

Sam Pauly: Welcome to the One Voice for Neurology podcast, a series of 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 in those living with a neurological disorder. I'm Sam Pauly, and you are listening to episode 14, zooming in on India, the importance of brain health.

Hello and a very warm welcome back to the One Voice for Neurology podcast. We're delighted to be back after our previous series of episodes during Brain Awareness Week in the spring. And of course since then, a major milestone has been achieved. The Intersectoral Global Action Plan on epilepsy and other neurological disorders was adopted at the 75th World Health Assembly in May. The Global Action Plan should have a positive impact on people living with neurological disorders and will address the worldwide challenges and gaps in providing care and services for people with epilepsy and other neurological disorders. It'll ensure a comprehensive coordinated response.

So in our two latest episodes, we want to focus on two areas of the world and look at the particular challenges that they face, how the I-GAP can be implemented and the impact that that could have. In our previous episode, we looked at Africa, but today we're focusing on India, a country with a population of just over 1.4 billion.

In today's episode, we'll be looking at neurological care and what level of access this huge population has to that care. We'll also be discussing care and neurological disorders across the life course from childhood to the elderly. And as we do that, we'll be discussing the impact that prioritizing brain Health could have. We'll also be hearing what it's really like to live with a neurological disorder. Later in the episode and as a first with a one Voice for Neurology podcast series, we'll be looking closely at pediatric neurology. We'll be exploring why to ensure a healthy neurology through the life course we need to consider and address developmental and childhood neurological issues. But first, let's focus on part of the life course where there is a large burden that is only set to increase the elderly.

You're listening to the One Voice for Neurology podcast with me, Sam Pauly. Joining me now to discuss the burden of neurological conditions in the elderly and the role of prevention and the brain health approach, I'm delighted to be joined by Dr. Bindu Menon, senior consultant neurologist and founder of the Dr. Bindu Menon Foundation, which focuses on awareness and reducing the treatment gap of neurological disorders across India. I'm also joined by Dr. Rajinder Dhamija, professor of neurology and director of the Institute of Human Behavior and Allied Sciences in New Delhi. Thank you both for joining the One Voice for Neurology podcast today.

Prof Rajinder D...: Thank you.

Dr Bindu Menon: Thank you, Sam.

Sam Pauly: Now before we start, just a quick reminder that accessibility is really important to the team here at the One Voice for Neurology podcast and that's why we transcribe all of our podcasts. So if you prefer, you can read along and if you can't see this transcript on the platform through which you're listening, then you can contact us at podcast@oneneurology.net. Now Bindu, to start us off, perhaps you could briefly explain the current situation in India in terms of the elderly population and neurological disorders.

Dr Bindu Menon: Thank you. Sam. India is a large country and we have a population of around 1.4 billion. And the serving neurologist for this large population is just around 2500 and which amounts and accounts to around one neurologist for a million people, I can say. And on top of that, the country is also passing through an unprecedented epidemiological transition. What I mean is that there's a change, there is a reason stride in the socioeconomic sphere. So there is a change from the communicable to the non-communicable diseases. Adding to that, the number of neurologists who are there are predominantly either in the metropolitan cities, the state capitals of the two-tire or the three-tire cities, and a very small proportion that is around two to 3% are there in the rural areas.

But the rural areas account for around, I should say around three-fourth of the country. So this demographic shift of aging population we are having as well as the epidemiological transition we are having, there needs to be a lot of neurological change and centers across the country, which needs to be in the setting that the NCDs are growing and we are seeing patients with stroke, epilepsy, Alzheimer's disease, dementia, as well as headaches coming and increasing in proportion.

Sam Pauly: And Rajinder, maybe just to pick up on one of the points that Bindu made, why are there so few neurologists?

Prof Rajinder D...: Thank you Sam for having us. It is an important question because of the large population and a small base of neurologists in practice in India. The numbers have traditionally been low because of the less number of available physicians in the country for medical education as well as for the neurology subspecialty in particular. But over the last few years, the numbers have been increasing, the numbers are likely to go up, but at the moment we are really short of neurologists as compared to the WHO standard numbers, less than one neurologist per 100,000 population, while required numbers are about 2.5 neurologists at least as in the western population.

To give the absolute numbers, the United States of America has about 3000 neurologists, a little more than 3000. India has also around the same numbers, 2500 to 3000, but the population of United States is one-fourth or one-third of India as compared to the landmass area and the numbers. So people who are aging now, we have 10% of the population over the age of 60 years, which is likely to increase to 20% in next 20 years. So the numbers are glaring at us. And

so are the neurodegenerative conditions like dementia, strokes, and all these conditions where we need long-term care.

Sam Pauly: Rajinder, when we're talking and looking at the picture of India, are there any particular neurological conditions that are particularly prevalent in India and that are quite specific to India in terms of that prevalence?

