**Interview with Dr. Brian Dickie, Director of Research Development for the MND Association**

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1. **There’s lots of interest in stem cell research. How might stem cells be used to screen new drugs and potentially aid motor neurone repair?**

A decade or so ago, it was impossible to study living human motor neurones in the lab. We relied on post-mortem tissue, which is incredibly important, but only gives a glimpse of what happens at the end of the disease process. Now, researchers can take skin or blood cells from people with MND and convert them into motor neurones in the lab, allowing them to study earlier stages of the disease. We can test thousands of potential drugs - and if any help keep the human motor neurone alive in the dish, it raises the question of whether they might also keep the human motor neurone alive in the person. Such ‘drug screens’ are the starting point in developing potential new treatments.

1. **The Amyotrophic Lateral Sclerosis Reproducible Antibody Platform (ALS RAP) – manufacture of ‘gold standard’ antibodies to selectively bind to proteins, like TDP-43 – is a promising research tool. Could you explain to our readers what this means for MND?**

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This initiative is all about giving laboratory scientists the best tools for the job. We know that in MND, some proteins in motor neurones become damaged and behave abnormally. The antibody ‘tools’ being developed will help researchers see which proteins are affected, how much of each protein is being made, where they are and whether they’re damaged, building a picture of what’s happening in degenerating motor neurones. If you consider that 99% of all drugs used in medicine act on proteins, you get an idea of how important this knowledge will be for developing effective treatments for MND.

1. **Having been awarded an International Alliance Humanitarian Award, your dedication to research into MND is far-reaching. As Director of Research Development, involved in ‘strategic guidance’ on MND research, how do you believe an effective research collaboration is achieved?**

We’re fortunate that the MND research world is very collaborative, compared with some of the more common diseases. The research community realises that with a relatively rare disease like MND, we can’t afford a ‘silo mentality’. A world-leading example of such collaboration is Project MinE, to understand how genes contribute to MND, with researchers and funders across 20 countries working together towards a shared goal of understanding and ultimately defeating MND. In the emerging era of ‘big science’ where highly specialised bioinformatics experts are using supercomputers to try and find subtle disease signatures within the biological noise, collaboration is essential. The MND Association is always looking to work with anyone who shares our aims.I often use the phrase ‘Joined-up thinking needs joined-up funding’. By this, I mean that if we expect researchers to work together, then the research funding bodies should do the same. Over a quarter of our research projects involve direct funding partnerships with other charities and government funding agencies.

1. **I like your analogy of acquiring MND as a set of balancing scales, rather than a single factor. Could you explain the 6-step theory of MND and what it means for research?**

If there were simple ‘causes’ of MND, we’d have found them long ago. As you say, it’s very clear that there are many different factors at play. Prof Al-Chalabi used an approach that came from cancer research to predict how many ‘events’ might have to take place for MND to occur. His research indicated that in cases of sporadic MND, where there’s no reported family history, there seem to be around six distinct events involved. Unfortunately, that doesn’t tell us what these events are, but it does at least give us the confidence that there’s something there to find! At the moment, major clues are coming from gene-hunting studies like Project MinE. Once we understand genetic factors at play, we’ll have a clearer idea of how to find environmental factors that have proved very difficult to find.

1. **I read a few months ago about an NHS DNA test to predict patients’ risk of developing conditions. What’s your view of ‘precision medicine’?**

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In 20 years, some aspects of medicine will likely look very different from today. People will have their genomes sequenced at birth and their phones and Fitbits will be monitoring their health. There will be a lot more focus on prevention of conditions that will occur later in life, as well as early diagnosis so that tailored treatments can be delivered as quickly as possible. That said, I was talking to a doctor recently who commented that in his hospital, paper files are still being pushed around in shopping trollies. Perhaps we’re not as prepared for the digital health revolution as the media suggests?

1. **This year, I helped run an awareness stall for the MND Association at the Exeter Medical School undergraduate conference, which led to an Arena session to teach medical students about MND. We gained three new student volunteers for the Exeter and East Devon branch, with others expressing interest. What are effective methods to engage students and harness skills, and how can we apply these to our recruitment?**

In the research team, we’ve focused on science communication with postgraduates and postdoctoral researchers rather than undergraduates, but you’ve identified an opportunity. The combination of cutting-edge science and the nature of MND and its impact on individuals is very powerful in engaging with science students.

1. **I read an abstract from a journal paper, in Frontiers of Neuroscience, investigating MND through Genome Wide Association Studies and gene knock-down using Drosophila fruit fly models and disease-modifying genes. From your perspective, can you explain what disease-modifying genes do and the benefit they may have for MND research?**

Steven Hawking once asked me why his disease has progressed so slowly compared to the textbook 2-5 years he was told when he was diagnosed. I suggested there might be something in his genetic make-up that hadn’t stopped MND from occurring, but was somehow pushing back against the disease, resulting in very slow progression. This idea of protective or disease-modifying genes is starting to interest researchers, who are paying close attention to these exceptionally long survivors. If we can identify genes that slow disease and work out the underlying cellular mechanisms, then we have a much clearer route into developing therapies that may do the same thing even more effectively. It’s not a new idea in medicine – some of the key advances in HIV treatment arose from the study of a small group of individuals who were HIV positive but didn’t develop AIDS.

1. **What’s your biggest challenge as Director of Research Development?**

A major challenge is ensuring that funding we spend on research is used effectively. One way is to partner with other organisations to share the cost and risk of research, whilst allowing us to get involved in much larger projects than we would on our own. We work closely with government agencies like the Medical Research Council and the National Institute for Health Research, as well as UK charities (like Marie Curie) and abroad (ALS Association of the US). Another challenge is communication. Whilst significant advances are being made in understanding MND, this hasn’t yet resulted in new and more effective treatments. Whilst I see the pace of research accelerating, for those with MND it’s still moving far too slowly.