MND Matters: Episode 36: Driving change for the MND community

Richard

Hi I'm Richard Evans. I'm director of engagement for the Motor Neurone Disease Association, and welcome to MND Matters. Today we’re going to be talking to Tanya Curry, Chief Executive of the MND Association about our new annual report. And this is just a chance to take a step back and talk about how we’re doing as an organization, the impact we’ve made over 2025 and also about our plans for the future. So I will welcome Tanya and Tanya any reflections as we publish the annual report on the year that we've just had?

Tanya

I mean, Richard, you and I are both members of the leadership team here, and every year, I think even every meeting, we all sit there reflecting on how busy it is. I guess when you look at an annual report, you're really struck by how much we have achieved, and I have to say, I mean, probably like yourself, I feel hugely proud, and I know from sitting in our meetings how ambitious we are as a team actually, and want to keep doing more and more for our community. But we also know there's some challenges around that, and it's not always as easy as we'd like to think it could be, but we've done so much, and that has really shown us from the last few years how much this organisation is growing and changing, and we have a few growing pains along the way, don't we? You know, that's not been easy, but when I look at where we've come from, where we are now, and what our strategy is going to be doing for us, that feels really exciting.

Richard

When we hear about the things that we are delivering, I think we gave more grants to more people. I think over 7000 people benefited from the grants, over 3 million pounds. You know that that is money that's making a real difference to people who we know all too well that MND is a massive financial challenge, as well as a health one. We're funding more research than we than we ever have done, and just the amount of research that's going on is just hugely exciting. I guess in my area, I joined part way through 2024 I joined at the at the end of April. But one of the really real things that the first things that we did as a team was tofersen campaign, where, for those who don't, tofersen is a treatment that for most people, it won't work because it's only works if you're one of the 2% who's got a particular genetic change, but for those people, actually, it can be the real game changer we've always been hoping for. And managing to get the National Institute for Health and Care Excellence to change their mind on how they were going to assessing it. It doesn't mean we're going to get the result we want, but it definitely has weighted the odds in our favour, and that for me, I think, was one of the big moments of the year that getting them to change their mind, yeah, we don't want to count our chickens, but there is a real hope that it that if we can get it over the line, then then actually, that's going to really save people's lives, in a way that that when, when we started the campaign, actually, it looked like it was really stuck, and we couldn't really see a way of getting it through the NICE process. So it's at least given a glimmer of hope. And that, for me, was one of the big things of the year, I think.

Tanya
I think that is such a brilliant highlight. And the thing people won't see and won't know from this organisation is probably three, four years ago, we never would have tried something like that. I remember when I started here.I remember someone talking to me about our organisation can be very slow and very risk averse, and actually people with MND have not got time for us to behave like that, because there is an urgency that the organisation has to match. You know, that people have with this horrific disease, and I think you know, I totally applaud and support you and the team for what you did with that campaign. And yes, it's not the slam dunk at the moment, and there's still more work to do, but actually, we've lifted our heads up and we found our voice that I think we probably hadn't done in the past, which felt so important.

You know you reference the grant programme, which is just amazing. We get so much positive feedback on what we're doing for people, but it's also how we talk to our MPs about that behind the scenes, how we have some quieter conversations to try and move things forward. It's not always about shouting really loudly as an organisation on everything, you've got to have a kind of multi-faceted campaign, and I think that's what we try and do. I think one of the highlights for me, actually, and I only sat in a meeting about this last week, was about our research nurse proposal. I remember the team really kind of looking at me like I'd lost the plot when we talked about, you know, we need to, we need to launch research nurses. Because I was hearing repeatedly from people with MND, they would go into a clinic, they would have their consultation with their consultant. There wasn't any option for research put in front of them. And actually we need someone that's going to really fight the corner, for the person with MND, and actually show them what could be possible, to actually give hope for the future and allow people to have a bit of control at such a devastating time. So actually, to be in a meeting to hear we've got potentially 18 research nurses being discussed in the pipeline, and will be coming on board. That was a little bit of a kind of spine-tingling moment of okay, so the crazy idea over a coffee when I was at the symposium a few years ago actually is actually coming a reality now, and it will make a positive difference.

