**How can we work with patients to drive research initiatives?**

**Behind the Genes transcript**

**Mel: Welcome to Behind the Genes.**

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**Mel: My name is Mel Dixon and I’m a member of the Participant Panel at Genomics England and founder of Cure DHDDS, a charity set up to raise awareness, support families and help drive research into the ultra-rare DHDDS gene variant. On today’s episode I’m joined by Jo Balfour, Managing Director of CamRARE, which is the Cambridge Rare Disease Network. This network unites patients, advocates, experts and leaders to address the challenges faced by people affected by rare conditions. I’m also joined by Rona Smith, Associate Professor at the University of Cambridge and honorary consultant in nephrology and vasculitis. Today we’ll be discussing the role of patients in setting research agendas and how their involvement can lead to more impactful and patient-centred research. If you enjoy today’s episode we’d love your support. Please like, share and rate us on wherever you listen to your podcasts.**

**Before we begin the interview I’d like to share a little bit of my story. In November 2022, following whole genome sequencing, we received the news that two of our three children carried a neurodevelopmental and neurodegenerative DHDDS genetic variant. At the time of our children’s diagnosis there was very little information on our gene, minimal research happening into it and no treatment pathway. Through our charity, Cure DHDDS, we have worked tirelessly to instigate research and create a collaborative scientific research community. I am a huge advocate for patient-led research and have witnessed first-hand the positive impact it can have on patient lives. Thanks to the work of the many scientists that we have had the honour of collaborating with, within two years of our children’s diagnosis we have a disease-modifying therapy in our sight and an ASO (Antisense oligonucleotides) therapy in development. We are incredibly grateful for the opportunities genetic testing has given us but I also appreciate how overwhelming a genetic diagnosis can be and how challenging it can be for families to initiate research projects with little to no resources, and that’s why initiatives such as CamRARE that we’ll be discussing today are so important.**

**On that note, let’s get back to our podcast guests. I wonder before we dive into today’s topic if you could both give a brief introduction, and, Rona, if you could also give the less scientifically-minded of us an explanation about what nephrology is.**

**Rona:** Thank you for inviting me today. So I’m Rona Smith, I work in Cambridge and I’m a nephrologist and that means somebody that looks after individuals who have diseases that affect their kidneys. My specialist interest is in something called vasculitis which is a rare autoimmune disease that affects all organs in the body but kidneys as well.

**Mel: Thank you. And Jo?**

**Jo:** Hi Mel. I’m Jo Balfour, the Managing Director and one of the founding members of Cambridge Rare Disease Network, or CamRARE for short. I think we’re often described as the ‘Chief Everything Officers’. I manage the charity and all of our operations and our wonderful team.

**Mel: Lovely. Thank you very much. Rona, I wonder also if you could explain to our listeners what is a research agenda?**

**Rona:** So in brief a research agenda is really a strategy that outlines key questions or topics that a research community, and that might be investigators, clinicians, scientists, patients, industry, and they are the priorities that they want to explore and address over a period of time. So it’s really a direction of travel and identification of areas of importance and where there are gaps in knowledge so that it then leads to the opportunity to form specific research questions that you can then go on and address.

**Mel: Why do you both think it’s important to involve patients in setting these research agendas?**

**Jo:** Well I think critically one of the things that I’ve learnt over my time working, not just in the rare disease sector but also earlier in social care and education, is that we should as professionals never assume anything; you know, we have not lived in their shoes and we don’t know what the daily life of people living with rare conditions is like. So gathering that day to day lived experience is really crucial. And I have a unique opportunity to see into that daily life with our local community of rare disease families who have a range of different rare conditions. I’m party to their conversations, to their daily trials and tribulations, the things that are difficult, the things that they find joy in but I still will always go back to them and ask their opinion. I see myself as a spokesperson for them as we’re an umbrella organisation but I certainly never really know what it’s like to live with their conditions. I think they bring with them diverse experiences which we really need and value in setting research priorities, they have unique knowledge of their own conditions. They ethically have a right to be involved from the start and to set that priority and agenda but, equally, it’s valuable for us as researchers because if we can involve people early we have definitely more chance of good engagement and later success, better outcomes for everyone.

