Season 2, episode 5: Research using lung MRI in CF

Lucy (host): Hello and welcome to season two of CForYourself, a podcast brought to you by UK charity Cystic Fibrosis Trust. I'm your host, Lucy Baxter, and I myself have cystic fibrosis. I'm one of over 10,900 people in the UK living with the cystic fibrosis.

Now, CF is a genetic disease that causes a build-up of sticky mucus in the lungs. So that means I can experience a range of different symptoms, like struggling to put on weight, feeling breathless and being tired. I was diagnosed with CF at two years old, but CF is part of my life, not my whole life. And it definitely doesn't define who I am.

In each episode of CForYourself, I'll be having a virtual chat with others in the CF community. We'll be talking openly and honestly about a whole range of topics from the latest research, employment and growing older to interior design and appearing on reality TV. We'll also hear from CF experts who will be sharing their knowledge and advice for everyone affected by CF.

Welcome back to season two of CForYourself. In today's episode, we're going to be talking all things research. Now, in July 2023, the Cystic Fibrosis Trust, together with the Cystic Fibrosis Foundation, announced the £1.4 million funding of two new strategic research centers or SRCs to target key research priorities identified by people with CF. SRCs are virtual centers of excellence, bringing together researchers from within and outside of the field of CF, supporting scientists and other specialists around the world to work together to address specific issues arising from cystic fibrosis.

Since 2013, the Cystic Fibrosis Trust has funded 25 SRCs tackling everything from joint pain to gene editing. The first new SRC **Pulmonary Magnetic Resonance Imaging for Cystic fibrosis** called the Magnify Study, is run by Professor Jim Wilde at the University of Sheffield, which will investigate whether an exciting new type of magnetic resonance imaging (MRI) could be used to track subtle changes in long health over time.

This could be used to manage the day to day health of people with CF, as well as checking the effectiveness of new treatments in clinical trials.

To find out more about the Magnify SRC, I'm going to be talking to two of the researchers involved, Dr. Laurie Smith and Dan Beever. Lauire, who is based at the University of Sheffield, specialises in understanding more about how the lungs of people are affected by the condition and developing better ways to monitor changes in lung function in people with CF.

While Dan, who has CF himself, works to ensure that patients are involved in determining the purpose, design and implementation of research studies and clinical trials. I'm really, really excited to be chatting to Laurie and Dan today to hear more about this SRC and their research. We'll also be hearing from Dr. Lucy Allen, the Director of Research in Healthcare Data Trust, to give us the lowdown on the research they fund and the importance of these SRCs for the CF community.

CForYourself is all about sharing honest insights into life with cystic fibrosis, the good, the bad an absolutely everything in between.

I'll be sharing some of my own experiences too, but my views are all my own, and not necessarily that of the Cystic Fibrosis Trust.

If you'd like to get in touch to share your thoughts on the podcast, we'd absolutely love to hear from you. So please email us at **podcast@cysticfibrosis.org.uk.**

In this episode we talk about some topics that you could find triggering. So if you'd like to speak to someone, the Trust has a helpline and you can call or email to chat to one of the team. They can provide information or support with any aspect of cystic fibrosis, offer a listening ear, or just be there to talk things through.

You can call them on 0300 373 1000 or email **helpline@cysticfibrosis.org.uk.**

Now without further ado, let's welcome Laurie and Dan to the podcast.

Hi Laurie and Dan, welcome to CForYourself. How are you both doing today?

Dan Beever: Yeah, great, thanks.

Dr Laurie Smith: Very well, thank you.

Lucy: Laurie, you go first. Can you kind of introduce yourself and how you're connected to the research and also kind of what you're doing in the in the world of CF? And then I guess same for you Dan and a bit about yourself.

Laurie: So my name's Laurie Smith, I'm a respiratory physiologist by profession, and I currently work at the University of Sheffield. But before that I spent a large period of my career at Sheffield Children's Hospital doing lung function testing as a day job and working closely with the CF team and along my career I've had various interactions directly with the with the CF world.

I did my master's degree at King's College in people with CF. And then after returning from that, I started working with the university on the kind of work that we're doing now. And I did a PhD looking at lung function and imaging in people with CF, and I've not stopped since.

Lucy: I mean, I have so many questions about that which I'll dive into after. Dan, you tell me a little bit about yourself.