Prof Rajinder D...: Yes, I think when we're talking about stroke, the incidence and the prevalence of stroke is declining in the western countries, but in India it has doubled up in last one decade. So the burden is increasing in numbers. The other thing is that the stroke is happening in younger population in India. They get younger than the western population. The reason is because of the more prevalence of heart disease like rheumatic heart disease that predisposes to this too. So that's the other thing. And the obesity and the lifestyle factors, which population is now because of the economic transition becoming incidentally lifestyle. So that way, the numbers are increasing as compared to the west and that is something to be concerned about.

Sam Pauly: Bindu, are there any other disorders that you think would fit into that category?

Dr Bindu Menon: If you look at epilepsy, there are some forms of preventable epilepsies in the country and they account to a huge number as well, especially neurocystic psychosis, which is an infected form, just simple hand hygiene and taking care of the vegetables eating pattern can prevent that. Also, the number of road traffic accidents in the country is a huge number and the RTA, the road traffic accidents related and then the scar epilepsies which are there, that is also a huge number in the country. These are the preventable epilepsies which form a big percentage and we can work on them and see that at least these can come down to a market degree.

Sam Pauly: In a moment, we'll talk more about potential solutions for those challenges. And today we're mainly going to talk about neurology in the elderly. That's our focus. But of course, that's linked with adulthood before becoming elderly. What do we mean when we talk about the elderly? Bindu.

Dr Bindu Menon: Adulthood, I would say that it's a period in a human lifespan where there is a full physical and intellectual maturity a person has attained. And from there, from the adulthood based, it starts at around 20 years to 21 years. And from there, the middle-aged starts from around 40 years and it's followed by the old age at around 60 years. So there is a transition from an adulthood to a middle-aged to an older age and then to an elderly. And over this transition is where we need to take care of the neurological health because each one is indeed interlinked because what we sow, that we reap. So if you sow right probably in the adulthood, then you will reap wise in the elderly person.

Prof Rajinder D...: Just to add to what Dr. Bindu had just elaborated, India is going to have a huge numbers of not only elderly population, but these elderly people would have

diseases also which are related to the aging. So double whammy in one is that the numbers are increasing and the second is these people will be living with the neurological disorders in the future and we have to take care of these disorders in general.

Sam Pauly: So Rajinder, how important a role then is prevention? How important role could that play?

Prof Rajinder D...: Absolutely right Sam. These diseases, most of these diseases can be preventable, treatable. So obviously, we need to focus on prevention so that we have the less burden of disease and the prevention in terms of physical activity increasing in these individuals, whether it is exercising 30 minutes every day for five days or 10,000 steps as we recommend for these people to have that kind of activity. In addition to that, the mental activity increase in cognitive exercises or cognitive fitness that we are advocating to have a more cognitive reserve so that it can be taken care of in case there is a brain ill health.

And then of course, reducing the risk factors in the community like hypertension, diabetes, cholesterol, all these risk factors which are modifiable, that can be used to prevent the neurological disorders in addition to the proper retention to your sleep. So all these preventive factors are very, very crucial in improving the brain health in the communities and particularly with reference to the elderly population.

Sam Pauly: And Bindu, just a quick word on brain health because that's a term that we hear quite often. What do we mean about that when we say brain health and is that part of prevention? Is that something that could be key here?

Dr Bindu Menon: That's very important because a good brain health, we always say good cardiac health, all the other organs had a good healthy system. But brain's health is a state of a functioning where your memory, your sensory, your motor, your social, your emotional and also the way you behave, everything is allowing a person to realize that they have the full potential across the life course. And that is irrespective of whether the person has a disease or a person doesn't have a disease. And as Dr. Rajinder said, a lifestyle does make a lot of difference in that.

And why this is important across the life course is that the person's individual's nervous system's resilience is dependent, it's markedly affected by this environment and the circumstances during that infant or the child development and in the adult, that amount of resilience with the brain, the good brain which the person has, that particular brain is less vulnerable to a subsequent neurological disorder. So hence, we shouldn't be starting at probably at a middle age and I suppose the focus should start from the childhood and the adult where we have a nervous system, we have a brain, have a healthy brain which is resilient and can see that even if it gets diseased, the outcome, output, and a better prognosis is there for that particular person.

Sam Pauly: And Bindu, is there enough focus on the importance of prevention at the moment do you think?

Dr Bindu Menon: I would say yes. I suppose a lot is being done in the country as far as various schemes are concerned, especially in the rural sector as well. The government is tending to send out some vans where they check onto the primary prevention of hypertension, take a check on diabetes and give medications as well. So I suppose that lot is being done. I must say the public is taking the initiative and taking and utilizing the services is always questionable because of several other factors. And just to put a small word on that, the public as well as the policymaker should realize that the disability due to a nervous system disorder is extremely high unlike any other organ in the body. And that's where we probably need to put in our extra effort to see that disability comes down. So prevention is extremely crucial in such a setting.

