

Sam Pauly :

Welcome to the One Voice for Neurology podcast, a series of seven podcasts exploring why it's time to make neurology a priority - how that can be achieved with a global and uniform response and what that could mean for the future of neurology and those living with a neurological disorder. I'm Sam Pauly, and you're listening to Episode Two entitled "Time to Act".

Sam Pauly :

Thank you for joining us on this special series of podcasts in which we're exploring the new One Neurology initiative across seven daily episodes. In our first episode, we discussed what makes neurology one and how, despite the different disorders, there are common challenges that must be addressed as one. But that this is not about replacing single disease initiatives. It's about complimenting them with a global and stronger Alliance, able to drive greater change among stakeholders. And today we're asking the question, why now? To answer that shortly, I'll be joined by a past president of the EAN, the European Academy of Neurology, and by the president of the WFN, the World Federation of Neurology. In today's episode, we'll also be hearing messages about why decision makers have been looking away and later we'll be putting stroke in the spotlight, as we case study what other neurological disorders can learn from its approach to awareness and clarify why it is a neurological disorder.

Sam Pauly :

We'll be joined by three guests to discuss stroke at an international, European and national level. But first, I'm delighted to welcome Professor Günther Deuschl, past President of the EAN and Professor William Carroll, President of the World Federation of Neurology. They are two of the co-authors of the paper, The Global Burden of Neurological Disorders: Translating Evidence into Policy. Günther and Bill, thank you for being with us. Before we chat, I just want to remind listeners that we'd love to hear your thoughts. So do make sure to join the discussion with us on Twitter. You'll find us at, @OneNeurology_ and we're using the hashtag #OneNeurology. So, Günther, let me start by asking you, what were the key findings in your research about the current situation?

Prof Günther Deuschl:

One of the key findings was that neurological diseases are highly prevalent. Globally, almost 50% of the world population suffers from a neurological disease. At some point, if we look at other aspects of quantifying the burden of disease, this is, for example, the disability then, worldwide neurological diseases are number one. Concerning death, neurological diseases are number two worldwide and in Europe, in both aspects, are number three, among all diseases.

Sam Pauly :

Bill, is there anything you would add to that?

Prof William Carroll:

Günther has explained it very well about the burden. By way of explanation for listeners, neurological diseases deal with the whole of the nervous system, so it's from brain to spinal cord, to peripheral nerves, to muscle. An enormous part of the human bodies is contained in the nervous system. So that's why, disability can be so great, with these forms of diseases.

Sam Pauly :

And are the figures in Europe then representative of the global situation. Is there a relationship between them, do you think, those figures? Günther?

Prof Günther Deuschl:

Oh yes! Of course! The situation in Europe is certainly the situation of a more developed country in the world. And there are differences when you compare it, for example, to Africa. But concerning the basic fears, the situation is very similar worldwide.

Sam Pauly :

Bill, the WFN is currently conducting and you're on a neurology needs survey. What's that looking at exactly, and do you have any preliminary data from that?

Prof William Carroll:

What the WFN needs registry is looking at is from the point of view of the individual member societies of the WFN, which comprise the neurologists on the ground in each of the countries, what they see as their greatest needs to be able to care for people with neurological disease, so it's the other way round of looking at the needs, uh, to, to manage neurological disorders.

Prof Günther Deuschl:

This is a very good point Bill, to understand what we can do in this desperate situation of increasing disease load due to neurological diseases. And I think what WFN currently does is really collect new ideas, collect solutions for this current situation.

Sam Pauly :

And so Bill, what would you say are the needs, the top needs that are coming out from that?

Prof William Carroll:

There is a striking figure that's come out. They looked at what neurologist in the 113 countries need to care for neurological disorders. And the major figure I guess that's worth looking at now is that the analysis not only found that just on 90% of member societies from low socioeconomic countries, rated the lack of specialized centers for stroke and epilepsy and the lack of neurology sub-specialty training as challenges to neurological practice, but so too, did just on 70% of member societies from the high socioeconomic country. So, neurologists around the world are, through this survey, calling out for improved specialty neurological care.

Sam Pauly :

Is it true to say that figures are soaring and do you think they will continue to soar?