Richard
I was talking to someone with MND who was saying that they wanted to be involved in research, not necessarily because they had hoped that it would be the game changer for them, but because they thought, well, let's try and make some tiny positive out of what's happened so that at least science can learn from that person's experience. And you know the frustrating feeling not to be able to get onto a

research programme or a clinical trial, almost felt like the door has been slammed in his face. So anything that helps us sort of open that door, I think, is just going to be really important. I think, you know, the research nurses will really, again, be up taking, taking us up to that next level. One of my first experiences here was, was the regional road shows we did in 2024 and it was like it was, it was completely luck, but you couldn't have prepared a better induction in terms of going around the country, meeting our community. And I think one of the things that really came across to me was that there was a lot of real positivity about how we were coming across. So people talked about how dedicated we were, how knowledgeable, how compassionate, and, you know, really valued those things and really get gave me the sense that I joined somewhere really, really special. But there was also a thing that people said, and it came up enough times that I thought, well, this isn't just a coincidence that that actually sometimes we do lack that, that sense of of urgency, as you said earlier, about the urgency that people feel, and a sense of really shifting away the bureaucracy and just saying, let's just get on with it. And I think a part of the thing that you know, I've been working on behind the scenes, and I think we're starting to see come to fruition, is that sense of of actually wanting to act with an urgency that matches what our community needs of us. And I think, as we've developed in the year, and we'll keep continuing developing this, that's something we need to see more and more because, because, as you say, it's not just about the impact you live today. It's about how you're making sure that the charity is something that's going to be there for the long term and be a bit be match fit, if you like, to be able to deliver people.

Tanya
Yeah, absolutely. And I hear exactly the same. And I think we are making some really good strides into a future where we are bigger and stronger and more active, actually, for our community. I mean, we're a national charity, aren't we? We have about 250 staff at the moment, 1000s and 1000s of volunteers, and everyone is out there doing their bit. And it's all the doing those bits that make a massive difference to the whole but I know as leaders, we want to lead a charity that is really making a difference doing the right things at the right time and really carefully considering them. But I know you know, we were so fortunate when Rob Burrow and his family kind of really shared their experience with the MND community. And before that, obviously Doddie Weir, I think it put MND on the map for people. And on the back of that, we had a huge amount of profile-raising moments for this organisation and a brilliant amount of donations. And when you think about the size of this organisation. I mean, it's doubled, probably tripled, actually, in a short number of years, and we have good amounts of reserves in the bank, which is great, but actually we need to work up plans, which we have been doing, and work as a really strong, ethical charity with real integrity about how we spend those. And doing that well and doing it wisely and not making crazy decisions just on the hoof for the community feel like a really important part of our leadership with ELT and the board

And when I look at research, I mean we come out of meetings where we hear there are so many research applications now, and we want to do more, and we want to make sure that we can actually fund that we're in a position where we're starting to do that, but these things do take a bit of time to come through the system. You know, you and I would love just to turn the tap on and make that difference overnight, but you can't always do that. But I think with the research avenue, with driving our grants, with really making sure we've got people properly cemented at the heart of this organisation, leading decisions based on their experience, living with MND or supporting with MND feels really important to me. And actually I'm seeing that in loads of aspects now of what we're doing, which is brilliant.

Richard
Yeah, and you mentioned the 40, just over 40 million we raised last year. We talked about sort of the year we've had with without even mentioning that. But actually that is a historic year like and if you look at last year, we were thinking, Gosh, we've really hit a high there, and we've gone up since then. And it just shows the the amazing work of the income generation team, but but more importantly, the amazing work and generosity of the whole community and actually the whole country. You know, you hear these amazing stories of of people who have been inspired by the stories that they've heard and it's just incredible that it's that it's given us an income is a platform for us to make even more difference. You can see that with the grants that we're giving out. The only reason we're able to give out that level of grants and make that level of difference is because people, the generosity of people right across the country. It's awe inspiring, really, isn't it?

Tanya
Yeah, it's huge. But we have a job to do that really well. And with the reserves, you know, you want to make sure that you're planning to spend them in a good way that are actually going to demonstrate impact for the community. So we're doing a lot of work now on how do we actually spend that money, and how do we talk to the public about that. And how do we make sure that we're giving the assurance that that's having maximum impact and return on investment for the community. Because we're a cause driven organisation, it's what we need to do. And that feels exciting. It feels challenging. You know, the organisation has grown in income, but actually it hadn't really grown purposefully in terms of its structure and its way of working. So we've had some growing pains, haven't we, over the last few years, and some of that's not always easy to deal with, because you're trying to right size teams and actually change the culture of this organisation to be different yet really fit for the future. And our job as leaders is to make sure that we're really looking for the future. And I'm not just planning for the here and now or the next year. I'm planning for the next five and 10 years, looking at what do we think MND is going to do over that time, and actually, how are we as a charity going to make sure we're leading the charge really well for the people that have got this disease.