Sam Pauly: And in terms of awareness that the public has, is there a disparity across the country in terms of the awareness of the importance of prevention in different parts of India perhaps?

Dr Bindu Menon: Yes. I would say that awareness about the disease are equally measurable we can say to the amount of education that that particular state has. If a particular state is low in its education level, they are still in the clutches of the old beliefs, the old stigmas, and the pattern of treatment that they have been following and they are unable to come out of that. So the education system is not there, the channels are not there, the newspapers are not there, the pamphlets are not there.

So there is no person who can guide them. But a state particularly where the education level is very good, the awareness of many particular diseases are good and the utilization of the medical services is also equal to that. So it is different across the various states. I particularly feel it'll depend upon the education level and also the policymakers who so are taking more initiatives in a particular place as far as health is concerned.

Sam Pauly: Well, we still have a lot to discuss, but first let's just take a moment to hear firsthand from someone living with a neurological disorder. Rammohan is living with Parkinson's disease and he sent us this diary from his home.

Rammohan: My name is Rammohan, I'm 68 years old, and I'm living in the state of the Andhra Pradesh in India. I'm a veteran and was associated with ship design, construction, and maintenance. My wife, mother-in-law, and I live together. I am affected with Parkinson's disease for the past five and a half years. In May 2017, my brother who's a pediatrician suspected that something was not right with me. A neurologist diagnosed that I was having Parkinson's disease. Until March 2020, I was not affected much by the disease except for a little slowing down of movements. In the core pandemic, significant deterioration took place in my condition.

The symptoms are difficulty in putting on or removal of clothes, constipation, filling of the legs, increased stiffness on the legs, handwriting became illegible. Slow down of reflex, difficulty in turning, and getting out of bed. In June 2021, I came to know about PDMDS Support Group in India and became a member. The group has helped me significantly. Every Saturday evening, Zoom meeting is conducted and once, physiotherapist, Dr. Shalini teaches us exercises, conducts brain games, discusses cognitive and noncognitive aspects, [inaudible 00:16:32] numbers. Participants exchange their experiences like a big family. The society has been human service to all the Parkinson's patients in India.

In my country, there is hardly any awareness of the disease. The challenge is faced by the patients. Specialized movement [inaudible 00:16:53] are very few and are limited to big cities. The public places are not much disabled-friendly, causing hardship to them and compelling them to stay at home. I hope in the near future, the awareness about this neurological problem increases and facilities for the movement and treatment of the patients improve.

Sam Pauly: Well, thank you so much Rammohan for sending that and great to hear that the support group is making a difference to you and other people living with Parkinson's disease.

Rajinder and Bindu. We've been talking today about the situation and challenges in India, in particular in terms of the growing burden of neurological disorders in the elderly. Let's turn our focus now to solutions. Rajinder, what would you like to be seeing being done in India in the approach to neurological disorders?

Prof Rajinder D...: Sam, a lot of things are being done in the last few years. We have seen the number of positions are increasing. Creating awareness is equally important as Dr. Bindu elaborated. So I think that we need to sensitize the policymakers, the public at large about the magnitude of the neurological burdens, how it can be prevented, and how we can improve or promote the brain health. So I would like to see more investment in public health, more investment in the health system improvement. At the moment, India is spending only 1% of its GDP in the public health. So we need to infuse more funds into the public health to improve the health system at large and provide almost all the districts, around 700 districts in India should have one neurologist at least in the public system in addition to the private hospital.

So, creating a neurological force in the public health system where the majority of the population would be the first visiting, that is important. Of course in addition to that, mass media and other players have to come and play a major role so that public as well as policymakers can join hands to create awareness about the brain health where we can focus on promotion, prevention, treatment and better outcome of the neurological disorders.

So we are all advocates, including the neurologists as well as the public, patients, and the caregivers, all have to come together to raise awareness for the brain health and investment in the brain.

Sam Pauly: Did you want to add anything to that? And in a moment, I just want to deep dive a bit further into specific services, but did you want to add anything to what Rajinder said?

Dr Bindu Menon: When we are trying to see that the neurological health has to be improved, the reasons are the non-availability of cares, inadequate health delivery system, the trained personnel as Dr. Rajinder has already said, and an absence of essential drugs. So an epilepsy if one can say that not one person with epilepsy should go untreated because of nonavailability of a drug, which is not an expensive drug if that comes to a rural sector, and so much funds need not be kept for that, only the willingness can be there and ensuring that it carries on. And also very important in India is that there is a prevalence of traditional beliefs and practices and one needs to break that and move out of it, which sometimes can be a difficult task but then it can be done.

Sam Pauly: How do you think it can be done?

