



MIGRAINE WORLD SUMMIT

TRANSCRIPT

INTERVIEWS WITH WORLD-LEADING EXPERTS

ADVOCACY, ACCESS & MIGRAINE AT WORK

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LONDON



Introduction (00:05): We are seeing waiting times for specialists getting worse, we're seeing a real need to improve GP education around migraine because the majority of people should be, in the U.K., diagnosed in primary care and shouldn't be referred. That's not happening. We're seeing A&E [accident and emergency] admissions rising quite significantly in the last three, four, five years. There's something going very, very wrong there. And we also need a real push around improving the management, the understanding of migraine in the U.K. And so, one of the things we're calling for is a real national drive in all the four nations in the U.K. to make sure that pathways that are now in place or in three of the four countries, which is fantastic, are adopted consistently, and they're not just a tip box, "Oh, we've got this lovely report," but actually they're actioned on.

Carl Cincinnato (00:56): In this interview with Rob Music, the chief executive of the Migraine Trust, we delve into crucial aspects of migraine treatment access and the importance of patient advocacy. Mr. Music shares insights from the migraine community and discusses the organization's efforts to improve treatment access and amplify the voice of patients through advocacy initiatives. This interview uncovers a valuable perspective on the ongoing fight to empower those living with migraine and to create positive change in our health and workplace. Mr. Rob Music, welcome to the Migraine World Summit.

Rob Music (01:28): Thank you, Carl. Thank you very much for having me.

Carl Cincinnato (01:31): You are the CEO of the Migraine Trust. Can you tell us a little bit about this organization for those who may not have heard about it?

Rob Music (01:37): Yeah, of course. So, the Migraine Trust is the U.K.'s lead migraine charity; we were established in 1965. And in terms of the work that we focus on, we cover all key areas of work, so we provide a range of support services [and] information tools. We focus on supporting the workplace, looking to improve public education, and awareness about that migraine. Also around those in terms of policy and health, and of course we campaign for change and improved care to people living with migraine. And we also fund research and primarily through funding PhDs and fellowships. So, trying to give a career path for brilliant young scientists in the field of migraine.

Carl Cincinnato (02:22): Fantastic. And are you limited to the U.K.? What countries does the Migraine Trust cover?

Rob Music (02:28): Yeah, so legally we're set up, so we are U.K. But I think that the beauty of — I guess since I've been with the Migraine Trust — is the really nice conversations, collaborations with experts and chief execs, Migraine World Summit — all across the world. So, I think there is that beautiful opportunity about sharing and learning and how you can bring those learnings back to improving the care that you can give within your own country, as well.

Carl Cincinnato (02:56): There is a real spirit of collaboration and support amongst the different migraine organizations, and this is just a testament to that, and it really is wonderful. Now, you're not new to patient advocacy; this isn't your first role. Can you tell us a little bit about yourself and what organizations you've worked for in the past?

Rob Music (03:14): Yeah, of course. In terms of the voluntary sector, I've worked for big and small charities for probably about 33-34 years now. Started life as a fundraiser at a charitable stroke association, and before the Migraine Trust, I was chief executive of two other charities.



One was Endometriosis U.K. and then Jo's Cervical Cancer Trust. So, having worked for big and small organizations, the bit that I know that I really like is trying to work with small organizations but with really big causes to try and do that bit about that turnaround to make sure the infrastructure, the internal work, the way we're set up is bang on right so we can be the most impactful that we possibly can be for the stakeholder group that we're supporting.

Carl Cincinnato (04:02): When you hear the term patient advocacy, what does that mean to you?

Rob Music (04:05): I guess top line, it's about giving people who are living with a particular condition a voice, and I think that can be many things. So, that could be giving them a chance to talk about their condition, to share that story. So, that's quite cathartic in itself. I think there's the bit about when you want to work with policy, campaign; those pieces of work — their stories are the most important stories. It is the pin-drop moments. If you go to a meeting, I mean, I can spout facts and figures til the end of the world, but actually it's not my story that makes a difference, it's that really personal impact. So, that's incredibly powerful, as well. I think it's about people who can advocate for others who may be struggling, as well.

