluation of how long term care functions, but it wasn't a hard sell, the government wanted to do it just as much. So those are the little opportunities. In terms of research funding, I think organizations have to creatively look at ways to stay relevant.

I've seen a lot of research organizations pivot around responding to solutions in light of COVID-19 and I think governments recognize that, are seeing the organizations that are taking the backseat, and ones that are pivoting and changing and adapting to try to make the biggest impact they can with what's in front of them. And I think organizations unfortunately are going to have to work harder and think outside the box to demonstrate the relevancy not only for their organizations, but purposes for research funding.

Barry Munro: Good point. Thanks, Peter. Kent, how has the economics affected United Spinal going forward?

Kent Keyser: Like I referenced earlier, the corporate support has been a welcomed lifeline not only for the organization, but for our consumers that are members, so we're very thankful for that. I think the jury is out on the economics, not only for States, but for the federal government. And I want to concur with both Matt and Peter that we are getting more attention now to the problems, but these are problems, at least in the States, that are so obvious that even I see them without doing too much inquiry at all.

The demographics are against us, that 24 million more people by 2030 will be using wheelchairs, 24 million people will be using wheelchairs by 2030. Let me say that one more time, 24 billion people will be using wheelchairs in within 10 years. That is an astronomical number and where the achievements going to come from to take care of these folks, right? So, is policy focused on that? No. Are they aware of that? Yes.

You tie the graying of America with the constant barrage against immigrants, having immigrants coming to America to help to work, to raise their families and prosper, and you just shake your hand. I mean, it's a constant wonder that there's no proactive policymaking going on in that sector and that's a huge problem. The economics of a retiring community of people nationally is going to affect every sector of the economy because we are not going to have the people to fill the positions from those who are going to retire and that's in the next 10 to 15 to 20 years.

So put COVID on top of that, where every sector in the economy is affected and where 70% of our GDP is dependent upon consumer spending and I see a crisis, ladies and gentlemen, perhaps I'm overreacting, but that's what I say that jury is still out, and it's an ominous jury. It could be any of that.

Matthew Rodreic...: I want to jump on what you just said Kent and add to it in the sense that U2FPs ethos really is driven by this belief that the people who are closest to a problem are the people that need to be leaders and decision-makers and the solution. And I think there is, there's a hidden opportunity as dire as things may look, that there's a recognition of that right now in the cultural discourse, as varied as it is and sometimes as divisive as it is, at least in the United States.

That philosophy is true, I believe, to any social problem there. If you're going to find a solution, you need to have people who are most affected by it as part of the process to figure out the solution and so we have an opportunity for intersectional work in our culture right now, and I'm assuming the same in Canada, that we can capitalize on some of these questions that are being raised to push that forward and say, we need to be a part of the solution.

Peter, you talked about the stimulus income in response to COVID. Kent, you talked about the need for equipment and technology in the future for the disability community, we talk about accelerating cures for a system that's working really slowly in our estimation. So all of them and you can add all the other stuff. If it's a healthcare system problem or a police brutality problem, or justice problem or equality problem, we have to capitalize on that and really, I think really push that message forward. We have some solutions and we need to be in the room to make those decisions.

Kent Keyser: That's an excellent point, Matt, because one of our mantras at United Spinal is if it will help us, it will help everyone, right?

Matthew Rodreic...: Right, right.

Kent Keyser: What solutions for us are absolutely solutions for the general population, so I think your point is very well, Matt.

Matthew Rodreic...: Yeah, yeah.

Peter Athanasop...: Yeah. No, I completely agree. One of the challenges that we've been having though, with legislation, legislators is the ability to connect with them, right? So, when COVID happened if you had a good network of people that you were engaging with in government, MVPS, ministers, then you can go back to that well and you can have those conversations. But as time goes on and as people are continuously isolated and not in network meetings, not in fundraisers for politicians where you get to meet and greet people and talk about issues, it's really challenging at times to get your voice out in a minority fashion because we get drowned out on bigger issues like the senior populations or the cancer populations and heart and stroke, right? Those are way bigger voices than us.

And our success is meeting with a policy advisor who's walking a minister to their next meeting, and talks about SCIO and that you need to give that person a call and then the call happens, whereas there's no hallway conversations to trigger, right? So, we need to start getting creative and creating new relationships with our policy advisors who help us get to the ministers because it's been hollow without face to face.