Dan: Yeah, sure. So I'm Dan Beever. I am currently the patient and public involvement and engagement lead for a lung charity called Action for Pulmonary Fibrosis. But I'm going to be leaving shortly to start the research that we're obviously going to be talking about. I also have cystic fibrosis, and I live in Sheffield, so I've worked in health research, kind of the vast majority of my career.

I worked at the University of Sheffield for a long period and I'm one of the particular areas of interest that I've had, which is very much behind my my current post is working to support the involvement of patient communities in the research that takes place, that affects them. So whether that is cystic fibrosis or other areas, it's really important that we have that input, so that we have robust research that that people want to get involved in.

So that's kind of always been a real passion of mine and that's sort of a big interest behind this project as well. But yes, I'll be guiding to be shortly one of the PhD students that's part of this research program.

Lucy: I mean, again, so interesting, and I think the whole kind of research into CF and other rare diseases is getting so important as as things are breaking through, especially kind of things that are treating not just the symptoms anymore and understanding a bit more about things that are happening.

I know there's a lot of studies also now in the process of kind of longevity with CF and sort of additional things that people with stuff may may face.

In terms of lung function, Laurie, it it's down to a bit of technique as well, isn't it, in terms of kind of learning the right way to do the FEV1 and also kind of understanding, I guess, what it's showing?

It's an important obviously part that's measured in in clinic. And also it's something that I guess from a young age, the techniques important.

Laurie: Yeah, I mean, you're correct and I joke to patients and families that my job title is really professional bully because at the end of the day I'm there to coach people through what's a really difficult and tests for people to do.

And we acknowledge that we know how hard it is and we we give people the time and energy to get through it. And actually the tests that people with CF have done for most of their lives has been really useful, but is actually one of the main reasons that we're doing the research in the first place, because it's a difficult test and it isn't actually necessarily telling us a huge amount about people's lungs and CF, particularly at the minute in in this kind of new era that we're in.

And it certainly doesn't relate back to how people with CF feel about what's going on in their chest. But yes, yeah, going back to the beginning, it's a really tough, difficult test to do because the technique is so important for the numbers to come out correctly.

Lucy: And I guess Dan growing up with CF as well, like, like me, when you're in paediatrics with the lung function, it was like a cake or it was a clown or something.

You had to blow it and it would blow the candles out or pop the bubbles, you know? And then as soon as you're adults, it's the graph and you kind of trying to make make kind of sense of it. What was what was that relationship you had with that with lung function?

Dan: I guess I'm probably showing my age a little bit in that I don't think I had any of those fancy things that paediatrics when I did it Lucy, to be honest.

It was a probably a much friendlier environment, I suppose, than than kind of the more grown up experience that you have in adults. Definitely. And I think, you know, I think there's a lot going on with lung function like we talked about with the technique. And also I think it's a very different experience going to do as an adult when your health isn't in a brilliant place and often you might be going to clinic on your own.

And that in itself can then be quite difficult if the results aren't great. Whereas I suppose you know, when I think back to my paediatrics experience, although I didn't have the fancy ballons and whatnot, I obviously I had my parents there with me and it was just probably just a lot of an easier time for me personally because although I did have some quite bad had some quite bad health as a young child, kind of a lot of my childhood was relatively stable, I suppose so, yeah.

Is it it's so something that I've really really struggled with and so I was, I'm kind of was naturally quite interested in the work that Laurie and his team have been doing, particularly, like I say, with the stage that we're at now, I guess with CF care where where we need to be, I guess, thinking about what does the future looks like and stuff like assessment as well.

mini interlude with slurping sounds, and a spoon stirring against a mug

Lucy: And I guess Laurie touching on, on what you are looking into and kind of research, tell me a little bit about about that kind of start at the beginning and kind of take me up to where you are or where you hope to be in, I don't know how long it will take.

Laurie: Big question. Right. The tests that we've just been talking about is called spirometry, and it is a very good test. Objectively, they can tell us an awful lot about where somebody's lung function is, but it's major limitation other than the fact but it's really difficult to do is that it's really not a very good test to telling us about early changes in lung function and subtle changes in lung function. And we're at a stage now where more and more people's lung function is in what we would call a normal range.

