Michael J. Fox: 00:00:06 This is Michael J. Fox. Thanks for listening to this podcast. Learn more about The Michael J. Fox Foundation's work and how you can help speed a cure at michaeljfox.org.

Introduction: 00:00:15 You're listening to audio from one of our Third Thursdays webinars on Parkinson's research. In these webinars, expert panelists and people with Parkinson's discuss aspects of the disease and the Foundation's work to speed medical breakthroughs. Learn more about the Third Thursdays webinars at michaeljfox.org/webinars. Thanks for listening.

Dave Iverson: 00:00:37 Hello, everyone, and thank you for joining us on today's Third Thursdays webinar from The Michael J. Fox Foundation. I'm Dave Iverson, contributing editor at the Foundation and a member of the Foundation's Patient Council. Welcome to everyone. We have a particularly interesting topic today, a little bit different than what we often discuss in terms of either the latest in Parkinson's research or Parkinson's symptoms. Today we're going to really focus on the global rise in the Parkinson's population, which is expected to double by the year 2040. And we're going to figure out whether or not we're ready for that possibility.

All right, let's go ahead and meet our panelists for today's webinar. Joining us is Dr. Bas Bloem. Bas is the medical director and professor of neurology at Radboud University in the Netherlands. Bas, welcome. Thanks for being part of our conversation today.

Bas Bloem: 00:01:32 It's a pleasure to be here. Thank you for inviting me.

Dave Iverson: 00:01:34 Thanks for having you participate Bas. And joining Bas is Dr. Ray Dorsey. Dr. Dorsey is professor of neurology at the Center for Health and Technology at the University of Rochester Medical Center in Rochester, New York. And together Bas and Ray co-authored a very provocative article that appeared in the journal Neurology recently, about this very phenomenon. And that's what we're going to explore today.

So let's look at what's behind some of the kinds of issues that we're going to be looking at. Why is it that the number of people with Parkinson's will double by the year 2040? What are some of the things that we can do to prevent that rise or contend with it as the global population does rise? What are some things that we can do to reduce the number of people with Parkinson's in the future? We're also going to talk about how we can increase access to care, given that rise in population. How we can make care more affordable as well. And what we
can do, of course, to also increase research funding for Parkinson's Disease to contend with this increase in the Parkinson's population.

Here's what we think is going on. And these statistics I think we'd all agree are truly breathtaking in a sense. It's now estimated that there are about 6.2 million people worldwide living with Parkinson's. That number has doubled, as you can see, since 1990. So this is not a new phenomenon. Parkinson's population has been on the rise now for some time. But it's going to double again we think to 13 million or more. And those statistics may even be conservative. It may be that this will rise even more quickly. And we see ... We note some reasons why for that that you see on your slides below and in the bullet points that are listed. And we'll get into those now as we begin to take up our topic.

But Ray Dorsey, let me begin by asking you. What's behind this rise when we see that it's doubled in the last 15 years? Going to double again ... Rather in the last 25 years. Going to double again in the next 25. What's the primary reason for why that rise is taking place?

Ray Dorsey: 00:03:58 Dave, thanks very much. The primary known reason is the population structure. So there are more older people today in the United States and around the world than there have been in the past. Just yesterday's newspapers had there'll be more people over 65 in the United States than there will be children by 2030 or 2035. So as people know, the incidence of Parkinson's disease increases with age. So that's the number one factor driving the increase. But there are other key factors. One of them is longevity. Not only are people older, but we're all ... One of the great benefits of the 20th century was an increase in life expectancy that continues into the present day. So as we all live longer, including those individuals with Parkinson's disease, there'll be more of us developing Parkinson's disease and more of us living with Parkinson's disease.

Perhaps, most provocatively is that Parkinson's disease may be, in large part at least, a product of the Industrial Revolution. So the seminal description of Parkinson's disease was in 1817 by Dr. James Parkinson, who largely observed people walking in London. And if you think about what else was going on in London in 1817, it was the height of the Industrial Revolution, and London was the capital of the Industrial Revolution. And subsequent research by Dr. Bill Langston, Dr. Carly Tanner, and many others have demonstrated that certain products of the
Industrial Revolution, especially pesticides, solvents, and metals, are associated with an increased risk of Parkinson's disease. And it turns out if you adjusted for age, the prevalence rates of Parkinson's disease are increasing throughout the world. And for example, from 1990 to 2015 the country that had the largest increase in age-adjusted prevalence was China, in which the prevalence of Parkinson's disease in that country doubled, more than doubled over the last 25 years.

And so that would indicate, then, as Ray is suggesting, Bas Bloem, that perhaps there are some areas that may be more vulnerable perhaps to this rise in the global Parkinson's population than others. Ray was mentioning China, a country that's become much more industrialized. Someone already sent in a question about that, whether or not we're seeing growth patterns that are greater in certain populations. Are we seeing that around the world? And would your supposition for that, Bas Bloem, be that exposure perhaps to greater levels of toxic elements in the environment? Be that pesticides or something else?

Yeah, that's a good question. And it's at the same time a difficult one. We know that Parkinson's occurs across the world, so there's no country that's being spared. Having said that, we do think that in industrialized countries such as China, which was already mentioned by Ray, the incidence is rising faster. And Parkinson's may be more common. And what I find fascinating is that at least several studies have shown that within industrialized countries, Parkinson's tends to be more prevalent in the countryside, which in turn we think could be related to the pesticides.