Prof Günther Deuschl:

The situation that we have in the world currently, it's pretty clear that there are two to three diseases, which really dominate the whole figures. One is clearly stroke. For example, if you look at the deaths in Eastern Europe, three quarters of the deaths, are due to stroke. It's a bit better in Western Europe where it's roughly 40%. What this shows is really that things can improve, that society can change lifestyle on the one hand, but on the other hand, what is equally important is to improve the care for these patients by developing stroke units, for example. And when you look at the development of the

different diseases, so more the long-term developments, then you can probably see that degenerative conditions are increasing over the past 20 years, by 60 to 70%. Auto-immune disease are increasing by 40%, stroke by 30%. So all these neurological diseases are increasing in terms of numbers. And, with that comes also the disease burden.

Sam Pauly :

Bill, why are we seeing those increases?

Prof William Carroll:

It looks as though the increased numbers, occurring because people are tending to live longer and they are more likely to be afflicted by these disorders still in productive years of their life. But in the later years, as well as in early years, and as Günther alluded to, the mix of these diseases, changes over the lifespan from earlier on from, in some degrees of infection and epilepsy, then we go into migraine and then later stroke and later still the dementia type diseases. But overall they represent a huge burden on societies which have to provide care for them.

Sam Pauly :

So if those figures are increasing, what does that mean in terms of how effective our current management and prevention is?

Prof Günther Deuschl:

Stroke is a perfect example because it really shows that, over the past 25 years, the development of new therapies, and particularly if the development of stroke units, which is a specialized unit, has really changed a lot. And those countries who have almost a 100% coverage with stroke units usually have a better outcome for stroke patients than others. That's a very good example. But at the same time, we need certainly much more research in the field, that needs to be internationally conducted and internationally agreed upon. So for example, the development of powerful therapies for Alzheimer's, for multiple sclerosis, for aspects of epilepsy, and so on.

Sam Pauly :

Bill, I think in many people's minds, neurological disorders very rarely kill... So, what makes the toll so high?

Prof William Carroll:

What makes the toll so high is that it's a combination of both mortality due to these diseases and living with disability with these diseases. So the two go together to give an overall disability index, which we call a DALYs - disability adjusted life years. And that's the sum of years lived with disability, together with years of life lost because of that disease. I think that's probably what makes it so large plus the increasing numbers of people that are being affected.

Sam Pauly :

Do you think that decision-makers have been looking away?

Prof William Carroll:

I just don't think they've been looking. They are not looking away. They just haven't seen it because it hasn't been brought to their attention, which is why I think these sorts of initiatives are so powerful. This threat is being broadcast so that people can plan and can develop strategies to meet this increasing tiredness of disability and therefore increasing burden on communities' economic status, as well as health status.

Sam Pauly :

Well Günther and Bill, let me ask you both the next question. What would be your message to policy makers or your reply to policy makers who say this isn't the time to prioritize neurology?

Prof Günther Deuschl:

Well, first of all, the burden is very high. The second thing is that we can do things. We can improve the situation. We have the means for it. Politicians always want solutions.

Sam Pauly :

Bill?

Prof William Carroll:

If the threat is large enough, as it appears to be in the global burden of neurological disorders data... Now is the time to prioritize these disorders. It takes time to institute mitigation and prevention strategies on a global scale. It has to be done by country by country, region by region. And it has to be tied to research for new approaches. So that whole area is an enormous amount of work and enormous effort. But unless you start somewhere, you won't start at all. You have to, we have to begin. And I think this is a very good sort of beginning to that.

Sam Pauly :

Let's just take a moment, Bill and Günther, because throughout the series, we've been asking stakeholders from across the field of neurology to leave a message on our fictitious One Voice for Neurology podcast Answerphone. This episode, we asked our callers, why decision makers have been looking away despite the highest toll. Let's have a listen.

Voicemail :

Hello, you've reached the Voicemail of the One Voice for Neurology Podcast, please leave your message after the tone.

Elena Becker Barroso:

This is Elena Becker Barroso, the editor of the Lancet neurology. I think that for a long time, our policy makers have focused exclusively on the economy and economic growth, but the COVID pandemic has shown very clearly that our economies and our health, go hand in hand and are inextricably linked. After this pandemic, I believe that nobody will question that to make societies welfare, they must be healthier too. The focus must expand from the economy, to health and especially the health and the healthcare of elderly people. Neurological disorders are the leading cause of disability worldwide. This toll is well documented by epidemiologists that is measuring mortality and disability systematically, worldwide. These are not problems for far away countries. Cardiovascular and brain diseases are the top causes of disability in Europe too. Alzheimer's disease, and other dementias are also among the top causes of

disability and the cause of death for millions of Europeans each year. It is essential to increase the budgets for neuroscience and neurological research. I am convinced that with relatively small investments, we shall see tremendous breakthroughs in treating neurological diseases. We are on the verge of discoveries that could delay the development of Alzheimer's disease for instance, or treat many severe disorders.