So when you compare the numbers that you achieve to what we would expect in a normal population, the numbers are not much different. But we know that there's still something probably going on in people's lungs that we might need to be aware of. And so the community in lung function research, for a long time, 20 years or so now in CF, has been looking at better ways of measuring those early changes in people's lungs.

And there are a variety of breathing tests that we can do now, which are a little bit better. They're not quite as hard work as spirometry. They involve maybe breathing into machine for a little bit longer, but not with any kind of force and then those are really good tests as well. There's a test called multiple breath washout, which measures the clearance index, which has gained a lot of focus in research, in recent years it's a test that can be done in the clinic and

can tell us some really useful things about early changes in lung function that we might need to deal on.

But what we specialise on in our group at the University Sheffield. So our group is called POLARIS, and led by Professor Jim Wild, and he has developed a technology alongside colleagues around the world, where we can image lung function using magnetic resonance imaging scanners. So a normal MRI scanner in the in a in a hospital when you program it correctly, so you need people who know how to do this, and prepare a gas called xenon, special gas, that we can essentially make a little magnetic, so that when you breathe it in, we can take a picture of where the xenon can reach in the lungs. And most importantly, if there are any areas in the lungs where it can't reach.

So we can take a 3D image of lung function in a standard MRI scan just by them lying in there, breathing in the gas and holding their breath for 10 seconds. One of the main reasons for this research being developed in the first place was people with CF, because we've always acknowledged that we need to be able to pick up the earliest changes as quickly as we can because we know that it's likely people will develop lung function problems and we want to get there early to treat it.

And we've subsequently shown over the last 20 or so years with this type of imaging that we can pick up really, really small, subtle changes in lung function that other tests are looking completely normal on. So we know we've got really, really good tests that not only quantify early lung function problems but be able to show people that they've got lung function problems as well, kind of where in the lungs it is, a very simple intuitive picture that shows that these problems are and the main kind of focus of this bigger project now is to establish this imaging in this new era of CF.

Ok, we did lots of imaging prior to Kaftrio being widespread. So we want to know what people's lung function looks like now, but we also want to be able to establish our techniques in most centers around the UK and there are other centers that tried this imaging in the past and we want to try and enable them to get up to speed to where we are.

And we'd also like to explore why other centers other big CF centers couldn't perform our imaging, if you like, and really try and make it more feasible for other centers to join in.

Lucy: Well, you want it to be replicable as well, don't you? And kind of accurate across all the centers. And I think it's just so interesting when it is when it has an is such an important part, you know, in the pandemic as well.

I know at my my hospital, the spireometer kits at home, but obviously they're not the exact same as the hospital one. And then you transfer your data and you're thinking, oh, gosh, on this percent here, I'm that percent there. And then you get told it doesn't matter about percentage, it's the liters. And then you look at all the different things and it's is a lot of stuff.

And I guess if stuff was picked to happen on your your test that or the test wouldn't wouldn't pick up on, what would then happen you. Say if there was something in that image, would that be something the doctors then could treat or is it something they'd watch or is it kind they'd be able to target that specific area?

Laurie: We we take clinical referrals in our center for cases where they suspect that something might be going on, but the tests showing it and they may create an image from from some of their patients and look at it and decide that maybe they need to potentially do a bronchoscopy perhaps or some need some more antibiotic treatment and then we can re scan afterwards.

And there's no the the advantage of MRI imaging is that there is no radiation involved. So we could do as many scans as we need to to try and get to the bottom of the problem. The the idea is first of all we need to establish what people's lungs look like at the minute and then widespread utility should be available in the same way that you use spirometry at the minuite, in an ideal world.

Lucy: By when?

Laurie: The aim of this project is to get more centers to be able to do it, we're hoping to be able to replicate the software and hardware, that the scanners currently need into other centers. We know other centers are interested in imaging, but we need to understand the barriers to implementation first.

Lucy: I mean, this is so exciting. And I think I think if research doesn't excite people like, you know, it's everything that's changing and there's so many like clever scientists and researchers and doctors like yourselves looking into it, and it's just like incredible.

Dan, I want to know why kind of how you got involved and how you two met and kind of your interest in research, too.