**Mel: Couldn’t agree more. And, Rona, is there anything you’d like to add to that?**

**Rona:** I think it really means that we measure what matters to patients and individuals that are affected. Often it’s really difficult to capture kind of the real impact of disease and there’s a tendency for researchers to measure things that are easy to measure and are reproducible, which of course is important but what’s most important is actually being able to truly capture the impact of an intervention on an individual’s condition. So I think that’s another key aspect of having people with lived experience involved right from the start.

**Jo:** Another thing that’s actually quite interesting that I’m going to mention here is that I think when you live day in, day out with a condition your perception of things like pain is different from your average person’s so you become almost accepting of your daily norm, and I think that’s really critical to understand as well. And it’s only by getting to really know patients and understand. When we say, “What’s your pain like on a scale of 1 to 10?” you know, something that I feel as pain because I get it rarely I probably am going to put it at a higher score than somebody who has that every day. So I think there’s subtleties and nuances like that as well which are really critical to get across by conversation with patients.

**Mel: That makes absolute sense. And I see that from the patient perspective myself. I was out with my friends the other day and they said, “Oh my goodness, you’re constantly taking your children to sports activities.” Because of their physical needs we’re constantly, they go to Pilates, they go to swimming, they go to gym class – we try to keep them fit and healthy – and we, even though they’re older, have to take them there and back and that’s become our norm but when you’re speaking to families whose children don’t have those difficulties they have no idea how much time that actually takes up. And I had no idea how much like time it takes up compared to what other people are doing because that is our norm, that’s what we’ve accepted as the norm. Patients and patient groups are incredibly driven and invested in their rare disease as well so they make really good rare disease research partners.**

**And, moving on, what do you see as the challenges and barriers to patient involvement and how do we overcome these?**

**Rona:** I think probably the biggest barrier is time. So, the most important thing is investing time to build relationships, to really understand in-depth perspectives both from the patient’s side but also the researcher’s side. And, inevitably, we always want to do things faster and actually this is one really, really critical aspect is investing time. Funding is also a challenge. Often you have to do a lot of upstream work before you have got funding for a project and that takes time from individuals and that’s another challenge. And I think the third thing for me is individuals that are patient partners in research, they’re not just patients, they’re people - they have lives, they have work, they have families, they have everything else that goes on in life - and so actually fitting this all in is really challenging.

**Mel: Jo, is there anything you’d like to add there?**

**Jo:** Yeah, I think just a word about diversity really and, you know, how do we uncover those hidden families and patients who currently don’t really have a voice. I think we’d all acknowledge that there are key voices within the rare disease community who will share the views of their community and they’ve become well-oiled machines almost at being great advocates but, as I mentioned earlier, even though I’m perhaps one of those people, you know, I speak for a community, I would never assume anything. So, I still need to uncover the thoughts and the feelings and the emotions and the needs and the what matters from those people, and, as Rona mentioned, that takes time and it takes building relationships and trust with people. So, we have a wonderful community in the Eastern region of England which is made up of families affected by all different rare diseases, and undiagnosed. And some are babies and have been lucky enough to get a very early diagnosis and others are young adults but what we’re finding through that is that experience is diverse and experience changes over time as families go through transition periods or they meet a roadblock and they’re having to navigate things differently. So, it’s about building those relationships. That takes times, it takes resources, it takes sometimes a reset in the way that we think things need to be done. So instead of asking questions all the time and putting surveys out and trying to get response that way it takes a bit of thinking about how do we listen better and how do we give those people who don’t have a voice, who are non-verbal or perhaps have a learning disability, how do we ensure that we’re capturing their views as well.

And we did a really lovely project actually last year, it was something funded by the NHS called My Story, My Way, where we actually spent three months with our young adults working out what it was they wanted from our community next, how did they want us to follow them into adulthood. And we knew that there were a number of young people in that group who were non-verbal and had some learning differences and we knew that we couldn’t just do it in the normal format, we couldn’t just do a focus group and ask their opinion, so we actually did it through photography. So each of the familiess well, the young person themself was given a simple camera. They basically had thirty-six shots. You got thirty-six clicks to capture the things, the people, the places that you love and then to share them with us as a community. And then we all discuss, you know, how these things might be something we can build into our future plans for them. And it was such a wonderful activity. We gave them plenty of time, plenty of opportunities to ask questions. If the young person themself couldn’t physically click the camera their sibling got to help them. And their sibling or their parent was given another camera in black and white so we had distinctive pictures, pictures that the kid themself had taken, pictures that the family had taken, but all together, you know, it gave this lovely kind of medley, this beautiful visual representations of what mattered to them. And I think it’s about taking the time to be creative with people like that and really get to the bottom of “How do we find out what matters to you?”