Dr Bindu Menon: I personally feel that Sam, once we keep talking about something which has got a scientific relevance, perseverance is very important. Most of the times, we see that as neurologist, we go to a place, people might not believe, especially in the rural sector. But if we continue to go there and we touch lives, we give treatment to people and they themselves experience that there has been a person with epilepsy who is now on his feet and empowered with the medical treatment and not with another non-scientific way that they were treating, I think we can make a difference in that way. Doing is important.

Sam Pauly: And in terms of the services that are available to somebody who is living with a neurological disorder and that might be the initial diagnosis or the treatment and the care or rehabilitation or perhaps even palliative care, are there any particular areas in India where there are particular treatment gaps or access gaps? Rajinder, let me bring you back in.

Prof Rajinder D...: Yeah, I think three parts, the curative part and then the rehabilitation and the palliative. All three needs to be equally given importance. The focus is at the moment more on curative part. So the patient comes in the hospital, gets treatment for seven days, two weeks, and then goes back home and is left for family to take care of his palliative through all the rehabilitation. So the neuro rehabilitation is still in fancy in India. So we don't have many more structured neuro rehabilitation programs for these patients who are treated after strokes and the other neurodegenerative disorders.

So we need to focus on this criteria to make neuro rehabilitation available, accessible, and affordable for each patient who has neurological disorder. So

rehabilitation is one area which is really in a primitive stage in India and we need to improve on that. Similarly, neuro palliative is really not heard in many parts of the country and focus is cure, not care. So we want to give a total care in terms of improving equality of life and making them much more symptom-free. So that is where we would like to see the policymakers investing in these areas and neuro rehabilitation and neuro palliative, particularly when the neurological disorders are labeled as not only crippling the body but crippling the mind also. So we need to take care of the total care.

Sam Pauly: Let's talk a little bit more about policymakers as well because the Intersectoral Global Action Plan on epilepsy and other neurological disorders was adopted in May at the World Health Assembly. How important do you think that is going to be in India and how much of a help will that be to policymakers do you think, Bindu.

Dr Bindu Menon: I suppose this has come out as a fresh wave you know. How this is going to help us is that if you take India, there are several of us in different sectors scattered across working in a different way, different type module, and we all are trying to reach out and see that neurological burden is reduced. But everybody has got a different way of working. Everybody has got a different target and it's all scattered. We are making a change but then it's not being bundled into one core area.

Now this I-GAP probably we feel that there is a stimulus to coordinate efforts. So there would be a coordinated effort, there would be policies, there would be guidelines, there would be things in place and it's going to leverage a momentum, it's going to increase, that's going to advance. There would be some agenda that we would be following.

So we know that yes, I need to do this, there is a target and I need to achieve it. And probably we would be taking into this movement and several other neurologists who have the urge to do it but probably did not have the way and they did not have the path to follow it and this would be easier for them. So I think we would be working, the whole neurological community is now going to work together and I-GAP is really going to help us for that and we'd really look forward to have that policy in place.

Sam Pauly: And maybe if you could both, if there are policymakers listening today, maybe if you had a sentence or a short message for them, what would that be? Rajinder, I'll start with you and come back to you Bindu.

Prof Rajinder D...: I think Sam, I would like to add what Dr. Bindu said. The policymakers have already taken a note of this and the Government of India has already started deliberations. The meetings have already been taking place of all the states together about NCD and in particularly neurological disorders is now in focus. And I have been participant in these two meetings in last one month only. So I can say that there is a visible change in the mindset of the policymakers and

they have taken cognition of substantial rising burden of neurological disorders. And I would urge policymakers to invest in brain health, create centers of excellence in neurological disorders, not only at the national and the state level, but at the district level, invest in district hospitals, invest in infrastructure, and invest in neuro rehabilitation and neuro palliative care.

Sam Pauly: Bindu.

Dr Bindu Menon: Yeah, absolutely, Sam, what Dr. Rajinder says, I would probably go with that. It's basically one, the policymakers need to scale up the treatment coverages. So particularly, I would say the entry point of I-GAP is also epilepsy. One needs to scale up the treatment coverage in all the national schemes which are there, probably neurological disorders were left out. But then as I-GAP takes momentum and the government policies take momentum, these diseases can be involved. Once it is involved, automatically a lot of focus, a lot of awareness. Public also realizes because Sam, I suppose we forgot to mention that people, the public still feel that neurological disorders are incurable.

And that's where we have been having a big challenge because we know that now epilepsy can be controlled, a stroke in time can be cured in around 30 to 40%. We have treatments for that. Dementia if recognized earlier, we can go a long way. Parkinson's disease at every point of stage of the Parkinson's disease, there is a treatment available as also headache, migraines, everything. We need to invest our energy, the patients need to come in time. So this recognition, I suppose when the government takes in an effort, people recognize it better rather than we talking. So it's a teamwork.