Rob Music (04:50): In 2022, we brought out a report around the impact of migraine in children and young people. We had parents who were fantastic advocates for the impact of what was happening for their children. So, I think it can mean many, many things. I guess it's also, for us as an organization, we can't be anything without people telling their stories. So, and that also includes research, the impact of their condition. One of our values of the Migraine Trust is about being evidence-based. And so, that is — we have to constantly make sure that we've got really good, rigorous, powerful, up-to-date data and evidence from people who are living with migraine or whatever it is we're focusing on. And that's really powerful for us when we have that conversation, whether it's with health ministers or local influencers. And it's the people who have told their stories — the people who have given us that data — who are advocating for us to help try and effect some positive change.

Carl Cincinnato (05:55): Do you think it's important for patients to be their own advocate?

Rob Music (05:58): Yeah, I think I do. I think it's very, very important. I think one — but we've got to make sure quite often for some people they may struggle. We've got to give them that feeling of comfortableness and empower them to do that. But I think it's very, very important if people are really struggling to give them a voice, to help them have a voice, both individually and as part of a community. We see the huge impact of mental health with migraine and being able to give somebody a voice and talk about what they're going through is very, very powerful and really, really positive.

Carl Cincinnato (06:35): One of the things that the Coalition of Headache and Migraine Patients [CHAMP] did with its members a few years ago was media training. And this was an eye opener for me in my advocacy development because they mentioned that having a patient story with lived experiences, which is sharing my personal story, for example, can be very powerful. But without the facts, it's not credible. And just having the facts and the research doesn't get the traction in [the] media, but it's when you combine the two, when you have a powerful patient story with the facts and the data and the research to back it up, that's when you can get real traction as an advocate.



Rob Music (07:12): I am amazed, astounded, and grateful for how generous people are in wanting to tell their story. That even though their life may be a real struggle, they want to make a difference and hopefully help others not go through what they're going through. And it is incredible — really, really incredible.

Carl Cincinnato (07:32): Yeah, it's inspiring, and it's courageous, as well. It's not easy talking about a stigmatized condition that has a lot of stigma and even discrimination attached to it, which we'll talk about. How does the Migraine Trust help people living with migraine become an advocate for themselves or others?

Rob Music (07:47): I guess maybe taking a step back, it's about talking about why advocacy is so important, what difference it can make in terms of: One, the objectives of the charity to try and effect positive change, but also, actually help them give them the confidence. Sometimes it's about giving them the confidence to actually have a better conversation with a healthcare professional. And even our services can do that. So, when people come to our services and afterwards that they come away, and we get really good data that says, "Well, actually, I feel more confident now about pushing back, having the right conversation, having that discussion." Because I think we're all very good at going to a doctor and then not asking the right questions about what we should be doing. For example, if we have people who will — we ask them to contact their parliamentarian, to meet with the charity, to talk about the work, to come along to events. So, they can do that. The sharing of the story I think is very, very important, as well. I think, the other thing is making sure it works in a way that works for them. If people are struggling with their health, they may not be able to come to a meeting, [or] may not be able to have that interview.

Rob Music (08:58): So, for me, advocacy has to be many, many different things. Just filling out a survey that says, "This is the impact on my health." That is really powerful advocacy. I know we are planning on touching on workplace later on, but that survey we had out for not very long and over a thousand people took part. It's astounding — absolutely astounding. And that data is so powerful, which we'll touch on, and that's helping us make inroads in conversations that we have with employers. There is no single way. And we've got to give everybody an opportunity to have a say in the way that works for them and the way that they want to do that. If we just say, "The only way is to share your story," well, we're probably going to get 10% of the people who support us.

Carl Cincinnato (09:40): What are patient access issues, and do you have any of these in the U.K.?