Dan: Yeah, sure. So so like I said, I spent most of my career working in health research in one way or another. So I originally did a degree in law and then switched into working in health research. I did my master's a number of years ago and I worked in different roles at the University of Sheffield. Paths crossed with Laurie there because he was doing his PhD.

So he was applying to do his PhD and applying for funding and that obviously, when he's project got funded, because he was looking to scam people with CF, I ended up taking part in that research. So then because I was having these visits, research visits, we obviously were chatting about the the work that what I was doing and so there was that connection there. My background in recent times has been working to involve members of different communities in research, so what we call public involvement. And Laurie approached me around this research study to say, you know, could you perhaps help us a little bit with the involvement we're looking to do in it. And then we just got talking from there. And actually a few years ago I had applied to do a PhD in something CF related as definitely sort of formed in recent years as an area of interest because you know I really love working in research and I guess having that

personal experience and interest around CF, it would be really nice to marry those two things together.

So I applied and obviously these things are super competitive and so I didn't end up getting anywhere, and I come to terms with that, just I find my way in another way in research. But yeah, then this opportunity came up, to be part of this lung research and to do my PhD. So, you know, it very much feels from my background like kind of when you won the lottery to to have this opportunity.

And, you know, I'm so grateful to Laurie and colleagues to have been able to involve me in this. And I guess there's some nice sort of circular element to this in that, you know, I assisted Laurie when he was doing the PhD and obviously he's helped me to have this opportunity to do my own. So obviously lots of hard work ahead, but really excited to be part of it.

Lucy: And I guess some people might be like, Gosh, your living with CF, you're doing a PhD. about CF with studies ins? Like does it not get a bit much? Do you ever get a bit too CF'ed out?

Dan: I mean, I think there's always that dangerous. And I did actually work on a CF study a few years ago and I found that was okay.

I think like anything in life, it's about having a bit of balance and doing other things Well, actually, you know, this is just something that's really meaningful to me to be able to use my own personal expertise with it as well. And I'm certainly not the only person who has CF and works in health research as well, because I know plenty of others.

But, actually there aren't that many people out there who perhaps have that close personal connection with the area that they're researching. So, I mean, to me, it's a privilege really to be involved in in this way, you know, I very much hope that it adds an extra dimension to the work that we're doing.

And hopefully that is something that's fruitful for the community at large but erm, but yeah, I've got a failing football team and a young family to sort of give me something to focus on away from the research so yeah.

mini interlude with slurping sounds, and a spoon stirring against a mug

Lucy: So Laurie, with, with the strategic research centers, how did this particular project come about. You talked about what it is, but kind of the fundamentals of having the idea of research and then actually being awarded the money, etc., to do it, How how did that happen?

Laurie: It goes back a little bit to what I was saying before about our history within our research group and working with people in CF. So, we've kind of been putting the the blocks in place, if you like, for quite a while and we receive some money from the CF Trust or certainly my, my boss Jim did in 2012, I think it was, where we started to really understand whether this imagery could be useful for people with CF.

And off of the back of the work that we we performed back then and then my PhD afterwards we knew that we had a good idea of what people's lungs look like on our imaging modalities and in lung function tests, prior to the kind of new modulator therapies that are now widespread. And after COVID, well, COVID kind of paused all of our CF research and we were looking into what we could offer the CF community now.

And we thought, well, actually, we don't know what people lungs look like anymore. We don't know what difference Kaftrio and other drugs have made to people's lung function, and it'd be really interesting to see firstly, what the people who had been studied before looked like, but also acknowledging that our technique is very good at picking up early lung function changes and for future trials of therapy, particularly for people who aren't eligible for modulators, we're going to need technology that is very good at picking up small lung function changes, subtle lung function changes, and we know our technology has the potential to do that.

And so part of this project will be to look at people who aren't eligible and see what their lungs are looking like, and kind of pitching our technology then as a trial endpoint for people to to use. So the motivation has been has always been there to keep working with CF.

And our collaborators who we've worked with before in Manchester, have a different approach to this, where they look at the kind of mathematical side of lung function modeling. So they will take our data and try and predict what people's lungs look like and what lung function tests are like. And so we've always had a collaboration with them and we knew that Nottingham have always performed our type of imaging as well. And they also have this long standing history of performing really good qualitative research in CF. And so we thought that the three centres together would be a really nice way of really pushing MRI forward in the CF world and trying to establish it better and from different approaches.