**Mel: Although it takes time to think about those ideas. That could be translatable across the board really, couldn’t it, throughout various conditions. I think that’s fantastic. Rona, I wonder if you can tell us how has the work that’s already been done through the patient-led research hub facilitated addressing research priorities.**

**Rona:** So just a tiny bit about the patient-led research hub. So, this has been now running for nearly ten years through Cambridge. It’s a partnership between the Cambridge Biomedical Research Campus and we’re based within the university and the Trust. And in essence it kind of was set up because of really a mismatch between what many patients wanted from research and what investigators’ views were. And so really the premise is that we welcome patients to come to us with an idea, a problem, an unmet need in their disease area – and we do focus on rare disease – and we work with them to see “Well actually what do we already know about that?” and then if there is a gap in knowledge we then move to kind of trying to work and develop a question that we can then address. And that might be a question that’s addressed through generating more information through surveys or it may actually be a question of an intervention that we can test.

So, we’ve had lots of projects come through and we, just an example of a project was from a group of patients with a rare kidney condition called autosomal dominant polycystic kidney disease, and that is a condition where over time you accumulate cysts in your kidneys and the kidneys become large, they become very painful and eventually they can fail. And a question that the patient group had was about whether drinking more water could impact the rate of growth of these cysts, and there’s a strong hypothesis behind that that drinking lots of water reduces down the level of a particular hormone. And we actually worked with the charity behind this group, the Polycystic Kidney Disease Charity, and designed a study to test a very high water intake to a normal water intake to see whether it was possible over a period of eight weeks for patients to actually stick to this. It’s quite difficult to do. And they recorded how much water they’d drunk, they tested their own urine and actually it showed that this was feasible to do this kind of work. So, I think the patient-led research hub is kind of taking the research priorities that are important to patients but working in a patient-led way to come right through to a project.

**Mel: That sounds great. And if the patients are engaged from the start of the project and it’s led by them they’re obviously going to be much more driven to take part in the actual research and see the research through themselves.**

**So, Jo, I’m very excited to hear about the launch of the Rare Disease Research Network. Can you please tell me what the research network is and what you hope to achieve with it?**

**Jo:** So the Rare Disease Research Network is first of all a bit of a mouthful so we’re going to try and encourage people to call it the RDRN. It’s a co-created project which really the patient-led research hub in Cambridge approached us about in 2022, I think, we started talking about this, approached CamRARE as a partner to apply for an NIHR partnership grant, and we were successful with that to really take the model that the patient-led research hub had already developed and found was successful, and perhaps too successful for its own good – they were receiving more applications and more ideas than they could manage – and to develop that into an online platform. So taking the same model, making it more accessible to a wider group of people, potentially worldwide, and providing the hand-holding that the patient-led research hub has always done, helping patients really consider their question, formulate that into a research idea, then do the literature search to find out “Is this question already answered, and if it is, great, can we provide that information to our community? If it’s not, how do we then build a team? Who needs to be in my research team? How do we then get funding together to take this idea forward?” So, it’s really taking the model, taking the good practice that already existed and creating an online platform to really attempt to replicate that as best we can.

So the platform will launch on 23rd November (2024) at CamRARE’s Rarefest which is a lovely in-person activity that’s going on in Cambridge, and that platform will be open to anyone who has an interest in rare disease research. But I think, critically, what’s different about this is that, you know, we’ve talked about setting research agendas and we’ve talked about patients contributing to that, contributing to setting the priorities, what’s different here is that the patients decide on the questions; it’s what matters to the patients coming from them and their community. And it’s an opportunity for them to showcase those questions and those idea on a platform and almost to have a call to action, “Is there anyone else on this platform who has similar research interests to me?” The platform will matchmake them together through a series of choosing tags, choosing tags about particular disease areas - It’s linked to the Orphanet database - choosing tags about the type of research that you’re interested in. That matchmaking process will happen, which at the moment is a very serendipitous process but we hope to take it a little bit further on from that. It’s still going to be a little bit of potluck who’s on the platform at the time who’s got similar interests as you but hopefully it will improve that serendipitous system. And it will allow them to access resources on the platform, which is the kind of hand-holding bit, and also, critically, some mentoring. So, there’s a real sort of opportunity here for professionals – researchers, industry partners, healthcare professionals – who have particular skills in research to be able to say, “Well I can help. I might not be able to be part of your team at this point but if you need half an hour on a Zoom call with me to think about your research question I can offer to mentor you on that.”

