Season 1, episode 8: CF Week: Research and CF

Lucy (host): Hello and welcome to CForYourself, with me, your host, Lucy Baxter. The podcast brought to you by UK charity, Cystic Fibrosis Trust. I'm one of over 10,800 people in the UK living with cystic fibrosis.
CF is a genetic condition that causes a build-up of sticky mucus in the lungs. So that means I experience a range of different symptoms like breathlessness and malabsorption. I was diagnosed with CF at two years old but CF is part of my life, not my whole life.

Welcome to this CF week special episode of CForYourself!

CF week 2023 is all about experiencing and celebrating all the incredible progress we've already made in CF research, and looking forward to the breakthroughs we can make in the future. Together as one united community.

To find out more, I'm going to be having a virtual catch up on this very podcast with the lovely Alice Collins and her brother Alexander.

Alice is a CF researcher and is currently finishing up her PhD at Imperial College where she is investigating the bacteria *Pseudomonas,* the most common cause of chronic respiratory infections associated with CF patients.

Her brother, Alexander is a secondary school teacher and has CF himself. In September 2020, at the age of 40, Alex received the life-changing news that he was eligible for Kaftrio.

"As I work on *Pseudomonas* which is the bacteria that Alex has, he finds it incredibly humbling that not only I chose to work in CF but specialise in studying this bacteria," Alice said in a blog for us last year. Alex said that Alice's work is more emotional and significant to him than receiving his Kaftrio treatment.

I'm really excited to be chatting to Alice and Alexander on the podcast today and to hear more about Alice's work, Alex's CF journey and what it was like growing up together.

CForYourself is all about sharing honest insights into life with cystic fibrosis, the good, the bad and 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 love to hear from you. Please email us at podcast@cysticfibrosis.org.uk.

In this episode we might be talking about some topics that you could find triggering. 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 aspects of cystic fibrosis, a listening ear, or just be there to talk things through. You can call on 0300 373 1000 or email helpline@cysticfibrosis.org.uk.

Now without further ado, let's welcome to the podcast… Alice and Alexander.

So welcome to CForYourself both of you. How are you doing today?

Alexander (Alex): Yeah, I'm great thanks.

Lucy: So Alex, first of all, could you tell us a little bit about your CF journey where you're at and things like that, please?

Alex: Yeah, sure. My CF journey being born in 1980 I wasn't actually originally diagnosed until the age of seven. Throughout childhood, I was always really unwell. I caught everything and everything, everything and anything you could think of really, and back and forth to the doctor all the time.

I know from discussions with my mum, for example, she take me back and forth to the doctor so many times with so many different illnesses that the doctor just basically got to the point where he where they were fed up of seeing myself and my mom, and just saying, just go home, we've got we've got nothing more to say to you in terms of treatments and things.

So it's kind of brushed under the carpet, so to speak. Now, I ended up around about Christmas time when I was when I was coming up to just about seven suffering from a viral infection which caused all my joints to swell and bruise and I just happened to be admitted to Northampton General Hospital, where the specialist consultant that I was being seen by, actually seeing that he specialised in cystic fibrosis.

So he spotted some of the kind of the telltale signs in terms of distended stomach, malnourishment, digital clubbing with my fingernails and just the simple things. So, I don't remember a lot about my diagnosis, so to speak itself, I just remember not really understanding what was going on. Lots of things like vividly remember having sweat tests and finding them quite scary and uncomfortable having electrodes attached to me, and I didn't really know what it was for. And I also really, really distinctively remember my first course of intravenous antibiotics when I was first diagnosed.

So then obviously, from that age onwards, it was a huge, huge shock to the system. Yes, obviously, I've been unwell throughout my childhood, but it was more the acceptance that there was something wrong with me that I think I probably would say I've struggled with the most over the years in general.

I mean, taking Creon®. in school, I've been through situations where I've actually refused to take them or I've had to go in in at lunch times to sit with a teacher to eat my lunch because it's the only way I would actually take my Creon®. because people would bully me 'Oh, you're taking drugs' and making you feel quite ostracised in a lot of ways.

So, as I've grown up, that's but that's often been quite difficult. I had worries. I mean, sitting around the dining table and things with my with my parents from maybe the age of 11/12

discussing and being worried about dying. So it was quite it was really very challenging because it's more the acceptance than anything.