So again, in Sheffield, we're going to do a patient focused study where we get lots of people through the door again to see what people's lungs look like. We're also going to do a project where we try and understand whether we can take the sequences of, so whenever we do an MRI scan, we call it a sequence, and so whenever we do an MRI exam, we do lots of different sequences on patients to image lots of different aspects of how the lungs work.

And so we need to be able to take those sequences to different hospitals, different scanners, see if we can make them work. And we also need to give them software to help analyse the images afterwards. So we're going to do a project around that as well. Finally, we've got the project that Dan is going to hopefully succeed on, which is going to be exploring what the images look like for people with CF, because they're very, very intuitive images.

You look at it and you kind of understand straightaway what it's showing you. And so if we're if people with CF are out there thinking actually my lung function is really good these days and we and we show them an image that maybe has a small abnormality on it that we don't necessarily know what it means yet, then Dan's going to hopefully help with how people read that and what they want to know from it and what clinicians want to know from it as well.

So we we approached the CF Trust when we saw this funding, pitched this idea forward, and we're really grateful that they thought that it was a good project to take forward. And we really believe that we can get MRI into standard clinical practice in the future.

Lucy: You kind of hit the nail on the head a bit earlier in your answer about how all research that's happening now is not just for post-modulator people, it's for everyone.

And in fact, those who aren't on on modulators, there are some really exciting things coming through for them for everyone. You know, it's not just and it's reassuring for those people that you're not just focusing on the ones that can take Kaftrio and and Symkevi, Orkambi etc. you're focusing on everyone. And I think that's a thing that will mean a lot to people and they'll think that they've not been forgotten.

Dan, tell me a little bit about kind of why it's important that patients are involved in these in research and clinical trials. You know, I've been in a clinical trial myself. I really am fascinated by science and all that kind of side. But but why is it important to get kind of a good plethora of people as well?

Dan: Yeah, I mean, I suppose it's two things really in terms of research and I guess the work I've done in the past and will be doing here in that, you know, we think about the context of participation, which is people taking part in research, which is obviously incredibly important because ultimately we can't generate the new knowledge and understanding of of any given area without people taking part.

So there's a huge it's hugely important that that people do get involved. But then there's also what like I say, we would term as involvement, which is another element to this as well. So that's how people actively shape the design and delivery of research and the two basically link so closely together because, you might have a study that's in a really, really important area but actually if it isn't designed well or perhaps the question isn't focused enough towards what actually is meaningful to your community, then people perhaps won't choose to take part or they might start to take and then decide actually that they can't continue through the lifetime lifetime of a project.

So that's something that will be really important in this work. So as well as doing the PhD, which Laurie mentioned, will be focused on developing this toolkit to aid that communication between patients and clinicians, I'll also be leading on the involvement work across the strategic research center, which will basically be how we involve members of our community in the work that we're doing.

So there'll be lots of opportunities for people to get involved in those as well. But yeah, it's obviously really essential that we have kind of a breadth of people that get involved, obviously by having that that, that variety as people, then obviously we have a greater understanding that what we're actually doing is then going to be meaningful and useful and when it goes out into clinical practice, hopefully.

But like I say there are lots and lots of opportunities that people have to get involved, not just in this project by actually research more generally. And I think sometimes people can look at opportunities and particularly with trials that can be quite restrictive in terms of criteria to take part, which can then be quite disheartening to people. And as we spoke about before, well as you touched upon before, you know people that are not eligible to have the modulator therapy, you know that that might be an exclusion criteria perhaps, but there is lots of research happening. And even if you can't take part in research, there are lots of things, like we would say, the term involvement opportunities where people can kind of actively provide that voice towards what is going on and really make sure that we're doing research that is meaningful to our community. And obviously the Trust does loads great work around involvement as well.

So I think that's something to people to definitely be aware of if they aren't already and ultimately we don't get to where we are now without research taking place and people taking part in that, you know, obviously, you know, I'm 38 years old and without research we probably wouldn't be having this conversation ultimately when you look at it like that.

So it's essential. And I think we have to do all we can to shout about it and also make it as inclusive as possible because we're aware that's a real challenge across research, not just in CF and making sure that people are aware of the opportunities and are able to access them.