Certain professions have been linked to Parkinson's as being more common. Welders, among them, who work with heavy metals. But another profession that's being currently linked to Parkinson's is farmers. And here again, the link to pesticides could play a role. People living nearby wells and exposed to mineral water tend to be more at risk. That's not to say that people listening to this webinar should think they shouldn't be drinking mineral water, but talking about naturally-occurring spring water.

So yes, there tend to be some tendencies for Parkinson's to be more prevalent where these environmental factors are more common.

And Bas Bloem, while I have you, the article that you and Ray co-authored that's so, I think, both provocative and challenging
for all of us in the Parkinson's community ... And I'd encourage everyone to read it ... But the title uses the word “pandemic,” and refers to this as the coming Parkinson's pandemic. I'm interested in, why that word? Because we tend to think of pandemics, of course, as infectious diseases. What are the parallels? The similarities that you see? And why are you and Ray both calling this a pandemic?

Bas Bloem: 00:08:35 Well, you're absolutely correct. The word pandemic is traditionally equated with worldwide massive epidemics of infectious diseases. And what Ray and I did in our paper is liken the immense rise in new patients with Parkinson's disease to such pandemics. And interestingly, the last time the word pandemic was associated with Parkinson's was in the early 20th century when there was a pandemic of a particular flu type which caused damage to the brain alleged to a rapid rise in people not with true Parkinson's disease but Parkinsonism related to this particular flu infection.

And our particular reason for mentioning or labeling it as a pandemic is that the word pandemic, if it had been an infectious disease, would ring all sorts of alarm bells among policymakers, fundraisers, researchers to get together and get into action. And Ray and I think there is a true Parkinson pandemic in the making and we purposely used that word not to frighten people listening to this webinar, but mainly as a call to action to policymakers and anybody else who has a keen interest in making sure we get rid of this disease and that we look after patients worldwide as best as we can.

Dave Iverson: 00:10:01 And we'll get into some of those steps that can be taken, the call to action that you and Ray have put forth. Parallels to another recent epidemic in more recent times, the AIDS epidemic in a moment. But Ray Dorsey, add your thoughts to this. Because I think part of what's key in our taking up this conversation is the sense of urgency that I know from our previous conversations that you really feel about the need to address this rapid rise.

Ray Dorsey: 00:10:30 Maybe the greatest health challenge of our time are neurodegenerative conditions. Right now the leading source of disability in the world are neurological disorders. And the fastest-growing of these disorders is not Alzheimer's disease, it's not stroke, it's Parkinson's disease. And heretofore, we've largely neglected addressing this disease. And we can grow through the day in terms of funding, in terms of even advocacy, notwithstanding the great work that The Michael J. Fox Foundation has done in terms of developing new therapies. I
mean, the most effective therapy for Parkinson's disease is Levadopa. It's 50 years old.

I think Bas and I would largely agree that we have no highly effective therapies for Alzheimer's disease. And so we're confronted with a wave of neurodegenerative conditions, Parkinson's disease and Alzheimer's disease, that's going to affect all of us directly or indirectly. And the response that we have mustered to date has largely been insufficient and will be insufficient to address the growing numbers of individuals that will be affected.

Dave Iverson: 00:11:30 Before we dig into the things that we can do and the AIDS parallel, which is so fascinating next, let me also ask you Ray to make some observations about one of the points at the bottom. We were saying these numbers may even grow faster, given the length of time that people are living longer and that this may be under-reported. These are projections. We actually don't know for sure the number of people that are out there.

But in between those two points, there's this provocative point which is the global population may rise even faster because people are smoking less, which would strike I think many of us as being counterintuitive. Why in the world would people smoking less, which we think of as being a good thing, contribute to more Parkinson's? Can you just briefly explain that, Ray, please?

Ray Dorsey: 00:12:18 So first, one of the great public health successes of the last 20 years has been decline in smoking. That has been especially prominent in the United States and many other parts of the world. It's fueled increases in life expectancy. Decreases in cancer, decreases in lung cancer. Decreases in cardiovascular disease. And decrease in deaths. So very few bad things to say about declining smoking rates. It turns out that smoking is associated with an approximately 40 [percent decreased risk of Parkinson's disease. We're not sure why that is.

People have looked at nicotine, people have looked at different elements of smoking and largely been unable to identify it. Bas might have additional suggestions. But as smoking rates decreased ... A recent paper by our colleagues in the journal *Movement Disorders* suggested that that will lead to a 10 percent increase in the number of individuals affected by Parkinson's disease to the extent that smoking is linked to the causative path with Parkinson's disease.
And I guess it also seems likely and that it's another aspect of people just living longer, right? So as people smoke less, live longer, therefore potentially it's kind of an unwelcome bonus to the fact that we have an ever-aging population.

Sure. And another thing I'd point out is that that was a public health challenge that we addressed as a society. All of us did. You know, it became unacceptable to smoke in hospitals. It became unacceptable to smoke in a closed environment. People realized the secondary consequences, not only just to the individual, but to individuals around that person from smoking. And we successfully addressed a large measure that public health challenge. And we're confronted with another public health challenge here in Parkinson's disease that we, too, think we can successfully address.

Yeah. And that leads us, I think, where we want to head next, which is to talk about the kinds of things that we can do to contend with this increase and do some very concrete things like prevention. Let's begin in the middle of this list if we might, Bas Bloem, and talk about the role of pesticides. We have known for a long time that there is this association particularly to a pesticide known as Paraquat that is associated with increased Parkinson's. It's always been very difficult to have a direct cause and effect determination, but there's clearly that association. Clearly larger numbers of people with Parkinson's in areas where pesticides are used heavily.

