

## MND Matters: Episode 10: International Symposium

**Intro:** You're listening to MND Matters, a podcast from the MND Association.

**Nick:** Welcome to MND Matters, brought to you by the MND Association. Alongside, members of the MND community, we bring stories, information and expertise direct to your ears. Remember to subscribe to ensure you don't miss an episode.

I'm Nick and I'm the Head of Research Development at the MND Association.

I am currently on the set of our 32<sup>nd</sup> International Symposium on ALS / MND, a conference we hold every year bringing together MND researchers and healthcare professionals from across the world. This year, like last year, is slightly different as our Symposium is once again virtual.

In this episode of MND Matters, we'll discuss what the Symposium is, its history, what it means for MND research and talk to some of the key people that make it happen. I'm here with Dr Brian Dickie, the MND Association's Director of Research Development. He's been at the Association for over 25 years, organising and attending many Symposia. Brian, could you tell us a little bit about the history of the Symposium and why it started.

**Brian:** Well Nick, the Symposium pre-dates even me, of course. It started about 32 years ago and it originated in a hotel in Solihull, which is on the outskirts of Birmingham, and we believe there were around 44 delegates attended so it was small numbers but there was a clear need for more communication between neurologists, healthcare professionals and researchers who at that point were in small numbers but scattered across the world. One of the neurologists who attended that first meeting actually says it was a little bit rough and ready, for example, we hadn't actually organised lunches so we actually had to go to the newsagents across the road for chocolate bars and crisps and, obviously, it's grown tremendously since then.

**Nick:** And could you just put a bit more colour onto that? How has it developed since?

**Brian:** An obvious way is in numbers, you know. We have 1,300 people attended the last on site meeting, we've had over 1,500 attended this year's online event, and it really parallels I think the huge rise in research activity across the world. One of the things we have noticed is, of course, as we learn more about this disease, we learn how complicated it is, but one of the advantages is that we're drawing in new researchers all the time with expertise in a whole range of different areas. So from other neurodegenerative diseases but also from the cancer field, from the diabetes field and, really, I think, you know, MND / ALS has become such a hot topic. It's moved over the past 2 decades from what I would have called a scientific backwater to really the forefront of neurodegenerative disease research.

One of the barometers for me for the importance of the Symposium, certainly in respect to the development of treatments, is the number of delegates with drug company names on their badges and we've seen that increasing year on year on year. And, you know, drug companies, yes of course they want to make the world a better place, but they also want to sell drugs to keep their shareholders happy and the fact that an increasing number of companies are coming into this field is because they think this is a tractable disease and that's got to be a good thing.

**Nick:** So, do you think our Symposium has made a difference to MND research and care?

**Brian:** I'd like to think so because it's a lot of hard work to put on but, you know, let me give you one example. So, many years ago, I think it was the Symposium we held in Chicago, where the ALS

Association and ourselves booked a room and we got some of the leading genetic researchers round a table together, and they'd all tended to operate in silos before that point, and they agreed that they would work together, they'd share their samples, initially focussing on familial MND. But out of that came the seeds of the Project MinE initiative, the worlds' biggest genetic research programme for any disease which now involves 21 countries I believe it is across the world. So, the seeds of that can be traced back to the International Symposium and that's a visible example but, you know, the Symposium is like an iceberg, 90% of the activity occurs outside of the lecture hall. It's in the coffee breaks, it's at the lunches, it's in the bars and that's where the new ideas are exchanged, the new collaborations are formed and, you know, if we're going to crack this disease, we've got to do it collaboratively.

**Nick:** And is the Symposium something that you're very proud of?

**Brian:** Yes, I am proud of it because it's a lot of hard work to put on. I have a great team that puts a lot of effort into making this 4 day event happen every year including your goodself, of course, Nick.

**Nick:** So, this is the second year we've run the event virtually and we've really tried hard to capture some of that networking and those collaborations that happen in the Symposium. Do you think we've achieved that?

**Brian:** I think we have to a degree. I think one of the great things about going online is it's more accessible and we've seen that in the increased numbers and the increased number of countries that are able to participate in this event, but there is probably something that is lost and, you know, if you attend the poster session for example at an onsite event, there's a palpable buzz. You can feel the atmosphere, the excitement. Particularly I think it's important for young investigators who are presenting their work. I remember when I was a young researcher doing my PhD and one of these Gods of the field came over and started asking me questions, you know, I was on an absolute high and, you know, that just increased my enthusiasm for the work I was doing. And so, you know, I think the face to face event isn't just important for the senior researchers but it's absolutely vital for the junior researchers because, of course, they're the ones who are going to come through and be the leaders of tomorrow and hopefully lead us to effective treatments for this disease.