But, likewise, I think there’s going to be lovely opportunities here for patient groups to support each other too because what we’ve always realised is that patient groups are at different points of their research journey. You know, we see some organisations that are really well-funded now who are in partnership with industry, you know, they have a group of pharma companies that are supporting the development of treatments and they’ve kind of reached that point where they’re very highly skilled and very well experienced. And then there’s others who are mum and dad who’ve just had a recent diagnosis for their child, they’ve gone searching on the internet, they can’t find information, they don’t have a patient organisation to rely on so they’re going to make one themselves. This happens all the time in the rare disease field. There are 11,000 different rare conditions and there’s not a group for all of them so mum and dad will often start something themselves and then in lots of cases want to do some research, they want to answer some of these questions. So, you know, they’re really starting from a very different beginning stage here where they’ve going to need some help, and sometimes the best help comes from their peers, it comes from other patient groups. So that’s in a nutshell what it’s about; it’s about providing opportunity for patient groups to showcase their great ideas, build partnerships and take research forward.

**Rona:** The only thing just to add there is I think, although rare diseases are individually rare, collectively, as Jo said, they’re quite common, there’s 11,000 rare diseases, and often, although they all have distinct features, there are common threads through rare diseases in terms of maybe symptoms that patients experience or challenges that their rare disease brings. So, for example, you may have symptoms of pain or seizures that are common across many conditions, there may be educational needs that are threads going through. And groups could work together maybe to answer a question that’s relevant to a number of conditions and so bringing people together for that. Or there may be another group that’s already tried to answer that question in their condition and you can learn what worked, what didn’t work. I think that’s the other thing, is there will be common threads that come through, and I think that would be a real strength of the network to draw those people together.

**Jo:** I think as well, Mel, if we take this back to what we said right at the outset about optimising success for patients by bringing them into the conversation early, I think this platform provides the perfect opportunity to do that. So we’re moving away from, we’re really turning research on its head, moving away from it being a researcher-led activity where they decide on the idea and the research concept and bring patients in at different points along that research journey and instead starting with the patient’s idea in the first place. It can only be a better system for all because it improves efficiency, it improves potentially the long-term outputs and, most importantly, outcomes for patients.

**Mel: We were that family, that mum and dad setting up the charity a year and a half ago for the ultra-rare disease that our children had. I think, you know, the match-making opportunities that are here are fantastic because finding yourself in that position is incredibly isolating. And not only the matchmaking opportunities with the researchers but, as you were saying, Rona, as well with similar diseases; there’s so much to learn from other diseases that may have, I don’t know, a similar phenotype in the cells or similar symptoms. That’s what we found from connecting with these other rare conditions. So, for us it’s lysosomal storage diseases, we’ve now got the opportunity potentially to piggyback on drugs better used for their diseases for our own ultra rare condition, you know, where for us to run a full-on clinical trial by ourselves with a new drug, I mean, we just wouldn’t have, there’s no funding, there’s not enough interest. So, I think the opportunities that lie in this network are really, really exciting. Jo, can you tell me a bit more about who can join the research network?**

**Jo:** So anyone with a rare disease research interest. That’s everybody from individuals affected themselves, their family members, their caregivers, the patient organisations, that support them, and then, you know, all sorts of rare disease professional researchers. So, we’re looking for PhD students who are looking for their first exciting project to undertake, have they taken a look at the Rare Disease Research Network to see if there’s any ideas that might pique their interest. We’re looking for established researchers, medical professionals who are undertaking clinical research but also I think, importantly, companies. You know, we hear more and more about concepts like drug repurposing for rare diseases where we’re looking at the opportunities for taking drugs that already exist and have been proven safe to be redeployed to other rare diseases. It’s quicker, it’s more efficient, it’s cheaper, so does it open up opportunities for companies that are using that technique to get involved. And also pharma companies. This platform is not all going to be about finding cures and treatments but it certainly will be a priority for some groups. So we really are welcoming everyone with an interest in rare disease research to get involved, be part of the network, collaborate, help where you can.