Richard
And I guess it in any organisation that grows from 20 million to 40 million, that that involves changing the sort of organisation you are. It just takes a different approach. And I guess a lot of organisations have gone through that growth. Probably quite, few have gone through it that quickly. So we chasing to catch up in terms of, in terms of making sure that the governance, that the structure we’ve got in place, are able to deliver what we need to deliver, and that and some of that background work is is as important for making us match fit for the future and some of the impact work that's delivering impact today, I think.

Tanya
Yeah, and it's such a gift, isn't it, when you've got income that's come in at that level, and it's a real opportunity. But my goodness, aren't the shoulders heavy because you want to make sure you do the

right thing? I remember a few years ago, working in a different organisation, where they almost had another 15 million pounds overnight. And quite rightly, the public look in on that and go, wow, that is absolutely fantastic, and it is fantastic, but we want to be in a position to make sure we've got plans in our strategy to spend money really, really well and do it in the right areas. So you're not just, oh, let's put a million over here and three over here. It's got to be totally linked to strategy, which we've worked hard on, to make sure that's led by our community. And I feel comfortable, you know? I feel comfortable with we've got those plans in place now.

Richard
And I think whenever we spend a pound, we always just need to remember that actually that's someone's money, a lot of people who wouldn't have a lot of money themselves given that, and we need to make sure we're spending it well. So you mention reserves, I should just explain that every charity is expected to have a level of reserves, money in the bank or assets that are enough to keep them running for a few months in the event of a rainy day. Now an organisation our size, we think the right level of reserves are around £23 million but because we've had successive years of higher income because of the amazing efforts of our fundraisers, that's actually increased over the past few years and now stands, our unrestricted reserves stand at £42 million. Now that's higher than we would ideally like it to be because we want that money to be having an impact for our community, but we're in a position now where we've got a strategy and we're really confident we know how to spend that money the way that's going to make the biggest possible difference for people affected by MND.

Tanya
Yeah, and we've got plans to spend it. It's not just sitting there with no planning behind it. So bigger research investment, there's some big prizes that we want to kind of put our money into over the coming years. Even the research nurse network, it's growing, it's going to be bigger, I think, than what we anticipated. Actually, our grant, you know, capability needs to be bigger. How much we're committing to our partners in the NHS and other organisations is all growing. So we're on a really strong area of growth here. But it's my job, our job, and the board's job to make sure that we're doing that well, and we're led by evidence and we're led by data, and I feel really comfortable that we are, but with a five year strategy to know we've got the spend plan alongside that. Actually, that's a real gift as a chief exec, but you also need that money to keep coming in. You know, this isn't we've got the money in the bank so everyone can take their foot off the pedal for a while. There is more to do. We're an ambitious organisation, and I want to keep that drive going forward.

Richard
And you mentioned prizes. We're literally funding the Longitude Prize, and we're the main funder of the Longitude Prize, which is just a hugely exciting thing, something that we've never done before. It's sort of a global prize where teams of researchers around the world can enter it, and it's a way of just getting different thinking, different brains into looking for that effective treatment that we all want to see. And we wouldn't have been able to fund a big thing like that, without that increase in income that we've seen. So a really good example, I think, of just how we're how that income increase that the community has jointly collected, it actually just allows us to go to the next level of developing that impact.

Tanya

Yeah, massively, Richard and it just gives us different opportunities than we ever would have had before. And when we when we hear Mike, our Director of Research and Innovation talk, and when we hear Brian, our Chief Scientist talk, actually, the landscape is really changing in MND research, and it's lovely when Mike comes to a meeting going, I've got 20 things that I really want us to be able to fund, and for us to know that we could fund those if they're the right things, that's different to where we were even a few years ago. And we've got to kind of be able to look across that whole international landscape and understand where the best research is happening and how we can influence that, and how we can make things right for the UK in all of that. So actually having all those opportunities and the financial backing to support those opportunities is a great position for us to be in, but we're only in that position because the MND community and all of our supporters have made that happen for us.

Richard
And we talk about the strategy. So if people listening are sort of saying, well, what's going to be different over the next five years compared to the last five. What will people notice that's different as a result of our strategy?

Tanya
I think they will see the ambition really coming through this organisation. Um, there's a hunch for me that there are probably more people with MND than we really think at the moment. That means there are more families and more people connected. And we need to do more for those people. We need to make sure our services that we deliver are really shored up. I'd like a bigger grants programme. The research nurses are going to be absolutely key. We want to make sure we've got all the right infrastructure into those care centres and networks, because that's where people go for their support, and actually making sure that all of our volunteers are trained, supported, given all the tools they need to do because they're supporting people with MND and their families on the ground. So we want to see all of that.