Sam Pauly: And just to finish, and you've spoken about all sorts of different challenges in terms of the geographical urban rural divide, about the aging population. So there are lots of challenges there, but in terms of the work that's already being done and the work that's going to happen from the messages you've just given to policymakers in light of the I-GAP, how hopeful are you both feeling despite those challenges about the future of care of people living with neurological disorders in India? Rajinder, I'll come to you and then back to you Bindu.

Prof Rajinder D...: I'm quite positive and quite hopeful that this I-GAP will make a change and I would urge policymakers to take note of it seriously and make neurological treatments and the rehabilitation affordable, accessible, and available to each and every corner of the country and each and every individual who suffers from neurological disorders.

Sam Pauly: Indeed.

Dr Bindu Menon: Yes. Yes, Sam. I am also very, very positive because we have been falling short individually as at every personal level as neurologist, where the policy and the health system who was probably not in coordination with us, now we have them. So the policy and the health system and our personal level actions will

definitely help us to achieve a healthy aging across long life course. And it would be done, I suppose. I'm positive.

Sam Pauly: Well thank you very much for both of you for your time today. A huge amount to reflect on after our discussion. Thank you Dr. Menon and Dr. Dhamija for joining us.

Shortly we'll be finding out more about the importance of childhood neurological care within the whole life course. But first, Dr. Tarun Dua from the World Health Organization was kind enough to send us this message on the importance of prevention, protection, and promotion of brain health and across the life course.

Dr Tarun Dua: Hi, my name is Tarun Dua and I'm head of the Brain Health Unit in the World Health Organization headquarters. For WHO prevention, protection, and promotion of brain health is a priority. That is the reason the unit I lead is called the Brain Health Unit and that is also why WHO recently published the position paper titled as Optimizing Brain Health Across The Life Course. The position paper is important because it provides a definition of brain health as the state of brain functioning across different domains, allowing a person to realize their full potential over the life course irrespective of presence or absence of disorders.

It talks about the interactions between various clusters of determinants such as physical health, healthy environments, safety and security, learning and social connection, and access to quality services. Optimizing brain health improves mental health, physical health, and also creates positive social and economic impacts, all of which contribute to greater wellbeing and health-advanced society. The position paper is a compliment to the Intersectoral Global Action Plan on epilepsy and other neurological disorders. This was endorsed in May 2022 by all WHO member states.

This is an exciting and challenging era for neurology because the action plan provides the roadmap of strategic objectives and actions that countries, different stakeholders should be undertaking to address the burden that is due to neurological conditions. Let's all work together to achieve the ambitious targets outlined in this action plan. Thank you.

Sam Pauly: Thank you so much Dr. Tarun Dua for that message and update.

You're listening to the One Voice for Neurology podcast with me, Sam Pauly.

Earlier in the episode we looked at the burden and care of neurological disorders for the elderly in India, but could opportunities to lighten this burden be available earlier in the life course?

Well, to discuss this further, I'm delighted to welcome Dr. Ramla KM, neurodevelopmental pediatrician from Kerala, India. Ramla is also involved with

a number of projects and trusts, including being the founder of a project called HEE, Health Education and Environment, which focuses on brain health in children and climate change.

And Dr. Sameer Zuberi, consultant pediatric neurologist at the Royal Hospital for Children in Glasgow and honorary professor at the University of Glasgow. Sameer has longstanding connections with India, including that he's trained many child neurologists who now work in India. His family is also from the country. Dr. Ramla and Dr. Zuberi, a very warm welcome to you both.

Dr Sameer Zuber...: Thank you.

Dr Ramla KM: Thank you.

Sam Pauly: So let's start by having a little look at the kind of overall picture. Ramla, what would you say are the major challenges in pediatric neurology in India at the moment?

Dr Ramla KM: India has a population of 1.4 billion. Out of this, 444 million children are there. Two-thirds of them live in the rural areas. This is a huge challenge in itself and the burden of neurological disorders in India is enormous. Added with this, we have a large knowledge gap, a treatment gap, and there is a lot of diversity between the states. All that's supposed to be a large challenge to India, especially when the workforce and trained personnel is not sufficient for this large number.

Sam Pauly: And why isn't there a sufficient number of trained personnel now?

Dr Ramla KM: The number of the population is very high. So despite there being more than 500 medical colleges in India, you still find that the number of trained persons in neurology is less, especially in pediatric neurology because it is a newer subspecialty. You can say that it is still in its infancy but steadily growing. So, there are a lot of challenges, but opportunities exist too.

Sam Pauly: So before we sort of dive deeper into more of those challenges, can we just start by talking about prevention? How important a role can prevention play? Sameer, let me come to you and then Ramla I'll ask you afterwards.