**Nick:** That's right. And where do you see us next year?

**Brian:** I hopefully see us in San Diego doing a face-to-face event. We will try and incorporate some of the elements of the virtual world. We clearly can't do everything - for a start, some of it would be very financially prohibitive and we are a charity, but we'll certainly see if we can try to pull together a hybrid event that, hopefully, ticks as many boxes as possible.

**Nick:** Sally Light, the Chief Executive of the MND Association, opened this year's Symposium. She joins me now. Sally, what does the Symposium mean to you?

**Sally:** Well, the Symposium is just one of the biggest highlights of the year isn't it? It's just an incredible opportunity to bring researchers and clinical staff from right across the world together to share best practice and up to date research, information and knowledge. I think the important thing for me is, of course, the information that's put across and the platform presentations but, more importantly than that, it's the human connections that are made. It's listening to people talking about collaborating, sharing data and just bringing their research together where there are connections and it really is all about those interpersonal relationships that are built at the Symposium and you see that happening every year. I've been to a number of them now and I've seen the research develop and I've seen how out of those conversations we're now able to offer so

much more hope to people living with and affected by MND than when I first started at the Association nearly 9 years ago and that is such an important contribution that the MND Association's made over all of these years.

**Nick:** I'm now joined by Jamie who is Creative Director at WaveFX, the company that we use to sort out all the cameras, the livestreaming and everything else needed to run the International Symposium virtually. Jamie, could you let us know a little bit about the set up and scale of what we're doing here.

**Jamie:** We're running a 4 day Symposium from a tiny corner of the office in Northampton and we've created a kind of studio feel if you get a chance to have a look. It's basically 2 bits of wood pointed into a corner, well lit and with a big plasma screen and a couple of cameras. We then bring some Zoom guests in virtually and the magic happens when we vision mix all that together and try and make, the best way to describe it is to try and make a TV production out of all the content that we've got. We try to keep it interesting with some fast editing and, of course, some good Q&A.

**Nick:** In terms of your set up, I know there's a lot of work goes into it, how many people have you got onsite.

**Jamie:** So today, well we had the set builders in before, and that's a couple of guys that take most of the day just to build the set. On site today we've got about 6/7 people; a sound guy, someone looking after just playing the videos, Tom's doing the Zoom, Pete's doing the vision mixing, Bob's taking a kind of producer role and I'm manning the cameras and sort of doing the edits as they come and getting them quickly up so we're a team of 7 today behind the scenes. It's 2 vans and a couple of days just to get to where we are now ready to go. We're a few hours off going live now. It doesn't take long to get out though. It's a couple of hours to get out and we're back on the road.

**Nick:** So how do you manage to sort of coordinate and get it all right - the number of guests that are coming in, all the people talking at different times, you know, what's the process?

**Jamie:** Yeah. So, that has been the challenge. I mean, historically, if you put on a staged physical event pre-Covid, it was just a running order, a schedule of people would go on the stage, stand on the lectern, there'd be a Q&A and you'd repeat that 50 times. What we're dealing with now is we're bringing in virtual guests and we're vision mixing them in and we're having to coordinate the studio with virtual guests and it does take a bit more organisation. And that comes with rehearsing, you know, we're an industry that loves rehearsing and these events only look as slick as they are if the guests give the time to rehearse and the crew really appreciate that.

**Nick:** And what are you most worried about?

**Jamie:** The internet. No-one can control the internet. It doesn't matter how much we back up with power generators or back-up internet, you know. We can bring all that on site but if the internet goes down that really is the end of the show.

**Nick:** You've done the International Symposium on ALS / MND which is our annual event a few times, what kind of things have you noticed changed over the years?

**Jamie:** What personally is great about this event is it comes at the end of the year for us and it's grown, you know, it's grown hugely. My colleague, James, from Assets has been doing your event for nearly 20 years and it's grown from a small operation in Northampton to this global event and it's seemingly continued to grow and now we're virtually online I'm sure the numbers will continue to

grow. So, this is, you know, there's a buzz on it. It's the one the crew want to be on isn't it? There's no hardship in trying to get the gang together for this one.

**Nick:** That's fantastic. Dr Ammar Al-Chalabi is an NIHR Senior Investigator and Professor of Neurology and Complex Disease Genetics at King's College London and is also Chair of the International Symposium Programme Committee. He plays a pivotal role in the conference. He'll be on screen, introducing talks and hosting question sessions. He joins me now. Ammar, could you briefly explain the importance of the Symposium for the future of MND research?