Lucy: And also is important for fundraising, isn't it, for the CF Trust and charities to be able to put money into the research which will effectively move the condition along and move the treatment along.

I'm guessing when you do your involvement with other CF people, having CF yourself, is it virtual? Kind of, how do you do that?

Dan: Yeah, it would be virtual. I mean, obviously that's a slight limitation I suppose, as being someone living with CF, but I suppose we also now live in a world where so much is done remotely in maybe ways that it wasn't done in the past. So yeah, so this study will be doing stuff online.

mini interlude with slurping sounds, and a spoon stirring against a mug

Lucy: And Laurie, you touched on it earlier about your interest in it. Do you remember a time where you like first, I don't know, learnt about CF or kind of that moment, like, wow, this is an interesting condition. Like, you know, you know at that moment that you wanted to you know, you wanted to invest a lot of your time professionally into looking into it?

Laurie: My profession as a respiratory physiologist, you're used to seeing lots of people come through the door. We test their lungs and then we say goodbye to them. And when I first started working at the children, I trained in adults at the Royal Hallamshire in Sheffield, and then I moved to paediatrics very quickly in my career, and it was working with children and then dealing with the CF clinic.

So I was like, oh, this is this is a very different place to the rest of the clinics that I was involved in. You're seeing people much more regularly, which was really nice. You get to know the families and from there I started to understand a little bit about why CF was unique from a respiratory point of view.

And then I guess it was when, so when the when the CF Trust funded the original research that our group performed back in 2012, my my current boss approached me as the as a clinical physiologist in the children's and said, would you like to be involved in this project? And so it probably stems back to then because that was my first involvement in CF research. Seeing what impact research could make on a respiratory entity and how interested people were in the findings. But then also seeing people engage with research on the other side I found fascinating, and then I kind of stumbled into a research opportunity at King's to do my master's in people with CF, and that was the first time I had to academically write about CF and, and I guess I've probably been hooked from there really. And I've always felt that I wanted to help people.

As a physiologist we don't treat people and we don't we're not involved in the management in that sense. So academia is a is a really obvious way for me to be heavily involved in in a process like CF. And I've really enjoyed that. I really enjoyed contributing to the science and contributing to the CF world in a little bit.

Lucy: When you're involved in a study, in a trial and research, as someone with CF, or you know, as anyone, you learn so much more about your condition and kind of when you're a child diagnosed or whatever age it's, when you've you've got a lot of mucus in your lungs, you know, you get tired easily, you struggle to put on weight, so you need your Creon®. But like the actual going into how stuff works, I didn't realise all of that and kind of the difference between Symkevi, Kaftrio, and like the difference in the CF mutations and what gates are open. And what was that like salt is it that doesn't get pushed out or whatever. Like that by being involved in the research you just learn so much more as well and then you're more educated about your condition and you're able to kind of figure things out as well. Would you agree with that Dan?

Dan: Yeah, definitely. I do think it's, gives you a real insight into different things. You know, some of the studies I've worked on, not necessarily just in CF, you know, you get a real insight into the specific details of conditions.

And yeah, definitely from my personal perspective and I've been involved in CF research, either supporting it or when I've participated in projects, it definitely does give you a much greater depth of understanding, and often there are tests that you might do as part of a research study that you perhaps wouldn't normally have seen in clinical practice, I guess. So that in itself is quite interesting, you know, just to get to be doing something else and find out something else about your condition. So yeah, absolutely.

mini interlude with slurping sounds, and a spoon stirring against a mug

Lucy: You first Dan, what are your hopes for the future in terms of research, but also maybe like obviously you'll finish your PhD and then be a doctor, kind of where do you see yourself and kind of your research interests?

Dan: I've got three, three long years ahead to get the PhD and, I suppose, nature of living with CF, maybe I've never looked too far in the future, but, you know, absolutely. I mean, what I want to do and what I wanted to do for years is, is to kind of forge a clear, I guess, more more in research. So being able to perhaps lead on some grants would be fantastic.

You know, I mean, real area of interest to me is qualitative research and, you know, having these conversations with people to learn more about experiences and opinions. That's always been a real area of interest. And obviously that's what I'll be doing in this study. So that lends itself well, hopefully to future opportunities to be involved in CF research.