So it would seem like, Bas Bloem, a pretty straightforward thing we could do would be to work on lessening the availability of those pesticides. That's been a difficult challenge. Bring us up to date on where we are and what you would really like to see people within the Parkinson's community advocate when it comes to pesticide usage.

Yeah, thanks for that question. First of all, the link between pesticides and risk of development of Parkinson's is clear. There's a great number of studies. And I'm personally convinced about the association. To all the people listening to the webinar today, it's good for you as an individual that it's almost impossible to link your Parkinson's to any specific cause. So if people are worrying, "Oh, I visited that farm", or "Maybe I lived in the countryside and if only I hadn't, then I wouldn't have Parkinson's", it's impossible to make that link. I'm just saying that to reassure people and not to waste energy on looking back at what might have caused their Parkinson's. Because, again, at an individual level, it's very hard. Yet at the population level, the link is clear. And one particular link that fascinates me
personally is that in more recent years, Parkinson's has also been linked to lifetime consumption of dairy products.

And one way through which the pesticides might ultimately reach human beings is by cows eating contaminated grass and the pesticides reaching dairy products. The link between dairy products and future risk of Parkinson's is also beginning to become more clear and convincing. And certainly, some pesticides which have been linked to Parkinson's such as Paraquat, have been found in detectable concentrations in milk products. And I think the clear answer … And I know there are some huge lobby in the farming world to keep the pesticides as is … But I think there should be a concerted action by all of us to begin banning these harmful pesticides. Some of them, lo and behold, are still around even though we know they have toxic effects on the brain.

Dave Iverson: 00:17:08 And Ray Dorsey, pick up on that if you would. Because I know that there are some countries that have banned the use of Paraquat in particular, but as I understand it from something you told me recently, in Great Britain, you can't use Paraquat. But in Great Britain they still make it and export it, including to the United States. So this would require a global effort. This isn't something that you can really tackle just in one country, because these pesticides cross international boundaries. Ray, your thoughts on that?

Ray Dorsey: 00:17:43 Yeah. So in 1962, Rachel Carson wrote the landmark book, *Silent Spring*, which launched the environmental movement on the indiscriminate use of pesticides. And here almost 50 years later we're still talking about it. So Paraquat, as Bas indicated, is well-associated with Parkinson's disease. The EPA even has on its website a line that says, "One sip can kill." And the United States has not completely banned it. It still has restricted use for it. People still die from inadvertent ingestion of Paraquat. England has banned the use of Paraquat in England, but there's a chemical firm in England that exports Paraquat around the world, including Brazil and even the United States.

You know, this is a global issue and, again … There's a great saying. Every society creates its own diseases. And Parkinson's disease, at least large portions of it, have been likely created by us. And to the extent that we have created our own diseases, including smoking, we can reverse them. We can stop creating these diseases. And the only reason, some will hedge in the voice of Bas and me about the risk with the disease is because just like smoking, we can't randomize people to smoke or not smoke and watch and see who dies. We can't randomize people
to ingest pesticides and not ingest pesticides and see who develops Parkinson's disease. You know, it's not ethical to do that.

So the way we have to do is we have to go back and look in the past and ask people about their exposures. So the level of evidence that we can obtain is harder to ... Is lower quality. But still, if you look at the brains of people with Parkinson's disease compared to those without Parkinson's disease, they have high levels of pesticides. If you look in the blood of individuals with Parkinson's disease compared to the level of blood in the blood levels in people without Parkinson's disease, there are higher levels of pesticides. If you give these pesticides to animals, they develop the signs and ... The signs of Parkinson's disease.

So the wealth of evidence that these pesticides ... Which, by the way, are neurotoxic by design and fat soluble, and the brain's very fat soluble ... Are implicated in Parkinson's disease. And again, to the extent that we create these pesticides and we administer these pesticides and we know which pesticides are harmful and we continue to do that, that's something we need to stop.

Dave Iverson: 00:20:07 And it occurs to me, Bas Bloem, that another aspect of this, in addition to people in the Parkinson's community perhaps getting engaged politically and pushing for the restrictions on the use of these pesticides, another aspect of this could be what you are suggesting to some degree before with diet. And we see diet as one of the points of prevention here which would imply that the ... Or perhaps more than imply, the importance of people eating more organic foods. Not only because those would be better for us and free of pesticides in terms of what we're ingesting, but it could also discourage perhaps farmers and the agricultural industry from using them. If we buy those products less, then there will be less incentive to produce in that way. Would that be right, Bas? I mean, that's a very I guess specific concrete thing that people in the Parkinson's community could do.

Bas Bloem: 00:21:03 I like your provocative ideas as always, Dave. I think that a wonderful way of shaping the revolution is by having us, the advocates and the patients as the ultimate advocates eat organic foods and turn the pesticide businesses out of business by doing this. I think it's a great suggestion. Just for clarity, you need proper research to demonstrate that organic food has a lower risk of future development of Parkinson's. While we're waiting for that evidence I'm a fan of organic food and I take it myself all the time.
The other thing about diet though, is I think everybody listening, so most of the people in this webinar will already have Parkinson's symptoms so it's too late to prevent the disease, but a healthy diet is critical. I can't repeat it enough, critical alongside physical activity to help maintain an optimal condition despite having Parkinson's. A healthy diet means lots of fluid, because constipation, delayed bowel movements, is a huge problem. It needs sufficient fluid intake, fiber intake and several other factors have been researched as being potentially beneficial. None of that is robust evidence yet but there are sufficient hints to already begin considering these things.