**Rona:** And also, as we’ve said before, once you’ve got that level of engagement and the patients leading these initiatives we’ve found, certainly with our group, the patients are much more willing to, say, find the MRI scans for the scientists, to have a blood sample done, to have skin fibroblasts taken. If they know and they understand and they’re driven and, as you said, the research idea has come from them as a patient group it certainly increases the chance of them being fully involved in the project from the start to the finish. And all these things are imperative to understanding rare conditions because without researchers having the opportunity to look at these various samples you’re not going to stand much of a chance of finding a treatment.

**Jo:** And we want the opportunity to upskill patients as well. I think there are many people out there with great ideas who haven’t yet found the confidence to promote those ideas because they’re not quite sure of what the research journey looks like or what it might entail or whether they’ve got the right skills. But I think by joining the platform and almost kind of watching how other people are managing these things and utilising the resources and the mentoring I do really hope that will build that confidence and those skills sets in people so that they can engage.

**Rona:** Yeah, just to add to that, I don’t think it’s just upskilling patients and patient groups, I think it’s upskilling everybody involved in rare disease research. This is quite a different way of approaching research, it’s something that maybe academics may feel a little bit uncomfortable with, it’s not how it’s normally done, so I think there’s a whole learning process. And the aim is that this RDR network will evolve and will develop and the direction it goes will be driven by the community that are engaging with it. So I think it’s a really exciting time just as we’re coming up to launch to see where this goes.

**Jo:** Mel, you’ve been involved in this project, it would be really interesting actually to hear from you. I was just thinking, as part of the co-creation community we had 25 individuals from the rare disease community who built this platform from scratch with us; Rona and I might have set out all the vision for how we wanted the platform to be or what we thought might be a good idea but ultimately it was the community who decided and they literally have fact-checked and cross-referenced every word that’s gone on the platform. What has that experience been like for you as a patient representative?

**Mel: I think it’s been really welcome to see a network that is truly putting patients at the centre of everything. So, from the very beginning foundations you have the rare disease community involved which is exactly what you’re trying to create through your network. So, I think it’s been very welcome to be involved in the project and I also think that hopefully it will sort of be self-perpetuating that this will start to press a reset button on how we think about rare conditions and how it needs to be a more equitable field with patients. Because I think, as you’ve both alluded to, while some clinicians and researchers are very onboard with this, for others it’s a new concept that they still need to potentially adjust to or get their head round because it is a different way of thinking. But in rare disease, well, in any condition really but particularly rare disease because there’s so few experiences to draw on, I think that patients are vital to moving forward and to making that change so that diseases and conditions that have previously had no treatment, like, hopefully this way of thinking can expedite those treatments because, well, as a rare disease representative myself for our community that’s one of our biggest drivers. We’re dealing with a condition that’s progressive that affects most of our community’s children; that is what we want, we want treatment, we want something that can stabilise the conditions. You know, you can have researchers doing random projects that would make no difference to the final outcome of patients but if researchers know it’s a priority of this particular group, hopefully that can channel in their focus and get the outcomes that the patients want in a more timely collaborative way. So, I am a huge advocate for what you’re doing, I think it’s an incredible initiative. Is there anything either of you would like to add to that?**

**Rona:** Rare disease disproportionately affects children and young people. So, 7 out of 10 rare diseases develop in childhood and at the moment the Rare Disease Research Network hasn’t really got a forum for including children and young people, and really that’s partly because, and Jo can speak much more eloquently to this with her experience. Actually, we didn’t do that at the start because we feel that this is actually a discreet piece of work that really needs to be done in collaboration with children and young people to make sure that it’s done well so that they can engage in the platform. So, Jo, I don’t know if you want to talk about how we’re hoping to take this forward.

**Jo:** Yeah, so we’re busy developing a project plan at the moment which we’re hoping to get funding for to work over eighteen months with a team of young adults with rare conditions, probably from our Unique Feet community and keep it local because we already have a good relationship with them and they have our trust. But the idea would be to work with lots of other young people’s forums. So there’s already ones established in and around our area, such as Pedal, which works with really small children, and there’s also groups that are set up for young people with cancer. So we’ve already had lots of great conversations with them about how we can work with them, how they can help us sense-check our project, and then in return we can help them better understand research and their ability to be involved in that. But ultimately by the end we want to run focus groups, we want to develop some peer mentors within our community, so young adults who’ve, you know, perhaps come out the other end of a period of transition into adulthood who can support other young people with rare diseases to also become researchers, to come up with their own ideas and their own questions, and to sense-check projects that come through the platform. So it’s a really exciting opportunity to truly involve the people who are affected most by rare conditions but we know through our My Story, My Way project that this has to be done gently, carefully, given time and done really thoughtfully. So that’s our next step and we hope to be able to share those learnings with people so that it can be done elsewhere.