Dr Sameer Zuber...: There are many neurological disorders that can be prevented through public health measures. We can think about prevention from antenatal care, the care of the mother to make sure that she's looked after well through pregnancy to minimize in utero infections, to promote nutrition for the baby and therefore brain development in the womb. And then when the baby's born, it's really important in that critical period that we can prevent through good obstetric care and antenatal care problems around the time of birth where children can have problems with lack of oxygen or difficulties with labor.

And then really critical is the issue of feeding of the newborn. So ensuring that the newborn also is breastfed. So encouraging breastfeeding is critical all around the world, particularly in countries such as India and in Pakistan because that promotes brain development and connectivity in the brain and then preventing infection, acquired brain injuries. So public health issues to keep children safe and preventing them from getting head injuries, whether that's playing in parks, whether that's road safety, there are many ways in which we can prevent acquired brain problems.

Sam Pauly: And which are some of the problems then that can be prevented?

Dr Sameer Zuber...: For example, there's a condition called meningitis where you get infection in the brain. There are now various immunizations that can prevent various types of meningitis. So ensuring that children have all the immunizations that are possible, just preventing general infections through good public health measures. Preventing infectious diseases can reduce brain inflammation and acquired brain injuries and certain types of cerebral palsy.

Sam Pauly: Ramla, those sorts of preventative approaches that Sameer was talking about. Are they being used enough?

Dr Ramla KM: India has several states and each state is sometimes as large as a country. So there's a lot of diversity between the states. There are certain states which have very strict immunization programs while in others it is not same. So even today you find that immunizations, which can prevent meningitis for example, it is still rampant in certain parts of India. And sanitary precautions, which has to be taken is not there in many states.

For example, if you're going to talk about epilepsy, 80% of epilepsy occurs in the developing countries. And India has a large number of children with epilepsy. And one of the leading cause of this is what is called neurocysticercosis. That is a tapeworm infection which can easily be prevented by awareness and simple measures like clean water sanitation.

Sam Pauly: Let's talk a little bit about these disparities because I feel like that's just absolutely fundamental in what we're talking about. It's the rural urban disparities I think as well as the state disparities. How can all of that be addressed? And we will talk more about solutions later. We'll also talk more about the I-GAP, but are there any kind of golden bullets for this issue of disparity?

Dr Ramla KM: India is a multicomunal, multicultural country and the literacy rate and the education level again differs from state to state. State policies also differ from state to state and there's a lot of misconceptions, taboos attached. And the latest adding to is the social media. There's a lot of information which is irrelevant and sometimes erroneous.

Dr Sameer Zuber...: Can I ask Ramla? So when you're thinking about erroneous information from social media, how do you as a pediatrician try and counteract that with your patients?

Dr Ramla KM: Sometimes they come to you asking the questions, sometimes they do not know. They just pass on the messages from one to another. Kerala is a very little state with almost 100% literacy. So it's very easy to deal here. And in fact, in fact in pockets where I work, it has become more difficult to explain to them why this is so. It depends on the regions and the level of understanding. I think understanding is very important, understanding of the right information and gaining the right knowledge.

Dr Sameer Zuber...: So I know that literacy varies a great deal between different states in India, I have a lot of experience of working also in Pakistan, particularly in Lahore, and you see how literacy varies between cities and rural areas. Are there ways in which you can promote education in neurological conditions without necessarily requiring families or patients to be able to read?

Dr Ramla KM: There's a lot of awareness created recently. Several state governments including the central government, certain NGOs, educational bodies, and even the public have involved themselves in creating awareness across the country.

Sam Pauly: And Sameer, let me ask you back, reflect that back to you then. In your experience in Pakistan, are there any methods that are being used?

Dr Sameer Zuber...: I know that particularly in epilepsy and I think epilepsy is an area where there is a lot of stigma and a lot of misunderstanding still all around the world in terms of causes and management. So there have been programs that the National Epilepsy Center based in Karachi have led on. For example, they involved a very famous Pakistani who ran the ED Foundation, who ran private ambulances through Pakistan. So he did a television campaign informing people that epilepsy was a real condition, that it could be treated, that people should go to their doctors, that it wasn't anything to do with what were called demonic possession or gins, which is sometimes thought of in parts of Pakistan. And I think that was very powerful, but there's still a lot more work to be done.

Sam Pauly: Well Sameer, you were mentioning awareness of epilepsy there. So this would be a good moment I think to take a break and hear from a young person living in India who's been living with epilepsy since he was two.

Let's hear Anzil's story.

Anzil: My name is Anzil Rahman. I live in a small town in the Nilgiri district of Tamil Nadu, India. I have completed my schooling and I just stepped into college in Arts and English literature. In my family, we four members, my father, my mother, and my brother. I have a disorder called epilepsy since the age of two and a half years old. My condition was diagnosed when I continue to show

abnormal moments of my limbs several times a week. The seizure occurs, has jerky moments especially of my hands. When this happens, I drop things. Sometimes I fall down. They occur suddenly when I get very stressed, very happy, or very sad. Sometimes it happens when I use a computer or a smartphone for a long period. After this I became unconscious for short period. It makes me feel weak for the whole day.