Mary Secco :

Hi, my name is Mary Secco, I'm the secretary general of the IBE, which is the international Bureau for Epilepsy. We are a global organization raising the voice of the 50 million people living with epilepsy worldwide. We operate through a network of 130 chapters representing each region of the world. Epilepsy is a lifespan condition, so it attracts both babies to seniors, all genders and all cultures. The toll of epilepsy is highest on people living in poor countries, for instance, those living in Southeast Asia and Africa. In these countries, having unprovoked seizures is met with enormous stigma and discrimination often based in fear of the unknown. Children with epilepsy in these lower income countries are not able to attend school. People are locked in mental health asylums, women are viewed as poor marriage partners, there are lifelong driving license bans and persons are seen as contagious, crazy, or bewitched. This stigma makes it unsafe to disclose and to seek treatment because people fear they will be ostracized or banished from their community. Stigma causes the person living with epilepsy to hide their condition, and they hide it from their family, their neighbors, their church, teachers, employers, healthcare providers, and policy makers. This stigma silences the voice of the affected family and allows policy makers to ignore the problem. It is foundational that in this time to act for neurology, that we seek protective legislation to make it safe, to disclose and to seek treatment.

Tadeusz Hawrot:

I'm Tadeusz and I'm supporting the neurological health through my work for the European Federation of Neurological Associations. Our dear brain is a wonderful organ, but it's also inconceivably complex. And that's why we have more than 400 neurological disorders. Unfortunately, we know from studies that they are responsible for the lion's share of global deaths. They also contributing to a massive decrease in our life quality and enjoyment. And what more, if you think that being robbed is an issue, consider this. There are even neurological disorders that can rob us of our memories and personality because our understanding of the human brain is still quite limited, and because neurology is fragmented. For a long time, policymakers haven't really seen neurological health as a distinctive field or a societal emergency, which they really are. This is now beginning to change, but the real change can happen if we all come together as a field and speak in unified and strong voice. And that's why the One Neurology partnership is so important.

Claudio Bassetti:

Hi, I'm Claudio Bassetti, Professor of neurology from Bern, Switzerland, and President of the European Academy of Neurology and you are listening to the One Voice for Neurology Podcast.

Sam Pauly :

So, Bill, Günther, our podcast coincides with brain awareness week. How can we position neurology in the conversation about brain health, do you think, without it being lost? Bill, let me come to you.

Prof William Carroll:

Look, this is a very good question. Brain health, in my view is a, a simple way to introduce the topic of neurological disorders and neurological disease. Everybody understands what the brain is, but don't necessarily know what neurological disease is. So if we talk about brain health, once that's understood, and what was also understood is that brain ill-health results from neurological disorders, then I don't think you're going to lose one or the other.

Sam Pauly :

Bill, how does the one neurology initiative would you say fit into the broader picture of the work of the WFN?

Prof William Carroll:

The work of the WFN is to foster brain health and quality neurological care worldwide. So what we're seeing now, I think over the last 12 to 18 months is an increasing number of organizations recognizing that the world itself has to understand what is happening with these neurological disorders and the threat they pose. My view is that somewhat pleasingly the more organizations moving in the same direction with the same broad message, the more attention there will be and the more positive interventions and results.

Sam Pauly :

Günther, I wonder if I could just ask you a quick question about COVID-19. What would you say is the longterm risk COVID in terms of decision-makers looking elsewhere and impacts on budgets? Could we feel some impacts from this, do you think, further along the line?

Prof Günther Deuschl:

In my view, it's the other way round. COVID has to be taken as a chance for neurology, to show its importance. The long COVID syndrome, you know, where people really suffer from COVID for many months or even years, we don't know yet, that is a situation that really highlights the importance of neurology. Many of these complaints are due to brain disease, and therefore we should really integrate that into our attempt to foster neurology and to bring that to the attention of people.

Sam Pauly :

Would you agree, Bill: is this an opportunity?

Prof William Carroll:

I do think it's an opportunity and it's also a very good example of how the world can act rapidly and decisively in the face of a major threat. So, what can be done with COVID can also be done with the neurological burden of disease.