Matthew Rodreic...: But one advantage of this virtual world is that their time can be far more used efficiently by a quick call from home on a Zoom platform where they can see to 100 people as we could fit three people in their office, right? So I think it's a good use of technology to employ it at every turn and offer that to them. I can offer them numbers and that gets their attention.

Barry Munro: Gentlemen, we're quickly running out of time, but I don't want to cut off the opportunity for questions. What I was going to ask is that those in the audience that if you do have a question and just want to a simple query, hold those questions or type something on chat, just let us know that you'd like to ask a question or ask the question. And while we're waiting for that, I'm just going to ask all three of you really in a summary fashion, you touched on so many things. What I'm hearing is there's some positive things that have come out of this crisis and we're going to have to, as we do, we adapt and survive and we are resilient.

But I'd like to maybe, if I can ask you to briefly summarize real brief, what you think is a positive that's come out of the crisis in helping you and your mission in the organization move forward on the continuum. I'll start with you, Matt.

Matthew Rodreic...: You always got to start with me.

Barry Munro: You know it's coming.

Matthew Rodreic...: Well, it's similar to what I piggybacks off Kent's comments. I think really at a high level, I think there's... one of our efforts is really at addressing sort of status quo systems and I think we have an opportunity right now to challenge them in a way and maybe there's a receptivity to challenging them because of everything that's going on, because of both an acute sense of the questions that are being raised in response to COVID and in particular, in the U.S. from the unrest that's come a little bit later.

We have an opportunity. I think the ground is a little bit fertile ad so I'm a little bit, I'm cautiously optimistic about that for the future that some of what we've been trying to do all along maybe we can get to a more mature or is maturing, and getting to a deeper level to make some real change that I think is again intersectional change.

Barry Munro: Thanks. Peter.

Peter Athanasop...: Yeah. I think, like I said, more people have now been interested in being more involved, so we're going to come out of this as a larger community, I think, is a plus. For us, virtual physician billing, having to be able to meet your doctor over the phone or through video is like something we've been crying for, for the last five years and the fact that the government has just flicked the switch after all that advocacy in a matter of days like, "What happened? Where are all the privacy problems and all the risks, challenges that kept on being the response to asking these questions for the last few years, suddenly all went away?"

So, I hope we can sustain some of that stuff and as well, the stuff I talked about with exposing the poverty levels that this government gives people with disabilities, this mishmash of support. A light has been shown on it, and I hope we can capitalize on it.

Barry Munro: Excellent. And Kent.

Kent Keyser: Well, Peter's story sort of stole my thunder on telemedicine, but the same miracle happened in the States. If literally overnight everyone can do telemedicine and we've heard great things, at least [inaudible 01:01:34] about all sectors of the medical community for SCI from physiatrists to VME deliveries. Everyone's just enlightened. All they're learning about are living conditions. They know how important that is and illuminating that is in their practices so that they can better service. And we've been, as Peter said, asking for this for years.

Another aspect of that virtual extinction though is the policymakers and just as that we've been asking for telemedicine to do it, I know locally, I mentioned this early on when we were preparing for this, I was dealing with our county board of directors, commissioners to please do virtual meetings one-on-one, that kind of thing? And, "Wow, we did this and we have it on the public TV channel," But now then guess what, using the Zoom platform and so our committees, advisory committees. Except ironically, they Disability Transit Access Committee, which is very small and easily can do a Zoom platform keeps canceling their meetings. Now, we've got more work to do, but it just goes to illustrate that where there's a will, there's a way.

As Matt said, we have to be the ones on the frontline continually pushing it. So, that's from the local level to the State level to the Federal level. Let people know we can meet with them anytime, anywhere, anyway because we have the virtual technology to do it and just make that case with them constantly. That's what I would say.

Barry Munro: Well, thank you. We have a question from JK. He said, "Great talk. I heard the various commitments of three organizations and I heard one specific measurable resolve, which was having zero COVID-19 cases. Are there any other specific measurable results for the future they have and a date by when? I don't mean the results like a cure or quality of life, but milestones with a date."