Rob Music (09:44): Different levels. So, I would say there are some — in terms of the general, the patient pathway and how it should be — there's a real challenge. And we produced a report in 2021 called "Dismissed for Too Long," which highlighted that, and we will continue to produce more reports and more pushing around this. So, we have patients who struggle to get a diagnosis; they have a struggle to see the right healthcare professional. In the U.K., in primary care, we have people struggling if they need it to see an expert in secondary care. Very long waiting lists may be referred inappropriately, so they're going round and round and round in a bit of a vicious circle and it's something I think we're all very much acutely aware of.

Rob Music (10:29): The NHS [National Health Service] and the system here is in a bit of a shocking place. Inconsistency, badly funded, and the report produced in '21 really highlighted that, and it got a lot of traction, and from that the report had 16 recommendations in it. And



we're seeing that some of those are, thankfully, being taken forward, but clearly there's much more to do. In terms of drug treatments, I guess after decades of people having to live with and take treatments for other conditions and the terrible side effects and all the things associated with that, it is brilliant that we are seeing the new CGRPs available. And a number of them have been approved in the United Kingdom. So, that's great.

Rob Music (11:15): The challenge is absolutely around access. So, we see lots of people coming to us unable to access them, despite the fact that they're eligible. We see differences both at a national level, with data we see coming through, we see differences at a local level. We'd have a postcode lottery where one region may — absolutely, it's absolutely brilliant — and they've got the funding in place and people can have them. For others, they are really struggling. And for those who are really struggling but maybe can afford them, maybe even if they can't afford them, they may end up going down the private route. And that's really not acceptable. It's just the huge inequality. That's one of the big things we continue to push for: For that to change. There is that equity across the U.K. in terms of the treatments and how they're being offered, and where they're being offered.

Carl Cincinnato (12:04): So, if the CGRP monoclonal antibodies are available, they're approved — what are the barriers getting in the way? Why is there such a disparity in access across the regions?

Rob Music (12:13): I think it's a mixture. For some, it may well be funding. So, it may be that the local commissioners are concerned that so many are going to be prescribed, that it may have an impact on their local finances — can't deny that. So I ask, is the setup within a particular local area good enough; have they got the expertise to actually look after the patient appropriately and refer them to have that particular treatment? So, it's a mixture of — and I think that's part of the challenge is that we want to see this consistency of care and the consistency of access across the U.K. Because at the moment, we are just not seeing that. I think the 2021 report — obviously at the time, I think the CGRPs were fairly new to market over here — but some places they weren't being offered at all. Some it was only 20%, 30% of those eligible we're accessing. So, there's a big piece of change that needs to happen there.

Carl Cincinnato (13:13): What about the gepants? These are an exciting new innovation that have been available in the U.S. now for over a year. Are they likely to come to the U.K.?

Rob Music (13:21): Yeah, so they're already here. So, I think rimegepant has been approved by NICE [National Institute for Health and Care Excellence] and SMC [Scottish Medicines Consortium]. One for acute and one for preventive, and hopefully we're pushing for that change so they'll both be acute and they'll both be preventive. And I think that'd be very powerful and very important. And obviously, then atogepant is being reviewed, and it may well be that that would be available as well soon. So, I think that's really positive, and it's good to see. And again, it is about choice, isn't it, as well. I think the acute side of things is particularly interesting and important at the same time.

Carl Cincinnato (14:05): What priorities do you have with the Migraine Trust when it comes to changing policy or discussing migraine with the government?

Rob Music (14:11): I think first thing, I suppose our work could have a bit of a dual focus in some ways. I suppose we are — there's that national perspective — but also, looking at local change, where everyone has a slightly different focus and a policy around it. My guess, let's take a step



back. I guess our frustrations we've touched on before, I suppose, is that we've — and again, it's what you see and others see across the world, Carl — is that ... migraine is consistently overlooked with health strategies. So, that's the real frustration about that. So, in England, for example, quite recently there was a major condition strategy for England. We submitted for that. There's nothing about migraine. There are women's health strategies, and interestingly, nothing about migraine. So, and I see you're nodding, and none of this is a surprise. But there's a separate bit which is the ongoing beautiful opportunity, about how we can collaborate together to make that change with this deep frustration.