Sam Pauly :

I'd like to talk a bit more about solutions now, but also I'd like to ask you first about this global integrated response that we're talking about with the One Neurology Initiative. How do we balance that with the need for specific tailored approaches? Do they contradict each other, or can that work together? Bill, let me come to you first.

Prof William Carroll:

Uh, we're talking about a global initiative here to raise the awareness of brain health and neurological disorders, through this program. We have a large number of different players, actors, participants, who will actually translate what they're already doing and what new information will bring them to each and every country, but workforce issue and the provision of resources to be able to provide those, are really, really important. And they vary enormously around the world. I think we have to sort out different approaches for different diseases, different problems, but nevertheless, ensure that there is enough impetus for that to happen.

Sam Pauly :

How do you both think then that the One Neurology initiative can support and help those different approaches that we're talking about?

Prof William Carroll:

Well, the purely by being one neurology and raising awareness is the first step. Second, to work with the World Health Organization, and it's upcoming call for global action plan on epilepsy in neurological disorders that will give enormous weight to what One Neurology is doing, what the World Federation of Neurology is doing, what the European Academy of Neurology is doing. So all of these things will build a momentum together, and then it's going to be up to different groups, maybe WHO regional groups, maybe individual governments to take up the challenge and to move. I don't think you can direct that it must happen and it will suddenly happen. It has to have people wanting it from the ground up and the ability to provide the information and help and resources from the top down. It all has to work together. I don't see how we can do this without that sort of combined cohesive effort.

Sam Pauly :

Günther?

Prof Günther Deuschl:

I would specifically mention the WHO here. Bringing neurology as the fifth non-communicable disease into play is probably one of the very important steps. And the campaign may help to really reach this goal.

Sam Pauly :

If we act now, what do you think the impact will be on the generations to come?

Prof Günther Deuschl:

My hope is that we have a development as we see it, for example, for stroke or for some other disease, like multiple sclerosis and that we really change the fate of a patient. That must be the ultimate goal of all our attempts. And I think we can reach that. It's different for different diseases. It is also very complicated for some it's easier for others. That would be the best outcome to see that patients live better.

Sam Pauly :

From all the work and research that you've both done, in a sort of bullets points, answer a kind of a wish-list, what would you say are the key priorities that we need to be addressing? Günther?

Prof Günther Deuschl:

There are so many keys to so many houses. Research is the key. And as soon as we have research for therapies, we can change things. That's what the history teaches us. So in that sense, research is really one of the key issues that I think we have to attack.

Sam Pauly :

Bill? Another key priority?

Prof William Carroll:

If you're looking at a disease process, then I would pick dementia and stroke because they're interdependent and have the same risk factors. So we get double effect for the same intervention. But if you look at the barrier side of it, the economics, the less well-off countries face is a huge barrier. If you look at the resources, the issue of manpower or neurological personnel power as important. So too is the cost of medication an enormous barrier. All of these issues have to be addressed. So I don't think there's any, as Günther alluded to, there's no one area that you can work on. There's a lot of areas that we have to work on. They are big issues, but big should never stop anybody from trying to solve them,

Sam Pauly :

Bringing all those issues together, as we finish, I would really love to hear from you both as a final word, what your hope and vision for the One Neurology initiative is? Bill, let me ask you that first.

Prof Günther Deuschl:

It's not a hope because I think it's happening. So I see this as another important part in the overall effort to raise awareness and to get momentum going to address this problem,

Sam Pauly :

And Günther, your vision for the One Neurology initiative, in a sentence?

Prof Günther Deuschl:

I mean, in addition to getting a good result for, having neurology as a priority, I think the initiative is also very good in a sense that it brings the key players together on an international level, on a national, on a regional level, it brings the patients and the physicians together. It brings the societies together. And I think that by itself is a very high value.

Sam Pauly :

Wonderful. Well, thank you both so much for joining us. It's been a really fascinating conversation. Thank you. Now time for our second in our series of audio diaries from people living with neurological disorders. Today, we hear from Elena Alexandra.