Epilepsy has affected me in many ways. I have felt that I was different from others. When seizures occurred at school, it made others look at me, it made me feel hurt and ashamed. But I got a lot of motivation and support from my school and parents. This made me feel better. Due to the epilepsy, my education was affected. I was unable to perform like other students. I also had difficulty remembering. I could not participate in certain activities, which made me feel sad. But because of the support I got, I was able to pass all my school exams.

For the past one and a half years, I have had no seizures. My life is almost normal now and I feel happy. There were many challenges to overcome. I realized that I have to continue medication daily though sometimes certain medication makes me feel weak for the whole day. My success was achieved by continuing medication, the psychological support I got from my family, friends, school, and doctors. Yes, I feel proud of myself. I would like others to know what it is to live with epilepsy and the difficulties and how they can cope with it and overcome it.

Sam Pauly: Thank you Anzil for sharing your story and many congratulations on your achievements.

Now, just before we heard from Anzil, Sameer, you said there's still a lot more work to be done. So let's talk about that. And I particularly want to talk about the Intersectoral Global Action Plan on epilepsy and other neurological disorders, sometimes called the I-GAP for short. Now equipped with that, what can policymakers do? What are the steps forward they can take? Particularly given the state system and the rural urban divide? Ramla.

Dr Ramla KM: India was one of the countries which has signed the path, so India's now willing to do it and quite a few states are willing to go ahead with the targets of the I-GAP and in fact they've asked for assistance in doing so.

Sam Pauly: And what would you like to see policymakers doing to address some of these challenges?

Dr Ramla KM: Policymakers are looking to the various aspects. For example, they're trying it with primary health centers. In fact, they're going to bring in more medicines to the primary health centers and they're training personal at different levels and also including a lot of awareness programs. All this together I think would help, especially when there is a single united voice to do so.

Dr Sameer Zuber...: One of the important things about the I-GAP is it is thinking about brain development throughout the life course and the life course begins in utero. So I think one of the important things in terms of policy is thinking about how this can affect not just neurologists or psychiatrists, but also influencing obstetric care, neonatal care for children as well and care within the community. One of the critical things as Ramla mentioned, is access to medications.

And I think this is really, really important because many of the medications, for example, for epilepsy are not necessarily expensive, but it's getting patients and developing pathways so that patients can see the right doctor who knows about the condition, who can diagnose epilepsy and give the person the right medication. So that's providing a pathway from maybe a rural health worker to a local doctor, to a more specialist doctor, to thinking about how those pathways can be developed in India and other countries.

Sam Pauly: You've just touched on it a little bit, Sameer there as well. Obviously in this episode we're also particularly focusing on brain health. What do we mean really by the concept of brain health and how does that play a role? Does that play a role in prevention or in protection or what do we mean? Sameer, let me come to you. And then Ramla.

Dr Sameer Zuber...: I think brain health is a very broad concept. As a neurologist, I'm biased. The brain is the most interesting organ and the most important and the brain is really the organ of learning and communication and it makes us who we are. So to have a healthy brain means that we're able to live a full life, that we're able to communicate, that we're able to learn, that we're able to move, that we're able to do all the basic activities that humans need to do to be part of a society. And that's not just diseases, but that's mental health as well and your ability to learn in school as well. So it's a very broad concept and therefore as we talk about health, we should not just be thinking about the services that the hospitals can provide, but also those additional services that schools may provide in terms of supporting children with brain illnesses and neurological disorders.

Sam Pauly: Ramla.

Dr Ramla KM: Emotional health is very important as part of the brain health also. And the other systems are very intricately linked to the brain. For example, the gut, the immunity, the mind, all together. So the brain is a very enormous pocket, a very expensive organ, and this itself translates to, healthy brain - we have a healthy economy and a healthy world.

Sam Pauly: And do you think this message of brain health is a message that's easier and more understandable to transmit in terms of raising awareness?

Dr Ramla KM: It depends again on the areas. There are certain places where the brain health itself, the term itself is played with misconceptions. What I actually observed is

it's very easy to make children understand. I've been working in schools for brain health and I've understood that they can understand things better. Simple things like proper sleep, diet, exercise either physical or mental, they're able to understand this and use this in their daily lives. And this again, is very important because the resilience of the adult brain depends on what the child brain was. So there are many factors, many sides to what is called brain health.

Sam Pauly: I want to pick up Ramla just a moment about that point about the childhood brain health in terms of the adult brain health, but just it makes me wonder as well if the younger people are more open to this education and better understanding it, do they have a role to play as a channel themselves in terms of their communities?