**Mel: And do you see the network also working with children with learning differences?**

**Jo:** Absolutely. We’ll invest a lot of time and energy in ensuring that materials are accessible, inclusive and suitable for the community that we’re working with.

**Mel: So looking to the future, how do you think, Rona, can patient-led research help to shape the future landscape?**

**Rona:** So I think, Jo used the term earlier, kind of this is really turning research on its head, so it’s really putting patients right at the centre of research, so it just makes sure that it’s absolutely driven by what matters to them to get the outcomes that matter. And, again, it’s just got all that benefit of efficiency and really answering those questions that matter.

**Mel: And, Jo, do you think this could lead to more collaborative partnership, for example, between industry and academia, potentially leading to quicker clinical advancement?**

**Jo:** I would absolutely like to think so. You know, as CamRARE we run a companies forum which is a roundtable meeting for pharma and biotech companies and other organisations like Genomics England who are involved in the rare disease therapeutic space and diagnostics, and I think one thing that I find really heart-warming about those meetings is that, you know, different companies are able to sit around a table as competitors but with a very open mind to addressing the barriers and the bottlenecks that prevent them from getting drugs to patients. Because of course it’s not just the research journey that’s a challenge, it’s the regulatory side of things at the end of that journey; just because you’ve created a great drug it doesn’t matter in the end if it doesn’t get to the patient. So, you know, access is critical and involving patients at the earliest possible moment to ensure that that treatment gets through to the regulators and gets access to patients is the only way forward.

We had a recent companies forum meeting where we were exploring health-related patient reported outcome measures, or PROMs, and we had a speaker from NICE who’s the regulatory body, we had a speaker from Sheffield University who was talking as an academic about developing PROMs for industry and for patient groups and we had Emily Reuben, the CEO of Duchenne UK, and we had an amazing discussion about the importance of involving the patient community from the outset. And the academic explained that developing a PROM for Duchenne UK had taken them two years and it had taken them that length of time because they’d followed this careful thoughtful pathway of making sure that they didn’t assume anything about what matters to patients. But that of course, as we said earlier, involves time, it involves financial commitment, it involves resources and the right attitude, but I do think that a platform like the Rare Disease Research Network can really try to harness all of those things by bringing the right people together – industry, academia and patients – to work together equitably.

**Mel: And with the network do you think you’ll be getting the regulators in at that initial stage as well so that, like you said, the patients can gain access while we’re dealing with their priorities, the regulators are informed at the very earliest stages so that we know the process that’s being followed will ultimately lead to patients gaining access to the relevant therapies?**

**Jo:** Yes, I think this is really important, and there’s actually, we’ve got a section on the new platform which really talks to each of the different stakeholders. ‘What’s in this for me?’ ‘Why is it important for you to be here and to join?’ And one part of that is funders and that includes the regulatory bodies. And at the next companies forum meeting we’re actually going to be bringing the Rare Disease Research Network Platform and its potential to the companies forum meeting and we’ll have regulators involved in that. So, you know, we are constantly talking to people about why it’s important for them all to be involved and all to see what matters. I think I’d like to advocate for an extra letter at the end of PPIEP - if we could squeeze a D in there at the end too. So over time that terminology has expanded to be Public Patient Involvement Engagement and Participation, which was added I think this year, but it would be lovely to have the D on the end and to include ‘Driven’ because I think what’s really important about this platform is that it’s not just engagement and involvement, it’s not just participation, it’s initiated by and driven by patients.

**Mel: So I think we’ll wrap here. Thank you to our guests, Jo Balfour and Dr Rona Smith, for joining me today as we discuss the role of patients in setting research agendas. If you’d like to hear more like this, please subscribe to Behind the Genes on your favourite podcast app. Thank you for listening. I’ve been your host, Mel Dixon, and this podcast was edited by Bill Griffin at Ventoux Digital and produced by Naimah Callachand.**