Elena Alexandra:

Hi, my name is Elena. I'm 26 years old, and I'm a patient with myasthenia gravis. My story begins in 2019, when I was diagnosed with myasthenia gravis, a neuromuscular and auto-immune condition that causes weakness in the skeletal muscles. At that time I was medical student and everything started suddenly. I had double-vision and a strong headache. I thought I was just exhausted from so many exams. The next day I realized that I couldn't move well anymore. I couldn't get up from the floor. I

couldn't chew or swallow easy. I went to the emergency room and I told them the symptoms and that I thought it might be myasthenia gravis or multiple sclerosis. They did not believe me initially. It was a bad experience. However, after three days I was finally diagnosed with this condition, myasthenia gravis, and then I did one month of hospitalization, even though I was used to illness and suffering because I was in medical school. I was so scared that I cried like a child. For seven days, I couldn't get out of bed to go to the toilet. I couldn't wash or comb my hair. And my mother helped me to drink water by raising my head. It was a shock for me. In the beginning, I couldn't accept that this is happening to me. I felt that all my dreams and hard work to become a doctor was gone. I thought that, that was the end, and there'll be a person with a disability. But it was different. The medical treatment received in the hospital helped me a lot. The medical staff encourage me so much as well as my family, my boyfriend, my friends, and they gave me all the reasons to fight for them, and for my dream to become a doctor. Two weeks after my discharge from the hospital, I started going to university again because I felt I was lagging with my internships, even though the doctors advise me to take a longer break for recovery. What did I do? I almost started a new life. I resetted everything. I completely changed my diet. Also, I started to think positive. I took yoga classes and I gave myself more time. At present, I can see that I live a normal life with ups and downs. But I manage to keep my condition under control and make progress in my career. Now, I understand differently the patients who are dealing with diseases. I understand the reactions and the fear they are going through. This is the reason that I tell my story, because I think it's time to act and to support more patients with neurologic conditions. In the future, I want that rare neurologic conditions to be better known so that patients can get a faster diagnosis. I hope that One Neurology initiative will help patients and will raise the alarm regarding the difficulties they face, related to diagnosis, treatment, or disease management.

Sam Pauly :

You're listening to the One Voice for Neurology podcast. And today we're talking about why now is the time to act together. Don't forget, we'd love you to join the discussion with us on Twitter. So you'll find us at @OneNeurology_ and we're using the hashtag #OneNeurology. Now, today, we wanted to focus on a disorder that has successfully positioned itself as a priority, find out why and what we can learn. Some listeners might even be surprised that this disorder is a neurological disorder. So I'm delighted now to be joined by professor Valerie Fagan from the World Stroke Organization, or WSO and from Auckland University of Technology and Dr. Hariklia Proios, President of Stroke Alliance for Europe, known as SAFE, Vice President of the Hellenic Alliance Action for Stroke and from the University of Macedonia, Greece. And Arlene Wilkie, Director General of SAFE and former chief executive officer of the Neurological Alliance. Thank you all for joining us today. Hariklia, let me start with you. And I know that you like to be called Harriet, so from now we'll call you Harriet. I wonder if some listeners might be surprised to here us talking about stroke in a neurology podcast. Does stroke often get misclassified and why is it a neurological disorder? What are the commonalities?

Dr Hariklia (Harriet) Proios:

Listeners may be surprised because it is true. Stroke was misclassified and it wasn't until the last decade, 2016, that the ICD, the International Classification of Disease, who moved stroke away from cardiovascular disease to cerebrovascular disease, and then to neurology. Stroke is neurological, because if you think about it, the end organ affected is the brain. Stroke results from either hemorrhage or from blocked vessels. While this is true that poor vascular health and the rest of the body increases the risk for stroke, stroke is like I said, a neurological disease because by definition, that brain is injured. Dr. Fisher had said we learn neurology stroke by stroke. What better example than that as neurology training programs place heavy emphasis on stroke, because there's so much to be learned about the

brain from stroke. As the second leading cause of death and the first of long-term disability, recognition and treatment of stroke is a big part of neurology and important for medicine in general. Effective care requires multidisciplinary care and attention to the long-term needs of all stroke patients.

Sam Pauly :

Arlene, how has stroke been successful in gaining awareness and recognition in the field of NCDs and how can other neurological disorders follow suit?