It's fruit that's rich in color, and I'm talking about berries, blackberries and the like because they contain high concentrations of antioxidants, which are probably good for the brain, as rodent animal research do suggest the benefits. We think it's good for human beings. A Mediterranean diet, so fish and oil and olives and the like is probably good for people with Parkinson's disease.

It may be wise to avoid an excessive amount of dairy products given the link to the pesticides. And strangely enough coffee, regular coffee intake is also one of the factors that's associated with a reduced risk of future development of Parkinson's and I generally recommend my patients to take three strong cups of coffee a day for multiple reasons. It also helps you to stay awake a little bit easier which can be a problem for some patients. It helps to promote your bowel movements. It could have some protective effects on the brain. So those are a couple of measures that people can already begin considering even today.

Dave Iverson: 00:23:47 We can talk about these questions of diet and pesticides for the entire hour but we have many more topics to cover and we need to move forward. We would be remiss if we didn't also mention, more than mention perhaps, the importance of exercise. You touched on it a moment ago, Bas, about that that's something that we could also do to both help people who already have Parkinson's do well with the symptoms that they have, because there's lots of evidence to support that, but perhaps also the role that exercise might play in a preventative role. Ray Dorsey, could you comment on that aspect of prevention, please?

Ray Dorsey: 00:24:27 Yes. There's increasing evidence that, well, most people know that exercise is extremely beneficial for people with Parkinson's disease. There's a large amount of evidence for that. There's increasing evidence that exercise may decrease your risk of
Parkinson's disease. Several studies have found that people who vigorously exercise in their 30s and 40s appear to have a lower risk of developing Parkinson's disease, for example, in their 50s, 60s and 70s. In animal models we can see trophic factors, growth factors that lead to growth of neurons and nerve cells in the brains that are linked to exercise and again we see the same evidence in animals who we give Parkinson's disease to, that those that exercise do better than those that don't. So strong evidence among humans and animal models of the benefits of exercise in Parkinson's disease and increasing evidence that exercise may be even preventative or may decrease your risk of developing Parkinson's disease.

Dave Iverson: 00:25:31

Our producer of this series of webinars, Maggie, has just reminded me that The Michael J. Fox Foundation is calling for a ban on Paraquat, which we were discussing a moment ago, one of the pesticides strongly associated with Parkinson's. We have a petition encouraging people to support that and we'll be sure to send out in a follow-up email to everyone participating in the webinar today, if you're interested in supporting that particular activity.

One more quick point and then we'll move on to our next slide, well not so quick, but it sets the stage for the rest of our discussion that I want you to mention, Ray Dorsey. That comes back to this question of what we can do to contend with an epidemic or a pandemic. You and Bas provocatively provided a model for what we could do in our overall response within the Parkinson's community, and that's to learn some things from what happened with the AIDS epidemic in the 1980s, something that was initially so devastating but which also points to some interesting lessons for how you can take on something that in the early days, at least, seemed so daunting and so difficult to contend with. Walk us through that, Ray, if you would please.

Ray Dorsey: 00:26:44

Sure. So in 1981 the New York Times ran an article highlighting that a cancer called Kaposi Sarcoma was found among homosexual men, cause unknown. Later it was found that this cancer was a result of immune deficiency later to be found due to the HIV virus. In 1996, 15 year later, protease inhibitors, drugs used to treat HIV were developed and led to near normal life expectancies for individuals with HIV. So in the span of 15 years you went from a newspaper report about an unknown uniformly rapidly fatal condition to a condition that had a near normal life expectancy associated with it.

What made that happened weren't great infectious disease doctors, although that was helpful. It wasn't great scientists,
although that was helpful. It was the community and the activism within the community and they did four things. They did one, they thought to prevent disease onset and transmission of the disease, again unknown at the time but they closed bath houses. The whole widespread use of condoms became because of them.

Two, they insured increased access to care. At the time prominent hospitals in New York City refused to admit patients who had this disease. Many doctors, including some of our teachers, refused to care for individuals with HIV. Three, to increased funding for research today. At the time there was no federal funds being spent on HIV. If people remember, Senator Jesse Helms from North Carolina, he steadfastly refused to fund research related to HIV. Activists put a condom over his house to get the message across. The message was received. Today the NIH, out of its $30 billion budget spends $3 billion a year on HIV. Parkinson's disease, which affects half as many Americans as HIV receives less than $200 million.

The fourth thing that the HIV community did is they had the foresight to realize that drugs that were going to be developed for HIV would be expensive and they sought to ensure that drugs that were to be developed would be accessible to all people including those least able to afford them. Probably today more people have access to drugs for HIV, which are expensive, relatively risky than people have access to levodopa, which is safe, inexpensive and it's been around for 50 years.

All of those things are things that we can do within the Parkinson's community, whether that's to focus on prevention as we've just been discussing, to focus on access to care, which we will take up next and also the question of course of increasing the amount of funds that are spent on Parkinson's research.

Let's turn then to the question of getting better access to care. We see again some pretty powerful statistics here that even in wealthy countries, that 40 percent of those with Parkinson's over the age of 65 do not see a neurologist. The statistics get more daunting, still, in this country when you look at in terms of people who face perhaps certain kinds of disadvantages or discrimination. Among those with neurological disorders, African Americans are 30 percent less likely, Hispanics 40 percent less likely to actually see a neurologist than their white counterparts. African Americans are also four times less likely to receive Parkinson's treatment, less likely even more so to receive surgical treatments like deep brain stimulation. You see
on the slide there the various citations if you're interested in looking up where those statistics come from.