So back to you guys, with sort of this heightened advocacy and I guess the pressures on, gentlemen. You've done such a great job, but, "What are you going to do for me tomorrow?" That's what I'm asking. What is the immediate goals set forward going forward out of coming out of this crisis? And maybe I'll start with you Kent, instead of you, Matt.

Kent Keyser: Well, I get the chance here to steal Peter's thunder.

Barry Munro: That's right.

Kent Keyser: And that is we to make telemedicine provision permanent, that's not a given and I think that's a tangible, reachable, definable goal that all of us together can do and make that a priority and I think that's something that could be done relatively easily and the best argument is it's there. We've asked NINDS to please measure the positive aspects of it, just to give us some proof. I don't know that that will be timely, but that's what ought to happen. If we can find a foundation support and corporate support to do that, maybe that's another avenue to do it, but we need to get that message to policymakers as soon as, and again, it's a tangible goal that I think is achievable.

Barry Munro: Excellent. Peter.

Peter Athanasop...: Yeah. So, Kent, point taken for Ontario and Canada, and we need to do the same thing. I think we've already made those steps in Ontario and we're quite confident it's going to stay because of some of the things that have happened in terms of technology companies coming into play building these virtual platforms aligning with different networks. It will be really difficult for them to unravel what they've started and we've purposely created that to do that. So I think it's here to stay for at least in Ontario I can't speak for other provinces, I'm not as intimately involved.

The second thing is we've commissioned an evaluation around homecare and the long-term care facilities. We expect to report and it's going to be public and we expect every recommendation to be acted upon. That is the accountability to this government for commissioning and evaluation. When you just do an evaluation, it's one thing. When it's commissioned, it forces legislators to actually respond to it. It's like the Auditor General's report as an example, right? So, we need to take advantage of that. We've already got the commitment of a commissioned evaluation, so we're going to move forward in that.

And also we're in talks at a national level to do an environmental scan around homecare, attendant services, and mobility device across the country showing the differences between each programs and the inequities within each of those areas because those were the three areas plus income supports that we found were the pain points across all the pandemic for our communities, so that was medical supplies, mobility devices, home care and income supports. Well, those are the four areas we're going to play harshly and loudly.

Barry Munro: Excellent. Thank you. And Matt.

Matthew Rodreic...: Thanks for giving me time to think about it. Ours are a little difficult, kind of like whoever asked the question not asking for a timeline for a cure, but I'm going to say three things. So, one of them is in our State programs, both in Minnesota and Washington over the last several years, we're upwards over 40 individuals as of today, that have had an intervention from studies that we have funded in those State programs that have restored a varying degree of functions, both in neuro modulation and in stem cell trials and also there's an even larger number if we add sort of supportive devices, adaptive devices. And so our hope is that in the course of the next two years that we will not only add more States that will fund this kind of research using our model, but the two States that we have added Ohio and Pennsylvania will also deliver more of those individuals to move things through the pipeline.

And then on a related note, the other two things, the second and third, are our neuro modulation workgroup, which has been meeting for two and a half years is very close. These are all scientists that we've been convening. We're very close to creating a consensus agreement on how they measure their interventions. And as esoteric as it may seem, it's really, really critical for these scientists if they're going to create what would be considered a target product profile. If you're going to take a technology out into the world and create a product from it, you need to know how it works, and who it works with and how you measure how that works. And right now, there's not really a great consensus.

And this group has finally gotten to that place where they can publish a recommendation consensus for the field. So, it's our hope that that will really accelerate in the field of neuro modulation, a treatment intervention that's market ready. And then the last one is our new project, which is I mentioned really, in brief, but my goal is for the next two years that we will be able to deliver a pathway to really identify the gaps in the process of discovering a new breakthrough in the science and moving it to human application.

Barry Munro: Well, that's excellent. And gentlemen, we're nearing close to this because of the time constraint, but I do have one question to ask you and it came up if you see on the chat, the question is, we're building this sort of army of advocates and it's getting bigger and bigger and one of the challenges obviously, we're all not for-profit organizations and we're always trying to "fundraise." And be honest, do you see an opportunity to tap into that community that is now kind of awoken and being more in the advocate sense of possibly fundraising via your new members and advocates that have stepped forward?