Lucy: Diagnosis at the age is is more unusual now with people with CF because obviously it's picked up on the heel prick when babies are born. So statistically, that's less common. But as you said, that was such a thing back in those those years and I guess that you've known a a pre CF life, you know, I was diagnosed at two, but I never remembered my pre CF life if you will, that kind of that kind of change you said like all of a sudden having to take Creon®, all of us having to exercise more and guess doing physio and that change mentally must have been harder, like you said about acceptance.

What kind of got you through that? I know obviously seven is still a young age but how long do you think it took to kind of accept that?

Alex: I think I've struggled with elements even throughout my 20s I became much much more accepting of it as I've as I've kind of grown into my late 20s and throughout my 30s. I also think in terms of management of the condition to make sure I stay as well as possible.

Because of the lack of acceptance from my teenage years. I do I mean, you do irresponsible things as a teenager anyway don't but I recognised as I was getting older and when I was at university and things if I did push it and not think about prioritising my health over everything else I would end up in hospital I would end up in IVs and as well.

But as I've become older I've become much much more aware of what what my limits are so to speak, and just just just general ways day to day to manage my condition more more effectively. We're, I'm definitely an over thinker and over planner because of it.

So obviously with British weather the way it is when, Alice can probably vouch for this, that I do everybody's head in because I'm like well what should I wear, how many jackets do I need or things like that, which is just it sound ridiculous but I don't want to risk getting cold and wet because it just makes me unwell.

Lucy: And then I guess so you went to university, bring me up to your 40th birthday.

Alex: School was really challenging back and forth because I would end up really quite ill at times. I had a lot of problems around about around my mid teenage years around my GCSEs so I was in an ounce of hospital quite frequently. I also ended up with glandular fever, so it meant that throughout my GCSE years, there was one point where I was only in school three days a week and though they were only half days at a time.

So when I received my GCSE results, I was pretty devastated to be fair because they were they weren't anything like I was expecting them to be. But through obviously the support of my parents at the time. I mean, this was before Alice was born as well or around the time Alice

was born. And so I did go to college and study at college, and I did apply and successfully that I've successfully done a business management degree at university.

When I went to university that was the wake up call that okay, I really need to start looking after myself now because up until that stage, I always had my mum and dad and my grandparents to kind of guide me and say have you done this, have you, reminders of medication. Yeah, because of some of the resistance and maybe some just natural teenage behaviour, I was

reluctant to listen to be told what to do in that sense. But I mean throughout my 20s I completed my degree, I did an industrial placement year as part of that.

And so I actually worked as a ski resort rep out in North America, which was awesome. I think that also made made me realise that yes, okay, I've got my CF but I can still have my independence as long as I'm sensible as long as I look after myself.

So after that, I then decided to complete a teaching qualification. So I've got my business management degree, but I also teach secondary education as well. So I'm a Business Studies and Economics teacher.

Lucy: So then, obviously, September 2020, you turn 40, and that was around the time that Kaftrio was coming about. So you actually started taking it around your 40th birthday. Talk to me a little bit about how that improved your health.

Alex: I think first of all the there was a little bit of anxiety leading up to receiving Kaftrio because although I knew I was following quite closely the approval process and things. I also know that in terms of my lung function, I've always been very fortunate with my lung function and I've suffered far more in terms of my my stomach and my malabsorption issues.

So obviously, as I'm sure you understand, CFs very different for everybody. There was a bit of to and fro between the hospital because the other thing, living in South Wales the approval was actually after it was approved in England. I suppose it was quite an anxious time, really. But yeah, when I received the phone call from the hospital to say that I was eligible and that I would be receiving the treatment.

It was It was unbelievable, really, to be fair. I really, really couldn't believe that that day was coming. And I think growing up and having a pre CF life so to speak. It didn't seem real. Just just for the fact that I never I mean, when I was diagnosed in what 1986/87. I think it was 86 I was diagnosed, they were saying oh, there's gonna be a cure in X amount of years, like 5/10 years, and I'm at the point where you hit your 30s like okay, whatever its never going to happen.

But I mean like I was completely overjoyed by the phone call. And then obviously the wait and things and receiving my Kaftrio starting my first dose on New Year's Eve, after my after my 40th birthday was just absolutely phenomenal. And within 48 hours of taking it completely transformed me. I mean, I've had friends have conversations with me since then, and I don't

cough at all anymore. Whereas people would be like, 'Oh, I know you're coming down the corridor because I can hear you cough before you even arrive or I see you'.