This is, I think, ought to be deeply disturbing for all of us in the Parkinson's community, that there are such inequities and care. So, Bas Bloem, when we have such a problem with this it can become almost too daunting. You see us like, "Well, that's so overwhelming. What can I do?" So what can we do? What would you advocate we do to make access to care for people with Parkinson's, regardless of where they live, regardless of the color of their skin, be more available?

Bas Bloem: 00:30:59

Well, it is a daunting question. I think we need to really reshape health care, the way we are delivering health care. We are facing an aging population. Parkinson's is rising fast. Other conditions are rising fast. The available number of young people to look after our increasing aging population is becoming smaller and smaller. As you point out, there is already today, and things will be getting worse if we don't do something drastically different, already today many patients are receiving insufficient care. Very provocative work by Ray Dorsey has shown that if you as a patient with Parkinson's, even in the United States, are not being treated by a neurologist, and I'm not even talking about a Parkinson's expert, but just a neurologist, you're more likely to fracture a hip or be admitted to a nursing home and I think that's just terrible.

Ray and I have also said in another provocative paper that in many ways we couldn't have designed health care worse. We're asking our patients to travel long distances to the hospital. We know there are driving issues for many people with Parkinson's. They sit in waiting rooms for ages until the doctor can free up 10 minutes of his time only to get a snapshot of what is otherwise a really complex condition. We have no ideas how patients are functioning at home.

So the scarce resources that we do have at our disposal are deployed in absolutely the wrong way. Professor Ray Dorsey has done some seminal work, he's really leading the field in developing telemedicine, bringing care, literally, into the patient's homes by web conferencing with your patients. You can also take that further and we are now partnering with Ray in developing tele-rehabilitation approaches, where you could bring experts, physical therapy, occupational therapy, dietary advice, also literally into the patient's home. So rather than asking patients to come to us for knowledge we bring knowledge into the patients' homes.
The second thing we need to do is stop thinking that Parkinson's is an easy condition that can be handled by anybody. It's a complex condition and it requires deep expertise. In my own work on ParkinsonNet in the Netherlands has shown that if you reorganize care with the existing personnel and rather than let everybody do a little bit of everything we have concentrated care among a limited number of experts with deep training and deep expertise in Parkinson's who see and attract a high case load, maybe not directly but it could be through telemedicine. And that approach leads to much better care. So we should make care more accessible through telemedicine approaches and we should make sure that we have experts on the table who can optimally take care of patients.

And credits to The Michael J. Fox Foundation. One of the things the Fox Foundation is contributing today is working with the Edmond J. Safra Foundation whereby they offer money to institutes to train extra experts, young neurologists, to get them money, to train them to become experts in Parkinson's. And I can proudly announce that we just heard last week that my own center is a recipient off an Edmond J. Safra Fellowship grant, and I'm thankful for that, and the Fox Foundation is to be really commended for this initiative.

Okay, move us to this next slide because it's summarized many of the points you were just making, Bas, about some of the things that we need to do to contend with those statistics that we were just looking at, from dealing with the approaches that remove time and barrier distance, like telemedicine, to training, more movement to specialists and making sure people get better treatment.

Let's pursue this a little bit more and more in a concrete way, Ray Dorsey, because as Bas just mentioned, you two are kind of joining forces and has lead the way in many ways in putting together this cross disciplinary approach to contending with Parkinson's. While we need movements to specialists we also need physical therapists or occupational therapists, sometimes speech therapists. So it really takes a more collaborative cross disciplinary approach, this disease of ours.

Ray, describe how you’re trying to approach this in Rochester, New York and upstate New York using telemedicine approaches but also working with Bas in the Netherlands' model to try to import some of those approaches into your part of New York state.
Ray Dorsey: 00:35:43 Well, the central premise behind what Bas was describing is we need to stop bringing patients to care and start bringing care to patients. It's fundamentally flawed that we ask patients with impaired mobility, cognitive ability, driving ability, to be driven by overburdened caregivers to urban medical centers to receive care once every three months or once every six months.

In the Netherlands, thanks to Bas and his great work with ParkinsonNet, you can go to the website, type in your zip code and find a physical therapist with dedicated expertise in Parkinson's disease right in your own community. In Rochester, New York, it's March and there's about six inches of snow on the ground and right now the only way you could get care is you have to drive to Rochester during snow storms to get access to Parkinson's diseases specialists.

Instead, with funding from the Greater Rochester Health Foundation, the Edmond J. Safra Foundation as well, we've created something called Parkinson's Disease Care in New York. You can go to PDCNY.org and what we enable is any New Yorker with Parkinson's disease can receive care from a Parkinson's disease specialist in their home remotely, regardless of who they are, where they live or their ability to pay. Any New Yorker with Parkinson's disease can receive care from Parkinson's disease specialists in their home regardless of ability to pay. And if we can do this for New York state, why can't we do it for the rest of the country? And Bas would say, "Why can't we do this for the rest of the world?" And the answer is simply, "We can." All we need is creativity and political will to tell Medicare to start reimbursing for video visits conducted in patient's homes and you could change the way we deliver care to Medicare beneficiaries tomorrow.

Dave Iverson: 00:37:26 On this question of that these are global needs, I want to ask you to pursue this a bit further, Ray, because while we have many challenges here in the United States, in some ways they pale in comparison to China, which you referenced earlier in our discussion. The numbers of people of China versus the number of people that have access to neurologists. Or in developing countries in terms of the expense of care, their access to that 50-year-old drug we all know and love, levodopa/carbidopa. So Ray, put that out there, as well, because it's important for us to realize the global nature of this challenge.