**Ammar:** Well, thank you Nick. It's basically, very important as a showcase for cutting edge research and that can inspire early career researchers and also spark new ideas in anybody listening or watching, and for senior researchers it gives a good overview of what's going on in the world and therefore helps to encourage us all to keep pushing forward until we can find a cure for motor neurone disease. When we're in real person to person conferences, rather than virtual as we are today, there's an additional benefit which is the networking that can happen that can also spark new collaborations and drive research forwards.

**Nick:** And how does it feel to be involved?

**Ammar:** It's very exciting. It's a great privilege to be the Chair of the Programme Committee. It's wonderful to see the studio here and see how all the behind the scenes equipment and crew work.

**Nick:** That's great. And do you feel optimistic that this kind of event is really making a difference?

**Ammar:** It definitely makes a difference. I've had a number of projects that have come out directly because of presentations or posters that I've seen at a Symposium. They always make a difference and I have many collaborations that have resulted from networking at such events.

**Nick:** And is there any particular magic recipe for those collaborations?

**Ammar:** I think trust and friendship are the two key recipes for a good collaboration. Obviously, you have to have a scientific spark as well but actually, unless you can work together well, that's the most crucial point. You have to work together well.

**Nick:** And would you say there's one key thing that you're trying to avoid by having an event like this. You don't really want people all working on the same thing at the same time and not understanding what each other are doing?

**Ammar:** That's actually, that's a very good point, yeah. So, there is a place for duplication of work because you want to replicate findings and know that they're real and if they've been done by two independent teams that both come to the same conclusion then you can believe it because science always has some level of uncertainty. But, yes, certainly an event like this means that everyone can carve out their own niche without accidental duplication that wouldn't be so useful taking place.

**Nick:** And do you feel that the event is accessible to people living with and affected by MND?

**Ammar:** I think when it's virtual then it's definitely accessible from the point of view of being able to watch it and provide questions. I think the scientific jargon used may make it inaccessible to anybody who isn't scientifically trained but there are ways around that. The face-to-face Symposium meetings are more challenging in terms of being made accessible because of the travel involved, but I think a hybrid system might be very useful in the future for that.

**Nick:** That's great. Thank you very much.

The International Symposium is aimed primarily at researchers and healthcare professionals and one of our really important roles is to disseminate the work that goes on at the Symposium to the MND community and one of the really great things we've done this year, it's been done by Mandy in the Research team, is the Symposium Blogathon. Mandy, tell us a bit about the Blogathon.

**Mandy:** Okay. It's a way of disseminating all the science to people with MND, so I looked through all the abstracts and I found all the posters and the talks that I thought would be of most interest to people living with or affected by MND and then I translated that science into terms that, hopefully, they can understand, and put that together in blog form for different topics that are being covered in the Symposium.

**Nick:** And how do people find that?

**Mandy:** It's on our blog. You can just go onto our website and search in the search basket for Symposium Blogathon and it will come up with all the blogs, and also on our Symposium website pages there's a tab for Symposium Blogathon which will take you to the schedule and you can click on any of those and it will take you straight to the blog.

**Nick:** And is it being well used?

**Mandy:** It has been, yes. I've been really, really pleased to see that, certainly as of the end of November, the blogs came out each weekday in November and, as at the end of November, they have been viewed nearly 7,000 times which is excellent I think and I'm really, really pleased with that.

**Nick:** That's wonderful, and we're expecting significant uptake during the Symposium I guess as well as the social media builds and people see which talks and content is being talked about?

**Mandy:** Yeah, I hope so. I hope that people will keep visiting the pages. We'll keep tweeting about it to send people in that direction and, yeah, it will give them all the information that they need to know and make it a little bit easier to understand.

**Nick:** Excellent, and what's next?

**Mandy:** Well, the blogs will be updated, hopefully, if there's any more to add to it. If any of the posters or the talks give a bit more information than their abstracts have shown the blogs will be updated, and any other talks that have been particularly interesting will also be blogged about after the event, so we will keep everybody updated with everything that's gone on.

**Nick:** Thanks for sharing that Mandy and I encourage everyone listening to go and check out the Blogathon and all of the other resources that we provide.

People with MND are at the heart of everything we do. Brian, I wonder if you could share a way in which we try to include patients in the Symposium?

**Brian:** I think one of the unique features about the Symposium is it doesn't just bring the scientists, the clinicians and the health and social care professionals together. It brings the charity representatives, the Patient Association representatives and, of course, the patients themselves.

And I think one of the things I've been very pleased to see is the growth of the Patient Fellows Programme which is giving people the opportunity to experience first-hand what the Symposium is all about.