I guess an area that you might want to talk about is the influencing work and how we want to do that differently. Because I think a lot of that will be driven now from our refined culture and how we want to work differently as an organisation, but actually having our voice out there and being round the table to influence some of these key people when they're making decisions that are coming out of the NHS or government. That feels really different for us, but something I guess the public might not see.

Richard
Yeah, and I think you know, we've, we've often, or in the past, had really good relationships with MPs, with policy makers, but I think one of the changes that we're trying to make is to really focus on a smaller number of policy areas that we really think by pushing them, by focusing on them, we can really make the difference. So we're going to be looking at things like home adaptations, which we people when you meet, when you meet people it's really clear that it holds people back in terms of living, living as meaningful a life as possible when they've gone got MND here we saw it in the Coronation Street storyline. It was brilliant that they sort of highlighted that as an issue. And actually, it's just completely unacceptable that people, people aren't able to get the home adaptation they need, and particularly when they need it. So so we're really going to be campaigning on that.

Tanya
On a national level. I think it's really important to say that sorry to interrupt you, but you know, we've done quite a bit of that work on local level with local councils, but actually we're seeing this as a national challenge, and actually as the charity for people with MND, we want to make a difference on that, don't we, so it's using our voice in a bigger way.

Richard
And louder and more urgent. I think it goes back to what I was saying about what the message I got from the community when I went to the road shows that that real sense that they are feeling this every day, people are experiencing living in a home without the adaptations, and they need to see us out there really, really making a noise about it, making sure that we're raising awareness of it, making sure that we're, we're banging on the doors of policymakers in a way that perhaps we did a bit tentatively in the past, and now, now with more of a thump, I think, is what we what we want to be, want to be doing, and, and, and really focused on, on the end goal, like, I think, as a policy sort of focused organisation, sometimes it can be about sort of raising awareness, and about which is important, but actually we really want to be be demanding change and and we've got a really good case to make, and it's important we make it urgently, I think.

Tanya
And what about the whole kind of access to treatment agenda? Because I remember joining the organisation a couple of years ago, and it was only just starting to emerge that there may be other drugs coming through the research pipeline that actually our community felt they want access to if we're going to get some game changing opportunities here, I think we have shown we're starting to work very differently in that space, but I'm guessing there's more to come.

Richard
Yeah, and, and I think it's a sign that the fact that we've only had riluzole until very recently shows that as a charity, access to medicines hadn't really been an issue we've been thinking about in the same way as a lot of cancer charities, for example, think about because there are those treatments coming online. So the fact that we are now going from not having that to actually this being an important part of our work, is a sign that actually the research is starting to pay dividends. But there's no point doing brilliant research that leads to leads to new treatments if actually you don't, then aren’t able to get them on the NHS. And I think we had a real great bit of a great start to the work in terms of tofersen campaign, because a lot of organisations try and influence the National Institute for Health and Care Excellence, and it can be really, really difficult, because rightly, they are sort of slightly arm's length from government, because they don't want the day to day of politics to sort of influence their decisions. But I think we made a really powerful case and a really strong case in the community and together. And I think for us, our approach is probably a microcosm of how we want our overall campaigning approach to be, to talk loudly, but also to maintain those relationships with NICE and not to stop talking to them privately, just because we're making the making the public, public noise about it, and that seemed to really pay dividends. But then it doesn't stop there. As I say, they've just changed the way that they're going to be assessing it. They haven't made the decision. So now that, from that perspective, that the work begins to in terms of making sure we're influencing the actual approval process, making sure that

people with MND, who've got this genetic change that means that they could benefit from tofersen, and they're actually having their voice heard as part of that, that we can play a really crucial role in that. And then while we're waiting for that, we're we're we've brought sort of almost a part two of the campaign where, where the drug company is giving it to people for free at the moment, while it's going through the process. We're hearing that there are some people who aren't able to access that just because of the cost of administering it, which, the fact that that some people are getting it, some people aren't is just awful. And so we're now trying to raise, raise that with government trying to make sure they're aware of it so that they could because it's so obviously unacceptable that there are people who could literally be dying as a result of not being able to access what is a drug that has been given to the NHS for free. So, again, that's all part of that, that urgent approach that really reflects the fact that people with MND don't have time for us to wait, don't have time for us to develop long plans we need, we need to get on and we need to we need to get the change we need to see now.