Rob Music (15:10): So, the report that we brought out, the thing we talk about a lot is because we're seeing waiting times for specialists getting worse, we're seeing a real need to improve GP education around migraine because the majority of people should be, in the U.K., diagnosed in primary care and shouldn't be referred. That's not happening, and we're seeing A&E admissions rising quite significantly in the last three, four, five years. There's something going very, very wrong there. And we also need a real push around improving the management, the understanding of migraine in the U.K. And so, one of the things we're calling for is a real national drive in all the four nations in the U.K. to make sure that pathways which are now in place or in three of the four countries, which is fantastic, are adopted consistently, and they're not just a tip box, "Oh, we've got this lovely report," but actually they're actioned on to make sure that GPs have got up-to-date training on migraine treatment and care.

Rob Music (16:12): A brilliant opportunity around pharmacists, certainly in the U.K., that they're empowered to support more patients. And we received some funding from the Scottish government to run a pilot in one part of Scotland around training and educating pharmacists. And that's happening at the moment, but looking really positive, and I think the way it's going that could then build onto something that potentially could have something around a national perspective. You also need better data. Data's pretty poor. There are lots of gaps, and actually we haven't got the right data, then we don't really understand who's being treated where, who's being offered what, what the gaps are, and how things can be improved.

Rob Music (16:55): So, there's a lot. I think the other thing — I guess when I joined the charity — that I felt personally at the time that perhaps we need to be more the voice of the community. That we also need to raise awareness of migraine more. People didn't know we existed. So, in terms of building positive relationships with parliamentarians, it was almost a bit of a starting point. So we've met with parliamentarians, and we've had parliamentary events last year and drop-in events, and we're having patient focus events this year. It takes time. It takes time to build reputation; it takes time to build trust; and again, it's that bit before about patient advocates. They're so important; they always come to these meetings, and they are the key bit as well, and they are the key storytellers at the same time.

Rob Music (17:44): So there's a lot to do, unsurprisingly. I feel like in the U.K. we are beginning to get some traction now, and it's about getting everybody on board. And that's a bit about how I see the Migraine Trust: That we can't do anything in isolation. So we have to have the parliamentarians who are knowledgeable on board; we've got to get the healthcare professionals on board; we have to get funders and industry on board; we have to get patients on board. And all singing from the same sheet, and all with the same call, and all with the same need because if we don't, it's not going to work. So, one thing I really hate is silos, and silo working is deeply unhealthy. It never works. So, I guess what I want for the Migraine Trust is to be almost that central hub and that voice for everybody.



Carl Cincinnato (18:30): I was pleased to hear that you bring patients to those meetings with government. Patients might be surprised to hear that, but I've had a minister tell me — a member of parliament — say that they're actually more important than the doctors in these meetings. They have a story to tell; they've got lived experience, and they can be really compelling when it comes to sharing this — just sharing their story and just sharing what they have to go through — for policymakers. Have you found that to be the case, as well?

Rob Music (18:56): Yeah, very, very much so. Part of our work within the four U.K. parliaments ... We launched migraine tool kits within each of those. Which provides information about migraine, impact within their own country, what they can advocate for their constituents, as well as the people that they work for, and trying to get their power to be a more migraine-friendly workplace or employer as it were. But for each of those, we had patient advocates come along, and they're the ones that, as I said earlier on I could talk about data, I can talk about the charity; it's the lived experience that is the most important thing. And I'm so grateful for those who came along. So, for each of those, we had a number of patients who came along and shared their story in Scotland. I think the health minister walked in; we weren't expecting her to come, but it was great, and she spent loads of time with them, and learning from them, and it was perfect.