I'm opening this up to the floor and feel free to answer that. Just curious if you think there's an opportunity for fundraising within your own organization now and getting donations from those individuals?

Matthew Rodreic...: Well, I can say quick yes, on a couple of fronts if you're referring to that question, particularly the ladder end from RA is their hesitation in the organization to ask for money, especially for folks who have an SCI, absolutely, and there always has been, but for us, I think there's two things that we believe. One of them, we have a number of monthly donors from the SCI community and many of them don't give a lot, they give a small amount.

And that's very important to us because we actually believe that that sort of makes you vested in the process. You're a part of the team and we tap you when it comes time to call legislators or when it comes time to speak up or to talk with us. I talk with our monthly donors a lot and irrespective of what they give, not all, not all of them certainly, but quite a few of them reach out to me. And so, that's sort of a way to become invested in the work that we do.

And then the other one is in a sort of tangential way, we have teams in the Boston, or not Boston, Chicago Marathon and the Twin Cities Marathon in Minnesota and there we anticipate Chicago is going to cancel, the Twin Cities has already canceled. And so, we created a virtual Run-Walk-Roll program. And what that does is it opens up the opportunity for a lot of folks that couldn't either run or wheel or walk in a marathon, there's a lot of folks that aren't going to do that, and certainly not going to do it virtually all by themselves, to do a shorter race, a 5K, 10K, what have you, which we've already had folks from the SCI community sign up to participate and that's a way that they can raise money throughout their own network and community.

So yes, I do think that, but we do also recognize and are empathetic to the hardships, not just of individuals in the SCI community, individuals in general and even organizations that are struggling. So I do think there's an opportunity, but again, if it's driven towards this sort of clear and intersectional work capitalizing on the opportunity that we have.

Barry Munro: Thanks. Any other comments?

Kent Keyser: To Matt's point about investment, I'm reminded of a story. My home state is West Virginia, one of the poorest States in the Union, and Senator Jay Rockefeller yet was governor and the United States Senator for a long time and I'm reminded of the story of the Washington lobbyist who when Senator first went to Washington, came to one of these fundraisers and the Senator was overly kind because he was a rather well-known lobbyist and said, "I'm so grateful for you to be here. This means a lot to me. Thank you so much, David." And he said, "Well, Senator, I had come because my dad would never believe that a Rockefeller would be asking me for money."

There he is, that investment opportunity, but at the risk of the United Spinal development team coming down on me, more than people's dollars, we need their time and certainly their commitment and time to look to their local networks and if they can raise money from their local networks to build the chapter, that's a wonderful thing, but there is that investment, the personal investment element, too and we certainly wouldn't turn it down.

But I would be hesitant to go out and solicit and to ask, but if people want to do that and feel invested, certainly. But more important, I think is the time and the commitment and their looking into their local networks to fundraise from that sector because there's a lot of opportunity there for local chapters as well as the national organization.

Barry Munro: Thank you, gentlemen. I'm going to have to cut it off right now. I'm surprised we kept it under two hours, but that's good. You guys are all great treasures to our community, the work that you've been doing with your organization has really been commendable and there are lessons, so many lessons learned by just following in your footsteps. And I urge everybody that's listening to share this information, and to connect with all three of these organizations where it's appropriate, and really, really support the great work that these gentlemen are doing in their organizations. Without them, we wouldn't be where we are today and I think with them and with our support, we can really target a lot of great things going forward.

I really just want to thank, on behalf of the North American SCI Consortium and as an individual who benefits from your work, I just want to say thank you so much for what you've done today and what you've said and what you've been doing over the last while and going forward.

So on that note, I'm going to say goodbye to everybody, be well. There will be an email going back out to all the registrants today. We're getting a copy of this webinar. It will be archived on our site along with other materials, and let us know if you want to reach out and connect with any of the individuals directly, that information will be provided as well, if that's okay with you guys.

But on behalf of all of us that our staff and Jessica, the great work you've done, I just want to say, thanks, gentlemen, for what you've done today. It was great listening. Thank you so much.

Kent Keyser: Thank you.

Peter Athanasop...: Thanks.

Matthew Rodreic...: Thank you, guys.

Barry Munro: Take care, everybody. Be well and be safe.

Matthew Rodreic...: You all, too, Barry.