Ray Dorsey: 00:38:12 Yes. In China there's about 2 million people with Parkinson's disease and there's fewer than 100 Parkinson's disease specialists. There's fewer than 100 doctors like Bas and me in China to care for 2 million people with Parkinson's disease. In
Bolivia when they do door-to-door epidemiological studies to see who has Parkinson's disease, of the group of individuals that they identified with Parkinson's disease, not a single one of them had ever been diagnosed or treated. This is despite the fact that Parkinson's disease is a highly treatable condition, as everyone listening knows, and the highly effective treatments have been available for 50 years. Those treatments are safe, largely inexpensive and highly effective.

Right now 40 percent of countries in the world lack access to anti-Parkinsonian drugs like Parkinson's disease, 40 percent. 80 percent of low income nations lack access to drugs that can take someone who otherwise would be wheelchair bound and make them walk, take someone who can't smile and enable them to smile, take someone who could be markedly dysarthric, (difficulty speaking) and enable them to communicate with their wife and their children. We don't accept that for HIV. Last I checked, 58 percent of people with HIV are on anti-retroviral therapy for the drug. The mere fact that people are taking drugs for HIV is leading to prevention of new cases of HIV. HIV deaths and number of new cases have both declined over the last decade. We have models for ways we can turn this wave around and stop this exponential increase in the number of people with Parkinson's disease. What we lack is the creativity and the will to do so.

And you look again at the AIDS model, one of the things that former President George W. Bush gets appropriate credit for is his efforts in making AIDS drugs more available in Africa. It seems like what you're suggesting is we need that kind of awareness, that kind of political will, that kind of desire, really, if we're going to make a dent in what we're facing with Parkinson's disease.

Let's turn to some of our audience questions that are coming in. We'll spend some time with that and we'll go back and review some of our other statistics and slides as they come up. We're getting some questions now about people wondering if they could start doing in their state, Ray Dorsey, what you're doing in New York? If someone wants to import the Rochester model by way of the Netherlands to Nebraska or wherever, how does one go about doing that? Ray, your thoughts first, and then Bas I'd be interested in yours, too.

There are a couple things. One, we've taken one of Bas's great things, his creative ParkinsonNet, called ParkinsonTV. So if you go to YouTube right now, YouTube.com and type in ParkinsonTV you can see educational episodes on Parkinson's disease that
Bas and I have helped create that address things about diet, exercise, physical therapy, occupational therapy. So at least you can get educated and informed. If you are a veteran in the United States, you can go to a different VA community based centers and be connected to a neurologist or a Parkinson's disease expert anywhere throughout the country in a federal program. If you're in prison and you have Parkinson's disease you can be connected to a remote Parkinson's disease specialist. If you're a Medicaid beneficiary you likely can stand to benefit from telemedicine because 48 states mandate that Medicaid covers telemedicine. If you're in Canada, one of our colleagues, Dr. Mark Gutman cares for lots of people in Canada and Ontario, even though he sits in Toronto.

And you can benefit from telemedicine, but if you're a Medicare beneficiary and you desire to receive care in your home, you can't, and the only reason you can't is because Medicare says that you can't. So, Medicare pays doctors, like me, about $200 to see patients with Parkinson's disease in community based clinics, no, in hospital based clinics. I'm sorry. $200 for hospital based clinics. In community-based clinics that are closer to patients, we get paid $100. To see patients in their home remotely, we get zero dollars.

And the only reason that is, is because that's what Medicare's policies are and Medicare was created in 1965 with a sole mission to guarantee access to health care to older American's at a time when half of older American's lacked that access. And some of your listeners have been paying into Medicare for 50 years and they rightfully expected that Medicare would meet their healthcare needs when they got older and retired and they should demand that they start to cover it. Medicare has slowly started to adopt it, but it trails prisons, it trails Canada, it trails Medicaid, it trails the private sector and it trails the VA in terms of its coverage of telehealth.

And, if you are interested in trying to push on the public policy, aside of these questions, as Ray is just advocating that we do, we'd encourage you to visit our public policy site, which is MichaelJFox.org/policy, if you're interested in becoming engaged in a pushing for some of the reforms, Medicare reforms, that Ray was just advocating.

Bas, you've developed this wonderful model in the Netherlands and I think people would like to hear more about trying to make that more widely available in this country and elsewhere. I know you've also working with people in Michigan and elsewhere, but any other suggestions that you'd like to offer for
So, our model in the Netherlands, which is called ParkinsonNet, is educating a restricted number of people to become deep experts in Parkinson's, seeing and treating many people and families with Parkinson's, working together effectively as a team, and investing heavily in patient education. That model in the Netherlands leads to better care, it prevents hip fractures, it prevents hospital admission. It actually saves the Dutch government, for Parkinson's care alone, $30 million in euros each year, year in, year out, and our latest research, published in *Neurology*, shows that expert physiotherapists are even saving lives.

So, we joined the king and queen of the Netherlands on a trade mission to Michigan to come and bring ParkinsonNet to the folks in Michigan and people were wildly enthusiastic about the approach, and end of the day, because the providers, the hospitals, are in competition because the payers are in competition. People were saying ParkinsonNet is mine because they wanted a competitive edge over their opponents and I think it's a disgrace that, until today, ParkinsonNet has still been installed in Michigan and the only way to change it is, I think, the voice of the patients.