Rob Music (19:56): What's really interesting around this piece of advocacy and trying to get parliamentary champions is [that] for the drop-in events that we had last year, probably 90% of the parliamentarians who turned up were personally affected by migraine. They, or maybe a family member. So, that's great, trying to build champions. The challenge, and I think we all see this, is, well, how do we get all the other lots to come along? Because they need to understand that 1 in 7 of their constituents lives with migraine — a huge impact personally, huge impact on their constituency, huge impact on local health. And I think that's the challenge ... I'd rather flip it around to be half full, and the opportunity is how we're going to make that much better moving forward. And I think it's the bit about — it's a long-term goal, isn't it? With policy, and [we] just cannot give up. And that's the bit that probably does frustrate people sometimes — that you can't affect change straightaway. But we are one of hundreds of thousands of conditions who feel we are the most important. So, it's how we can push through that and make sure we get our voice heard, and that does take time. And so, it's trying to manage that, the hope and the expectation and the degree of patience at the same time.

Carl Cincinnato (21:03): Yeah, I mean, we tell our representatives in parliament that it's 1 in 4 households in your electorate. In your geography, 1 in 4 households — which [are] your voters — have migraine. So, if you want to show some thought leadership, if you want to win more votes, this is a key way to do that.

Rob Music (21:19): That's really good, actually. I like that; I might just steal that.

Carl Cincinnato (21:21): How do you kind of explain your approach? I think you alluded to it in sort of working through that to try and seek constructive avenues for discussion, dialogue, and collaboration with and not getting into silos, but how would you respond to someone who's saying, "This is outrageous; this isn't good enough. We need to be kind of marching on the streets, or writing aggressive letters, or being firmer in our approach."

Rob Music (21:47): It is about — you have to have a sensible, helpful discussion with ministers or parliamentarians — I guess it's a bit about reputation of the organization and the trust that they want to speak, learn, and work with you. I can understand the anger, I can understand the



frustration. Actually, shout at me and shout at us, but we'll understand that, and we'll try and turn that into part of our call for change moving forward. But if we go into parliament and we shout and we scream, people are just going to push back, and they'll say, "I can't work with you." So, it has to be a reasoned approach. Even sometimes, when you don't always feel like you want to, but you have to. It's just the way it works, and it does take time, as I said before, and that can be a frustration for people, as well.

Carl Cincinnato (22:39): Yeah. No, I think Dr. Robert Shapiro said that the pace of change in Congress in the U.S. is glacial. I think that's a good way to describe it.

Rob Music (22:49): It really is...

Carl Cincinnato (22:49): You just have to show up year after year, and be consistent, and channel some of those emotions ... into constructive ways. What can people who are watching that live in the U.K. do to support the efforts of the Migraine Trust if they want to become an advocate and maybe attend some of these events?

Rob Music (23:10): Follow us through our website. We've got a page about how you can get involved, and that could be the way that works for you. So, whether that's get involved in research, tell your story, sign up to parliamentary events, information about how you can contact your MP [Member of Parliament] to tell them your story, ask them to meet the Migraine Trust: So, we find lots of different ways for people to get involved in the way that works for them. And as I said before, I'm just eternally grateful to them — absolutely extraordinary group of people.

Carl Cincinnato (23:41): Do you get the sense that there's a higher level of family and household stress and strain due to the rising costs and sort of world events that have now — had someone told us all of this five years ago, we probably wouldn't have believed them, but now this is just part of our daily lives. Do you think that's affected the status of migraine and the burden of migraine within the U.K.?

Rob Music (24:03): I think if I go wider than migraine first, you're absolutely right. I guess the economy — it's a real challenge. Things are costing so much more money: from food, from petrol, from home heating. I think most people's bills doubled or tripled over the most recent winter in the U.K. We are seeing so many more people now having to use food banks. It's devastating to see, and I'm not quite sure when we're going to see the end of that. I think people living with migraine, obviously, you've got the financial impact with — allied with — the challenge is around getting the right healthcare aligned with the myths and stigmas that still abound with migraine, around the challenges in the workplace, the mental health issues.

Rob Music (24:51): So, I think all of that — and we know obviously stress is a major, major cause for many people with migraine and mental health — that things I would say are getting worse. And we are seeing in our helpline we are seeing increases in longer, more emotional-related calls around mental health. Calls are lasting longer because they're struggling to get the support and the care that they need. Some are almost just calling other organizations because they're literally at the end of their tether. So we are definitely seeing the mental health aspect in particular, a growth in terms of people who are coming to the charity for support.