Tanya
And it's just not acceptable, you know, and it's things like that that we're seeing as a charity. And I think the difference now is we are standing up, going, this is not good enough, and it's not okay, and it's our job to kind of fight the fight with the community. So I think there's lots going on. I think as well with the NHS, you know, they are under huge pressure. There are so many changes that I think are going to be coming down the line, and we're waiting to hear about the 10 year plan, and then we as a charity, have got to think about how we respond to that and how we support our community. And do we need to have the agility in our strategy to turn on a sixpence if we need to? Yes, we do, but again, it has to be through good discussions and good decision making. But I also want to be running an organisation that has the ability to flex and change. And it's not like turning the Titanic every time you want to do something differently. And I think with all the research happening, we are going to see new opportunities and new ways of trying things, in repurposing drugs, in precision medicine, that are going to mean that we've got to learn and operate in a slightly different way to keep up with all of that. And I guess, not only keep up with it, but be more on the front foot. So that feels really challenging, and I think that's going to challenge us, but it feels really exciting. And actually, if we're not doing it, who is doing it? We should be doing that for people with MND.

Richard
And for me that is a crucial thing. And I think while we're focused on the impact that we want to have over the strategy, actually, that all depends on on how we perform as an organisation, and how the community keeps raising money. And I think one of my my fears, I suppose, is that we've seen quite a lot of charities have had a lot of media focus over a short period of time, and they and they generate lots more money, and then actually, that goes away again as they go out of the spotlight. And I guess my worry is that if we sort of, if we don't manage this opportunity as well as we can, the same thing could happen to us and it would be an absolute tragedy if we, if we were to go back to being a sort of a an organisation raising less than 20 million pounds, not because money is important in its own right, but it is the is the sort of lifeblood of what we need to be able to do the work that is making the difference and funding the research that hopefully is going to lead to to those new treatments. And so a really crucial part of the strategy is making sure that we don't just stick with the 40 million that we've got, but actually we step on to the next stage. I often talk to my team and say, let's not make this, this 40 million

pound a sort of a peak that we descend from, but actually, let's make it a base camp that we continue to climb from and I know that the fundraising team are really focused on not just making the most of the public interest at the moment, but actually putting in place those foundations that meanwe can predict that we're going to be getting that money year in year out, to make the maximum long term impact, as you say, we need to be here for the next year or two years, but for the next 5,10, even, even beyond that, to make sure that people are getting the support they need, but also that we're able to push the research agenda forward so that we get those treatments that you know that can can make it more a more livable condition that it is at the moment.

Tanya
Yeah, and one of the first conversations I had when I came into this organisation was how much kind of choice and control did people with MND really have? And the answer was not very much actually. And we want to be in a position where people do have choices about how they manage their diagnosis, how they actually want to manage treatment options, because then people are in control of their disease, and actually that's a much better place to be in the driving seat and making those decisions. But as an organisation, we also want to have choice, and we want to be purposeful, and we want to plan very well, and I think there are still options for us in terms of growth and what more we can do. I think the community probably needs us more than ever, if I'm honest, and that takes time and resources and money to make all of that happen. Our job is to make sure that we're spending it on the right things in the right way, right time, and doing things that really make a difference for people and what they need. And actually, we want to be leaders of this organisation that really do that, because that's the legacy we leave, you know, when we move on and making sure this organisation is absolutely match fit and ready for the future feels where we're heading. So that's good.

Richard
I'll just end by so if you got that one word, you would sort of say how you feeling about the organisation now, and one word you hope it is in the future, sorry to put you on the spot!

Tanya
No. And, you know, I can never do one word. I just I feel really inspired, if I'm honest, we had our leadership team meeting this morning, but I reflected on the conversation that I started this podcast with about research nurses and how I was so proud in a call last week to hear there were 18 coming online, and I the team laugh at me when I have these crazy ideas and go, let's just make it happen. But I kind of felt proud I'd had that one crazy idea. So I think there's lots of hope for the future. Thank you.

Richard
Thanks Tanya, and thank you everyone for for listening. I hope that's been useful. And, and, but here's the next few years and, and as Tanya says, we were not going to be able to do that without the whole community. So I just really encourage you to get involved, whether it's volunteering, making a difference in that way, whether it's fundraising, whether it's campaigning, there's there's lots of, lots of ways everyone in the community get involved in and we’ll only be as strong as the as the collective group of people that we are so so thank you for everything you do, and thank you for listening.