Dr Ramla KM: I think so. And in fact what have a service that schools are place where they are willing to learn, they're willing to think about things. And in fact, if you could include brain health as part of a curriculum, I think this personally, I think this would provide rich dividends in the future.

Sam Pauly: How much of a burden is created from children who are living with neurological conditions and that, I mean that's quite a broad question because that sort of looks at the children themselves, but also one therefore assumes that they could be living their whole life with their neurological condition and therefore, so how much of a burden Sameer, you are agreeing with.

Dr Sameer Zuber...: Yeah, I think we have to think about the burden on the child and the family. For the child themselves, obviously there's the illness which is often lifelong and many neurological disorders are chronic, and so there's a burden for that individual child, but there's also the burden on the family as well because many children require a great deal of care and often that burden particularly falls on the mother. That's the same all around the world. And we know that to lift up societies, the key thing is to empower women, that's basically the message that we've had all around the world.

And empowering women also means that allowing women to care for their children, but also access to employment and education and having a child with a neurological problem often limits that for many families. And we know throughout the world that if you have a child with a chronic neurological disorder, one or both parents typically either gives up their job or loses their job because they're caring for their child. So it has a significant economic impact on the family as well. So we have to think about the other resources that societies can provide to support children with neurological problems and their families.

Sam Pauly: And Ramla, those children then become adults living with neurological disorders as well.

Dr Ramla KM: Yes. So actually this translates a child with a disability has so many issues that translates to the family and into the society and into the country at large.

Sam Pauly: And do you think this burden could be lifted then by focusing on this message of prevention, protection, promotion through brain health?

Dr Ramla KM: Definitely. Prevention is a core aspect and protection of the brain and promotion of the right knowledge really does help.

Sam Pauly: We're nearly out of time, but I just want to ask you a couple more questions just very quickly. Sameer and then Ramla, what would your message be to give to policymakers, any policymakers that are listening here, what would you like to take away from our conversation? Sameer.

Dr Sameer Zuber...: Without healthy brains, we don't have a healthy society. If you want productive individuals, if you want people who can learn, contribute to society, then we all need to have healthy brains to promote the best possible education in society.

Sam Pauly: Ramla.

Dr Ramla KM: My message would be a healthy brain, we have a healthy world.

Sam Pauly: We've talked about a lot of the challenges, again, the rural-urban divide and the state divisions and the disparities. Given all of those things, the solutions, possible solutions we've talked about and the I-GAP, how hopeful are you both feeling for the future in India and the Indian subcontinent in terms of pediatric neurology? And how important maybe is the I-GAP in that. Ramla, let me come to you first.

Dr Ramla KM: Because of the awareness that has been created and especially with the I-GAP coming in, I think the future does hold hope.

Dr Sameer Zuber...: I would agree. I think it's really important. Often there's been a lot of focus on mental health, which is absolutely really important. But I think widening that out into brain health, thinking about brain diseases, illnesses, preventable genetic conditions as well is critical. And I think the WHO and countries who are supporting the I-GAP means that there's a potential policy framework moving forwards for the next 10 to 20 years.

Sam Pauly: And so you feel hopeful as well, Sameer, for the people actually living with the neurological conditions.

Dr Sameer Zuber...: Yes, yes. I have to feel hopeful. I have to feel hopeful. I know there's lots of challenges all around the world, but I think we have to feel hopeful and enthusiastic because if we can transmit our hope and enthusiasm to policymakers, that will be critical because I think policymakers want to make changes. They want to have an impact on their locality, their society, their country, their region. And I think if we can emphasize to them that making changes to the way children and adults with brain diseases are cared for, they can make a real impact on the society.

Sam Pauly: Well, thank you both. We'll leave it there. But thank you both so much for joining us today and for such an interesting discussion and we'll look forward to the future and what that holds.

Dr Ramla KM: Thank you.

Dr Sameer Zuber...: Thank you very much Sam and thank you Ramla for a great discussion.

Sam Pauly: Well, it's been really interesting to focus on India today. There are some clear and major challenges, but there's clearly commitment and passion to address those challenges. And the Intersectoral Global Action Plan could be a key driver in that. It was so interesting to hear that all of our interviewees were aligned on the importance of prevention, protection, and promotion of brain health, and we hope that that can be prioritized going forward.

Thank you once again to all of our guests today, and thank you to you for being with us and listening in. We have lots of episodes already available, so if you haven't already listened, do check in to those, especially our most recent one on Africa. Until next time, bye-bye.

You've been listening to the One Voice for Neurology podcast produced on behalf of One Neurology, a global partnership conceived by the European Federation of Neurological Associations, EFNA, and the European Academy of Neurology, EAN. The podcast was produced and hosted by Sam Pauly. Thank you for listening and join us again soon.