The patients, just like the HIV community did in the 80s, should go to the streets and say, "Look, the evidence is out there. There's no reason to think why it shouldn't work in the United States." In fact, because of the limited number of neurologists, because we know that the rate of hospital admissions is even higher in the states, ParkinsonNet is bound to be effective to lead to better lives for people with Parkinson's. And, I think the only way to change it is the voice of the patients demanding better care and demanding implementation of models such as Ray's telemedicine approach that he's doing in New York state and my ParkinsonNet approach that we're now deploying, not only in the Netherlands, but also several countries in the world.

Just to build on that, Bas has demonstrated that you can provide expert Parkinson's care to just about everyone in an entire country. You can provide expert Parkinson's disease care to just about everyone in a country, get better at health outcomes, and oh, by the way, save money. I think Bas and I come hard on looking for activism from the community because, if you look at the history of the world, neurologists
don't change the world. It's ordinary people who are moved by different conditions and different events that change the world and we have, Bas and I, can come up with new care models and new means of delivering the care, but the people who drive adoption and drive change are the people who are most effective, stand the most to gain, and sometimes the most to lose from lack of adoption of new tools and technologies and approaches that we're trying to develop.

Dave Iverson: 00:47:00 And I think that's also true, if I could observe, throughout history in this country. The great social change has taken place when people in communities become active, whether that was the age, the model that you have both suggested. It's also, of course, true in the civil rights era, perhaps true again now, with what young people are doing since the shootings at Stoneman Douglas High School, the high school in Parkland, Florida, rather, is perhaps bringing about change in that regard as well. So, I think it's something we can all consider about the role of each of us have if we're going to make more progress.

Let's go back to more of our questions. We have a number of questions coming in. People wondering about the genetics of Parkinson's disease. I don't want to sidetrack into that topic right now, but I think it's coming up because we've talked a lot about environmental factors, and so I just want to encourage that there are indeed genetic factors that are relevant in Parkinson's disease. We just did a whole webinar on that topic, so if you're interested in learning more about the genetic part of Parkinson's disease, do go to michaeljfox.org/webinars and look for the webinar on genetics and that will hopefully provide some additional information on that score.

Yes, go ahead, Ray.

Ray Dorsey: 00:48:24 Yeah. Just one link on that real quick. It appears that some genes that are implicated in Parkinson's disease, for example, might make animal models more susceptible to the effects of pesticides, so there might be a link between the genetics and some of these environmental exposures.

Dave Iverson: 00:48:39 Right. And we're learning, of course, that there is that interplay, I think, across so many diseases, not just Parkinson's. Yeah, thanks for that additional observation, Ray.

Just let me come back to our statistics, just for a moment, because we've got this interesting question from one of our participants, Bas Bloem, which is, "How is global data collected and how reliable and complete are that data?" It's a really good
question because these are projections, and one of, of course, our great needs still, and it's something that we're also pushing for the in the United States is to have a better registry so we know actual numbers, not just population estimates. Can you comment on that, Bas? How do we really know this is the case when we look at these population projections?

Bas Bloem: 00:49:27 That is, again, a very good question. Certainly, registries in some countries are better than others. So, our estimates, for example, for western countries are better than for economically less well developed countries and areas such as Africa. Yet, at the same time, there are in many, many countries, different types of registries and what we're looking at is converging evidence. So, for example, Sweden is known for its excellent healthcare registries, so data in a country like Sweden, or the Netherlands for that matter, are very robust.

Just recently, and we're about to submit a new paper that, United Kingdom has excellent death records. So, causes of death, and the very recent data, just been published, on causes of death in the United Kingdom show an alarming rate of people who died with, or from, Parkinson's disease, so, again, independent source. So, I think our estimates are best in countries where those excellent registries are in place, but at the same time, many countries do have at least some form of registry. But, I think, your call for action, we are talking, really today, about a call to action, would be to arrive at more uniform ways of registering Parkinson's. Not only its incidents, but also maybe to track its symptoms. So we begin to understand Parkinson's as a worldwide phenomenon much better because that ultimately is the basis for treating the disease while people have it. And ultimately, hopefully, leading to prevention of the disease, so the need for a worldwide more uniform registry is heartfelt.

Dave Iverson: 00:51:14 And if I can just mention again that there's a real effort going on right now in this country to fund something that the CDC, Center for Disease Control, has been authorized to do, but hasn't been funded to do, which is to create a registry of neurological diseases. If you're interested in pushing more in that direction and advocating for that, I would, again, encourage to go to michaeljfox.org/policy to learn more about how we can do just that.

Here's a question that's come in, a sophisticated question, I think, about understanding, teasing out what's going on behind the global rise. This person asked, "How do you reconcile that pesticides are clearly an issue, yet, diet is an important way to
address Parkinson's, perhaps, but do we know that choosing organic is really enough? How do we know how to address this best?"

And, Ray Dorsey, let me get your thoughts on that, because like so many things with Parkinson's, it's really hard to know, as you guys were both describing early, what caused my Parkinson's? That's a really hard question, impossible question in some ways, to really answer. So, in some ways it's also impossible to know if I eat an organic apple that, that's necessarily going to make a difference. I guess, is this, Ray, one of the situations where we shouldn't let the perfect be the enemy of the good? In other words, just because we don't have definite knowledge, shouldn't keep us, necessarily, from doing certain things. How would you respond to that particular challenge?

Ray Dorsey: 00:52:49 Absolutely. And so, I think we need to know more about the food that we eat and we need to demand that information. And the more information we have, then we can make the trade off as to the health risks, but if we don't get information, we're at the mercy of those who are producing the food. And, if you think about the economics of food producers, their desire is to make food taste as good as possible and to make it as cheap as possible and you don't need to make too much of an extrapolation to figure out how they would like to make it as cheap as possible.