And not all the treatments are obviously available to everybody as things currently stand, and so it's really really important that those people don't get forgotten. And I'm sure they won't with with things coming down the line. But it's the transformation in CF care, I suppose when I think back, even just in the last five years or so and then certainly going back to when I was a child, it's just been absolutely incredible.

So, you know, let's just hope that we continue to have that same rate of progress in stuff. And, you know, I'd love to be able to provide a contribution to that in some way, you know, because I'm so incredibly grateful, like I say, for everything research has given me, both personally and professionally.

Lucy: Yeah, and, you know, like you were saying about research, I mean, Creon®, DNase, Pulmozyme®, that was a big one, you know. And then the modulators, like they seem to be, seems, just off the top of my head that were big game changes in in our treatment. You know how do you even have time for you know your research, you said you've got like a family, like like every credit to you.

Dan: You know I think it comes with having a very understanding wife in the first instance. And yeah, I mean, everyone's got lots of things going on and I think that's always the nature of living with a long term health condition. There are lots of challenges to keeping all those, sort of, plates spinning, you know, like I say, I'm very, very grateful to be able to now have this opportunity to kind of focus on this research for the next three or so years.

But yeah, I think it comes definitely comes with having this very understanding family I think, so I'm very, very grateful to that. And I think that can often get forgotten amidst all these things. Obviously, you know, I might be the one that's working on this particular project but there's lots of the people that obviously help to enable that in one way or another so.

Lucy: And then I guess, yeah, same question for you, Laurie, kind of obviously this study and this research will be what you're obviously focusing on, but kind of what are your kind of future, future hopes for the research in cystic fibrosis, what you would maybe like to do next?

Laurie: Yes, I think I think we're at a stage where we can we can roll this type of imaging out on or certainly explore how we can get this imaging into other centers, because we really believe that it is the best way of measuring people's lung function in terms of detecting the early changes that we need to be able to see these days.

And so I think ultimately that's going to be a focus for for a little while is is helping other centers that want to to do this, giving our experience to them and hopefully accelerating them and not having to go through the same processes that we've had to over the years. And and that's. And that's certainly been my boss's ambition for a while.

And then ultimately, that then gives everybody with CF access to this type of technology, if if the other major centers can also do this, I mean, we currently we can we can have a referral from any other center to us, if they wanted this this type of imaging. But obviously we don't want people to have to travel and miles to be able to do it.

So I think the main ambition is to understand this type of imaging better in all of CF, everybody, and get people access to it. So we specialise in a type of imaging where we can measure lung function. But in terms of trying to replicate what a CT scan can currently do, so that if you've ever had an image before, it'll be a CT scan or an X-ray.

But the CT scan gives you more detailed and historically, MRI has never been able to get anywhere near the level of detail that a CT scan, a CT scan can. But we're now approaching that in a different type of MRI technique that we can do in the same session, and that's going to get even more and more advanced over the next few years.

So, you know, maybe we can even start to replace the number of CT scans that need to be done by using MRI, either as a screening method for those who most need a CT scan or ultimately maybe not needing it at all. For example, in children. So yeah, there's the two types of MRI scans, both measuring lung function and the structure of the lungs that we hope we can really push forward.

And certainly the structural imaging to replace CT is going to be a much easier thing for the other centres to be able to do. So, I think that, in terms of CF, that's that's what we want. And then I'm broadly, as well as a pediatric specialist in the past, I want other paediatric respiratory problems to access this technology too. So we going to try and replicate this broad, more broadly as well.

Lucy: I could listen to you chatting all about this all day and it's just so, so interesting. And yeah, something I'm looking forward to kind of hearing more about as time goes on.

Thought it'd be fun to end the podcast seeing as how you're from the University of Sheffield, with a fun Sheffield fact that I have, which you might know you might not know, but did you know that there are more trees than people.

Laurie: Greenest city in Europe, supposedly.

Lucy: So I want to thank you both Laurie and Dan today, for coming on the podcast chatting about that. It's been really, really interesting and I think it'll kind of open, open doors for people who maybe haven't really ever listened to things about research and kind of want to get more involved and and hear more about it. So thank you.

Laurie: Thank you for your time as well as. Thanks you for the invitation.