Arlene Wilkie:

There are several reasons for this. One is, there are a large number of people who suffer from a stroke in Europe, so I can talk from a European point of view. We know that in 2017, around 1.5 million people suffered a stroke. And we also know that because of stroke, we have around 9 million people living with strokes. So there is a large number of people. We also know that stroke is expensive. And we know in 2017 that the cost of stroke was around 60 billion, in a study that we carried out. If we do nothing to improve the stroke situation, this will increase to near 80 billion by 2030. So the figures are big. So that helps the stroke cause. From a medical point of view, it is preventable. We also know that it's treatable. So we know that if people suffer a stroke, or think they're having a stroke, the quicker they get to hospital, the less impact the stroke will have on their brain. So it's a condition that the medical world are interested in because they can treat it and they can prevent it. But also it's a condition that are policymakers are interested in because it's an expensive condition to treat. And so anything that we can do to reduce this, it's of interest to our policy makers, money talks. What other organizations and conditions may want to do is to think about how to build a strong advocacy support in your country, build strong groups, build them from that patient point of view: what do they want, what do they need? How can you work with your medical partners? What do you need to influence your policy makers? And we're possible, working in collaboration with, with other neurological conditions. If you can find common issues, we can work under the One Neurology voice for the patients.

Sam Pauly :

Valery, I know that you've developed a stroke riskometer app and the WHO defines prevention and treatment of stroke as a best buy. What does that mean? What's the evidence?

Prof. Valery Feigin :

Stroke is indeed the major contributor to deaths from neurological disorders. And two fold increase in the build-on from stroke globally in many countries, strongly suggest that currently use primary prevention, high cardiovascular disease strategy is not sufficiently working. And there is an urgent need to implement other more effective strategies that unlike high cardiovascular disease strategies would be free to use motivational, educational, evidence-based and available for everyone who has a smartphone or an internet connection. At this moment, there is only one app that meets all these requirements and internationally endorsed by all major organizations. The app has been developed and owned by our Oakland University of Technology, in 2014. It has estimated that about 700 million people living in remote areas of poor countries, our app actually could be the only reliable source of information about stroke, stroke risk factors, and how to avoid it. And stroke riskometer app could be the only available medical tool for this majority of people. Therefore, the global policy committee of the World Stroke Organization is convinced that this free stroke riskometer app must be urgently included in the essential or priority medical devices endorsed by the World health Organization. It would fit very nicely, as you mentioned, in the WHO best buy policy.

Sam Pauly :

Harriet, as we've heard already a little bit, clearly there is a major case for prevention in stroke, what's important when considering prevention and what can other neurological disorders and brain health learn from that?

Dr Hariklia (Harriet) Proios:

We know that the best treatment of brain disease is prevention. The good news is the advice for patients about addressing risk factors for stroke is also true for other cardiovascular diseases, but people should also know that strokes cannot only cause motor speech and visual deficits, they can also lead to other neurological problems, such as dementia and seizures. In the general population, epilepsy and dementia resulting from other causes are not preventable, but whereas, we can't clearly prevent dementia or epilepsy on their own, we can help prevent them as a consequence of stroke by decreasing the incidents of stroke. At the population level, we need to look at modifiable risk factors. These include lifestyle changes and training the general public about early detection of symptoms like we're doing now in our educational program, Fast One-One-Two heroes, where we're training even children as young as six years old, to identify stroke symptoms in their grandparents. We need to continue to create innovative ways to deliver widely low cost preventative approaches.

Sam Pauly :

Arlene, I know that SAFE has also a focus on life after stroke. What do you mean by that in terms of impact on the patients? And again, what are the commonalities that other disorders could learn from?

Arlene Wilkie:

I thought I would take the opportunity here, just to give you an example, from one of our stroke survivors who works very closely with us. So our stroke survivor, she was 22 when she had her stroke, she had to wait until she was almost unconscious before the hospital would admit her. After a week of an induced coma, she finally got the scans, which showed that she had large clots, which were the cause of her stroke and her paralysis. And it took five months of work before she could keep her first steps. Her stroke changed her life. She's now 49. And since that stroke, she has had ongoing issues with her movement, so needs continual physio support. She has speech issues as well, so needs to see a speech and language therapist. The stroke has had an impact on her mental health. She has had issues with intimacy and having relationships. She has had issues around going back to work. And of course that started with going back to education. So I think you can see that from this one story, stroke has a devastating impact on the individual, not just when they have the stroke, but after they have the stroke on the ongoing issues, people with stroke face. And I hope that we've given many examples here of situations, other neurological conditions and patients face the same issues. So this is what we mean by the life after stroke. The stroke happens, it's quick, but you may have tens and tens of years of your life still to live with the impact. So it's a great focus for the stroke Alliance for Europe is to make sure that yes, we get great care in hospital, but we must make sure that people live a great life after their stroke. So I think what SAFE is doing around raising the profile of life after stroke will not only impact on stroke survivors, but will also help improve the care for other neurological patients as well.