If we eat, if we demand that we eat foods free of pesticides, at least food free of pesticides that are known to be linked to Parkinson's disease, companies will change. If you want an example of that, look at McDonald's. They sell apples and they're probably one of the largest seller's of apples in the country, if not the world, and the reason they sell apples is, because consumers said we are tired of pumping our kids full of fat and French fries.

So, we can demand that behavior change and we can by becoming more informed about the risk associated with different pesticides and different chemicals and demand that we have transparency into how our food is produced and brought to us. And we can make decisions about what we decide to buy and not buy, what we decide to eat and not eat, what we decide to service and not serve, and all those small decisions have a cumulative, big effect.

Dave Iverson: 00:54:18 Just have a few moments left and I want to give each of you a chance for some closing thought, but, Ray, just one more question from Steve who asked, really, several questions, but
I'm just going to tease out one of his about what we know and don't know about the nature of the population that is increasing with Parkinson's, but he asked another provocative question too, Bas Bloem, which is, "Do we know that the numbers are really increasing? Or are we just getting better at diagnosing?" It's a kind of chicken and egg question, but thoughts on that?

Bas Bloem: 00:54:52

No. It's, again, it's a good question. I think we are getting better in diagnosing Parkinson's. There are, I think, very important and relevant discussions ongoing about redefining Parkinson's disease. There are now research criteria that now try to define Parkinson's even in the many years prior to us being able to make the formal diagnosis based on motor symptoms. So, now, we think that people with a REM sleep behavior disorder, people acting out their dreams, plus constipation, and reduced smell is going to be the new Parkinson's disease because you want to tackle the disease as early as we can.

And through this recognition of these early symptoms of Parkinson's, our recognition is better. Yet, at the same time, remember, Parkinson's disease was first described by James Parkinson observing people on the street. This is a disease that's not easily missed. Unfortunately, people on the line here today, just know too well what an impact Parkinson's has. So, our better ability to recognize and define Parkinson's does play a role, but it doesn't explain the Parkinson's pandemic. There's something else happening and need to take action.

Ray Dorsey: 00:56:02

And just to add on that, we're missing lots of people who have Parkinson's disease that aren't being diagnosed. You shared the evidence about African Americans and Hispanics. I do a lot of work, used to do a lot of work in nursing homes, and we would have many people who would develop Parkinson's disease after moving into a nursing home, never been diagnosed, never been treated. Numerous people are shuffling around and having a little bit of tremor and being attributed to normal aging and that's going on in the U.S. and Europe and, if you go to other parts of the world, there are just large numbers of people that aren't being diagnosed, aren't being treated.

I think almost all the estimates, including estimates that my colleagues and I have put out, are off by like 50 to 100 percent in terms of underestimating the true burden of the disease and we do need to recognize that and wake up and, I think, just people's own observations here, I think people know more and more and more individuals being affected.
Time for just a quick last closing thought, as we are out of time, from each of you. We began with a kind of talk about the importance of acting, that there is a need for a call to action, for all of us within the Parkinson’s community. So, I want to give each of you a chance to make that call one last time. Bas Bloem first, and then to Ray. Bas?

I hope that my comment will be complimentary to the one that Ray will make. I think there’s two strategies. We need to prevent Parkinson’s from developing in the first place and we need to take better care of people affected today. My passion is that, by changing healthcare into a system of experts who bring the care to the patient’s homes, we can improve quality of lives and even save lives today and I think anybody on the line, and any other people listening to this webinar, should take action, raise a strong voice, that you deserve a better care and that providers and payers should avoid their competition and get their act together and make sure that we deliver better care to you folks.

I wanted to extend Bas’s ideas in a note of hope. In the lifetimes of people on the phone, we’ve seen an epidemic of polio, and we’ve eradicated it, almost removed polio from the face of the earth because of the activism of people who were affected in the 1950s, in literally, a March of Dimes. People mailing in dimes to the White House to raise money so that Jonas Salk could develop a vaccine that could essentially almost eradicate polio from the face of the earth.

We’ve talked about HIV. If you want another modern day example, look at breast cancer. Three quarters of breast cancer today is preventable by early detection and early action. We have seen numerous examples throughout history where societies have addressed health challenges of their time, whether that’s smoking, whether that’s polio, whether that’s breast cancer, whether it’s HIV. We need to do the exact same thing to confront Parkinson’s disease and other neurological conditions. I know The Michael J. Fox Foundation, others, are working on a national action plan to lay out a plan by which we can do that, but the success of that plan and those efforts rely on the activism, activism and the resolve of the community that’s most directly affected by the condition today and in the future.

Ray, thank you. My great thanks to both doctors, Ray Dorsey and Bas Bloem, not only for their participation in today’s webinar, but for their pioneering work and leadership in this regard. I think all of us in the Parkinson’s community owe the
two of them a great deal of thanks. Bas and Ray, thanks so much.

That's all we have time for on today's webinar. I thank all of you for participating. We'll be following up with an email where you can give us your thoughts and suggestions for future webinar topics. We'll back again on the third Thursday in April, when my colleague and friend, Dr. Karen Jaffe will host. We're going to talk about how people can participate in Parkinson's research. That'll be our topic a month from now.

Until then, I'm Dave Iverson.

Michael J. Fox: 01:00:15 This is Michael J. Fox. Thanks for listening to this podcast. Learn more about The Michael J. Fox Foundation's work and how you can help speed a cure, at michaeljfox.org.