Lucy: It was lovely having to catch up with Laurie and Dan. It was so interesting and they were just so passionate about research and in particular their SRC. Thank you so much to the both of you for joining us on the podcast and sharing your expertise and knowledge with us. And best of luck with the PhD, Dan.

Izzie (Content Lead): A big thank you to Lucy and Laurie and Dan for sharing their expertise and stories.

Now we're going to be finding out a little bit more about the importance of funding our research here at Cystic Fibrosis Trust. My name's Izzie and I'm Content Lead at the Trust. And now I'm joined by Dr Lucy Allen, our director of research and healthcare data.

So hi, Lucy, thanks so much for joining us on the podcast today. Would you be able to explain a little bit about how SRCs work?

Lucy Allen: All right, of course. So SRCs or our strategic research centers are Virtual Centers of Excellence, and they bring together different groups of researchers, either from the field of CF or from outside of the field of CF and their funding that support scientists and other specialists in the UK and also around the world to work together and come together to do research that addresses the specific needs of the CF community.

And so, for example, we've got SRCs looking at helping us understand cystic fibrosis related diabetes, how gene editing can be used for cystic fibrosis, better understanding tummy symptoms and infections. And so there's just various SRCs that we're funding that look at different challenges and priorities for the CF community with the aim at eventually helping to develop new ways of treating cystic fibrosis.

So usually the lead researcher is based in the UK and then they can include partners from around the world. So we fund collaborators in Europe, across Europe, also in Canada and the US and then so the SRCs are grants of up to £750,000 and they're funding for 3 to 4 years, and they were started in 2013 and since then we've funded 25 associates and that's funded over 140 scientists and they're across 50 different cities and 15 countries around the world.

So they're a great way to bring in different types of researchers together to help us tackle some of the really tricky, challenging problems in cystic fibrosis.

Izzie: And why are they so important for the CF community?

Lucy Allen: Well, they're really important because they're a great way for us as the Trust to fund research that we know is really important for the CF community and also because they're

quite well respected within the research community and are relatively large scale funding grants, they mean that we can attract more research and build research expertise in cystic fibrosis, primarily in the UK, but also internationally.

So again, that helps us make sure that we're funding research to address the areas of most need. And also in the application forms for the strategic research centers, we ask the researchers to tell us why the research they're proposing is important to the CF community and to tell us what impact that's likely to have at the end of their funding or throughout the funding, and then through our grants review committee and which includes members of the CF community, they review this information and then that helps us make recommendations on which strategic research centers we should be funding.

So through that process, we make sure that our funding is being used to set up these SRCs, which are helping to address the research challenges which are most impactful for the CF community.

Izzie: Why is funding so important and why do we need more money for research?

Lucy Allen: So the funding is really important and we are really appreciative of the fundraising and the funding from our supporters because without that, it simply wouldn't be possible to fund this really important research.

And as you'll know, last year we asked the CF community, clinicians and researchers to tell us what they felt the research priorities for cystic fibrosis were, and we want to be able to fund more research that helps us address these priorities. And throughout the funding cycle and through that process of reviewing these applications for strategic research centers, we have to make some really tough decisions about which of the applications we can fund, and we'd love to be able to fund more research than we do already, to make sure that we are addressing these priorities and are delivering research that supports the entire CF community.

Izzie: So for people that are listening that might maybe want to donate, where can they go to do that?

Lucy Allen: There's lots of information on our website. If you go to our website and look at the research pages, there's lots of information about the different types of research that we fund and that will give you an idea of the sorts, the breadth of the research portfolio, and also shows you the different ways that you fund research. So through our SRCs and various other ways of funding as well.

And then if you go to the **'Get involved'** pages of our website, the Trust website, there's lots of information about the various ways that you can donate and help us support and fund more research, which is obviously really important to us.

Izzie: Amazing, thank you so much Lucy for joining us on the podcast today.

Lucy (host): Thanks so much Lucy and Laurie and Dan for sharing their expertise and experiences and a huge thank you to you all for listening.

For more information on what we've talked about in this episode or to donate and help, make sure everybody with CF can live without limits, please see **cysticfibrosis.org.uk/podcast**.

If you've enjoyed listening to this episode CForYourself, don't forget to subscribe rate and review so you can keep up to date with when each episode comes out. But that's it from me for now. Thank you so much for listening and we'll see you next time.