Sam Pauly :

Valery, how has stroke been approached at a global level and what impact does that have?

Prof. Valery Feigin :

Yes, that's a very good question. To be most effective and cost effective and have a largest effect on the population in terms of improving health, health preventative initiatives for stroke and other neurological disorders must be part of other prevention activities dealing with other major non-communicable disorders. And in this respect, interestingly, stroke riskometer app, maybe consider it as an integrative tool, because 17 risk factors included in the app are common for a range of other non-communicable disease orders, such as cardiovascular disease, diabetes, dementia, even subtypes of cancer. Therefore, World Stroke Organization started forming collaborations and alliances with whereas global NGOs, such as One Neurology partnership, NCD Alliance, Diabetes and global coalition for vascular prevention. Secondly, as stroke incidents is the most sensitive disease of all other neurological disorders to effective reduction of exposure, to risk factors, especially blood pressure and smoking in the first place, it would be very reasonable to use changes in stroke incidents and mortality rates as an indicator of effectiveness of the One Neurology initiative overall.

Sam Pauly :

Harriet, what are the main differences would you say in the way stroke is approached between European and national level? Are there any differences?

Dr Hariklia (Harriet) Proios:

Helping inequality, as we know, exist in Europe, along the pathway from healthcare access, access to services and community support, and these are not uniformly representative of certain demographics. We know for example, from SAFE that in Eastern European countries, priorities are different from West and North. And even within the regions of countries, where there is stroke registers or stroke units and community support, we need to have more ethnographic studies and that's true for all disorders, all neurological disorders.

Sam Pauly :

So finally, just to ask you all the One initiative isn't about replacing single disease initiatives, but complimenting them with a global Alliance to drive change. What outcomes would you hope for from a stroke and a neurological point of view? Arlene, let me start with you and maybe just in a couple of words.

Arlene Wilkie:

So from a stroke and neurological point of view, I think the One initiative is a fantastic initiative. It will help not only raise the profile of stroke and neurological conditions, it will raise profile of the prevention and treatment of these conditions, and also the gaps that exist. This will lead to greater awareness and focus not only at a global and European level, but also at that national and regional level, which will impact change and can only improve the outcomes for stroke and neurological patients.

Sam Pauly :

Valery, let me ask you the same question.

Prof. Valery Feigin :

We know that the incidence rates, mortality rates are going down except last few years. But overall they have reduced quite significantly, but the absolute number of people who are affected by stroke, disabled by stroke or die from stroke is increasing and increasing very fast. That's what I would like to see: reduction in the absolute number of people affected by stroke and trend downwards in that

reduction. And secondly, I would like to see equity in the health services among high-income countries and low and middle income countries. We know there are huge gaps in almost every aspect of care and community care, acute care, and we need to reduce that gap.

Sam Pauly :

And Harriet finally, let me ask you as well.

Dr Hariklia (Harriet) Proios:

We estimate there's going to be an increase about 30% growth in the number of people surviving their stroke until 2030. And because of the ageing population and combined with this economic burden that was mentioned earlier, stroke, we need to have national stroke plans in place in every European country. And this is where one global priority can really help in order to improve stroke care, we need to strengthen stroke survivor organizations throughout Europe and only with good communication and coalitions can we drive this change and build capacity.

Sam Pauly :

Well, thank you all so much for joining us and sharing your thoughts. Well, that's all that we have time for on today's episode, thank you to all of our guests, for sharing their experiences and for their insightful views. Don't forget, we'd love you to join the conversation on Twitter and share your voice or even better share a video. You'll find us at @OneNeurology_ using the hashtag #OneNeurology. We look forward to chatting there. Now do join us again for our next episode, episode number three, living with a neurological disorder, when we'll be hearing more about the challenges people living with disorders face and what commonalities there are as well as the wider impact those challenges can have. And we'll be looking forwards to find out how the one Neurology initiative could address some of those challenges and bring benefits and hope. I do hope you'll join us again. Thank you for listening to the One Voice from the Neurology podcast, produced on behalf of the European Federation of Neurological Associations and the European Academy of Neurology, the umbrella organizations, representing patient organizations and neurologists in Europe with active contribution from the European Brain Council produced and hosted by Sam Pauly.