**Nick:** Yes. So, although the Symposium is primarily aimed at MND researchers and healthcare professionals, it's also really important that we make it accessible to people living with and affected by the disease which is ultimately the community that we serve. So, the Alliance Patient Fellow Programme is really good for this and is now an integral part of the Symposium. I'm pleased to say that I'm now joined by one of this year's Patient Fellows, Jack Grey. Jack was diagnosed with MND six years ago and is going to share a bit about his Symposium experience. Thank you for joining me Jack. So, you're one of the Patient Fellows. Could you just explain to us what a Patient Fellow is?

**Jack:** Yeah, so basically it's a person that represents the ALS community. I have been diagnosed with ALS. I have a slow progression, of course, you can see the bulbar affects my speech so I represent the patients that are very interested, of course, in ALS and all the research and all the activity that's going round the world.

**Nick:** In terms of what you've seen and heard at the Symposium this year, what's most interested you?

**Jack:** Well, I find everything intriguing but I really appreciate the opportunity to listen in and gain more knowledge on the research and, of course, all the research that is out there and available. With my bulbar speech, I'm participating in a couple of different programmes. Everything ALS in the US has a programme recording my speech weekly and so I find it very intriguing to hear any discussion in that area and using speech as a symptom for ALS and a progression of the disease.

**Nick:** And lastly Jack, as someone living with MND, how is it to see researchers and healthcare professionals from across the world coming together, united, collaborating, a real melting pot of ideas to try to accelerate and drive forward the fight against MND.

**Jack:** Yeah. I find this work most impressive. You know, we all of course live in our communities and only have a vision of what's going around us. We may have the opportunity to meet a few people with the disease but then when you come to a Symposium like this you see all the research, research and money and effort and brainpower from all walks of life around the world. It's so very encouraging and very impressive for sure and I have my hopes and my prayers that we will have a breakthrough and they'll be able to find an effective treatment and maybe an effective preventative technique or treatment or drugs or other things to help those that are showing signs of this disabling disease.

**Nick:** Thank you Jack. That is incredible and we really appreciate having you at the Symposium. Ultimately, this is what the Symposium is all about. It's about people living with and affected by MND and it's great that you've been able to join me today and to represent the ALS / MND patients at our Symposium.

I know that researchers and healthcare professionals really appreciate having people living with and affected by MND attend the Symposium and it's something that's really important to us. And also, very strongly in our minds we know that behind every data point, cell line, sample is a person or family and we never forget that.

**Nick:** I'm joined once again by Dr Brian Dickie and we've just wrapped up on this year's International Symposium. Brian, what do you think has been your standout moment?

**Brian:** I wouldn't call it a standout moment Nick but there's been so much chat about biomarkers and that's something that I always bang on about. We're getting closer to finding decent biomarkers at last that could really help clinical research and drug development to I think start to shift through the gears. You know, whether that's speeding up diagnosis which would open up what's called the therapeutic window of opportunity by hitting the disease early, or it could be biomarkers that accurately predict how the disease is likely to progress within an individual which has implications for both care planning but also for clinical trials. And then, of course, there's biomarkers that can tell us quickly if a drug is hitting its target inside the body and protecting nerve cells.

The other thing that's been great this year is there's been a lot of industry speakers. Not just presenting trial results but discussing the whole drug development pathway from early stage drug discovery through to the trial platforms that will allow us to run shorter, faster and smarter trials. It gives the lab scientists and the Universities a clearer picture of what they need to do to feed that drug discovery and development pipeline where industry can pick up that ball and run with it through to the clinic.

**Nick:** I completely agree. I think that's a really big gap that needs to be filled and it's great to see it happening here at the Symposium. I also think what's outstanding is the sheer amount of people that have registered and the amount of work that's been presented so, despite lockdown and what we've gone through in the last year or more, so many people have attended the meeting. There's always that doubt that, you know, would it really happen and be successful and there's been a huge amount of work presented and some incredible collaborations so it's really great to see that the fight against MND and the discoveries are still moving forward despite what we've had to endure. So, I'd just like to say thanks for joining me Brian.

**Brian:** Thank you Nick.

**Nick:** Well, that's it. The end of another International Symposium on ALS / MND. Thank you all so much for tuning in. I hope that you've learned more about the Symposium and how we hope that it will help lead us to MND treatments and, ultimately, a cure. Thank you also to all the researchers, clinicians, healthcare professionals, patient fellows and anybody else that attended this year's conference. We hope to see you again next year, be it in person or virtually.

If you'd like to learn more about the Symposium or read our Blogathon, then visit our website [Symposium.mndassociation.org](https://Symposium.mndassociation.org). You can send our team your questions too via [Research@mndassociation.org](mailto:Research@mndassociation.org). Thank you for listening.

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