Carl Cincinnato (25:39): You mentioned migraine at work. What are you seeing about how migraine affects people at work?



Rob Music (25:44): Oh, it's massive. I know that you are doing some brilliant work around it as well, Carl, and really trying to break down some of those barriers. It's huge. So, in the U.K., it is around about 43, 44 million days a year are lost. It costs about £9 billion a year for productivity and absenteeism. So, we fairly recently undertook a survey to understand what the impact is of migraine. And some of the data was just devastating: 43% felt that their workplace didn't believe them if they took time off work, [and] about a third said their migraine wasn't taken seriously. And again, around a third were both either harassed, or victimized, or discriminated against. It was absolutely shocking. Less than half the companies offered reasonable adjustments. And so many were affected financially, either having to go from full-time to part-time or even to give up their work.

Rob Music (26:46): And it's devastating. Because you've got loss of livelihoods, you've got the loss of finances, people feeling invisible, people not being believed. And so, it is quite shocking — really quite shocking. So, I guess for us there's that opportunity to turn that around. So, we've been working with companies; we're running awareness sessions with big blue-chip companies to try and prove that we're getting really positive feedback around that. We're looking at about how we can do some pilot pieces of work about a more deep-dive consultancy piece of work. So, we can run surveys with the companies, we can work with their managers, work with HR, work with their champions, and see how we can improve that. Because there's some really good data out there.

Rob Music (27:33): Was it the *Harvard Business Review*? There was a really interesting article a couple of years ago about how you can make those changes and how it benefits the people who live with migraine. It benefits the employees who don't live with migraine, who actually understand it, and they stop that discrimination, the stigma that happens. And obviously, there's the business benefits to the company, as well. I mean it's an utter no-brainer. And I think for us that turning this half-empty to half-full, is — I would expect to see it over the next few years across the world: What you are doing, others are doing, as well. That companies will be massively changing their practices and their policies, and you'll be seeing healthier, happier companies as a result of it.

Carl Cincinnato (28:17): I couldn't agree more. There's a huge opportunity, and I think it'd be great for the ecosystem and for the advocacy organizations themselves to establish corporate partnerships, to diversify their funding base, and to be empowered as a result. I mean, it'd be amazing if every migraine advocacy organization had a dozen corporate partners that were helping fund their initiatives, and support their work, and improve awareness, and reduce stigma and discrimination within their own workplaces.

Rob Music (28:45): Yeah, I couldn't agree more. I couldn't agree more. And you're right, it's a big area of opportunity and need because migraine, again, interestingly, we think about inequity, and I know we've talked about this previously. It's hard to fundraise for, and it shouldn't be considering how common it is, considering how impactful it is. And that goes back to the myth and the stigmas, and that's the thing that we are all really pushing to change [so] that people really get it. So, we will get there; we are getting there, but there's a ways to go. But yeah, opportunity. The only way is up without trying to break into song. But anyway ...

Carl Cincinnato (29:21): Rob, it's been so fantastic to catch up. Where can people learn more about you or follow your work or the work of the Migraine Trust?



Rob Music (29:28): I mean, the best place to start is our website, which is migrainetrust.org. So, there's a range of information there about what we do. If you're in the U.K., then have a look in terms of the treatments and things, etc. But the support services that are available. Again, it is interesting that we are not as well known as we should be, as people aren't always being told about services that we can offer and the support that we can offer. So, thank you for giving this opportunity to talk about the Migraine Trust and the ways we can help people.

Carl Cincinnato (30:03): Well, on behalf of everyone in the U.K. that lives with migraine, thank you for the advocacy and the work that you've been doing and that the Migraine Trust has been doing for decades. Rob, it's been so great to have you. Thank you for joining us on the Migraine World Summit.

Rob Music (30:16): Thanks Carl. Thank you very much for having me.