I just I've got far more energy. I mean, I haven't had the energy that I have now since I was about 20 so you're talking over 20 years ago. I think also not just the physiological differences and the energy levels and also being able to take less medication now as a result of it. I think obviously psychologically and my mental health I'm much much happier as a person. I think that partly the one of the biggest thing is I think it's because I'm not permanently exhausted from everything.

Lucy: Before I started taking it, I was very apprehensive is it gonna be work like people are saying and I think the kind of after the 24/48 hours the pressure does just go off your shoulders you feel like you're able to enjoy food without feeling you have to eat it to put on weight or you're able to exercise for fun without feeling you have to fully do it for your lungs. It's an incredible change.

Alex: Yeah, this is it its choice rather than you kind of doing it out of necessity isn't in terms of things like exercise and things like that. So yeah, I mean, it was well it wasn't, it still is completely life changing. I mean pre Kaftrio with my job, I've been in jobs in positions where I've

been averaging a 65 hour working week and I've also had 12 hours of commuting in the car on top of that if you look at it together.

So but I mean, I think that is likely to make anybody pretty exhausted. But I mean even when I haven't had that level of pressure, I look back and I just can't believe how I've managed to get through the last the last number of years while I've been working full time. I've also my family have lived abroad including Alice for a number of years as well. So I've had to I've had to be fully independent and fully look after myself in in that time as well.

Lucy: Let's bring Alice into the discussion. And so you're obviously Alex's younger sister. You've always known him to have CF you've not had that kind of adjustment. How would you describe him if you were to describe him in a couple words, what he's like?

Alice: In a couple of words. Wow. So where there's an almost 16 year age difference between the two of us so like you said, ever since I can remember I've heard cystic fibrosis. I've known what it is. I don't know. I think probably I would say that, some of the words that I tend to think of like one of the first things that comes into my head is brave. I'm getting emotional now. I think one of my first memories of Alexander, because we we lived in between America and Dubai for a number of years.

So when he went off to uni at 18 I was two. So we basically have grown up almost like, we joke like, like only children and our parents have been parents for double the amount of years of everyone else and I remember being over in the UK one summer. I think I must have been

about five or six and going to the hospital with him to see him have his portacath flushed, and that really freaked me out.

That was really scary to see. I mean, I knew that you know, 'oh if you're sick don't give Alexander a kiss or anything like that', when I was little, Don't try not to be too close to him and that kind of thing. And that was normal for me, but I think it really I really started to understand what it was at that point.

And he was so blase about it, obviously, because you know, he was so used to having it done, or this is like this big scary, I'd never been in a hospital before, you know. And I just remember thinking how cool he was about it. And I just thought how brave he was and how he just took it all in his stride and I just couldn't believe it. And I just, you know, I felt a little bit in awe of it. I'd never experienced anything like that before. So.

Alex: I obviously hid that well then, because I used to hate having that flushed. I was fortunate enough actually because I wasn't having IVs very regularly. In 2010 they actually removed my portacath and they said they did they there wasn't any need so actually have a new one put in. And the reason it was removed at that particular point was because I think I was going for 18 months to two years without IVs at that particular point. I mean, I've had plenty of orals in between, but yeah with the fact I've grown as well, they just needed to remove it because of the age and the safety aspect as well.

Lucy: I think that kind of for people with CF, like it's just our everyday life, isn't it, things we do, tablets we take, blood tests we have, things like that, I was particularly unwell over Christmas in

hospital with flu and that was probably that that was the first time my fiance had seen me that ill in hospital kind of, he's lucky they only kind of see me in the Kaftrio days.

And I remember having my long line put in and he was like looking at me like I think he was gonna faint and I was like, why it's just uh, you know, a needle, tube is going up my vein for two weeks. What's wrong with that.

Alice: The one story that like my mum likes to tell that Alexander alluded to. He really really remembers his first long line experience and how much he hated that. And our father is a little bit, he faints at the sight of blood. So my my dad basically almost faints and half the nurses are looking after him and half the nurses are trying to get the line in and my mum is like what is happening.

Alex: Alice also has a scar on her forehead to match that that situation because there was one Christmas when I mean this was only what how long ago was it Alice?

Alice: I think it was actually the summer because I remember it was just before I went and started year 10 and I was really embarrassed because I had all these bright blue stitches up my forehead because.

Alex: We were at home I was having home IVs and all of a sudden she just said something. 'oh I feel a bit faint.' And obviously I'm sterlie at that point and so is my dad, and instead of sitting on the chair right next to her she tried to wander up the corridor and she keeled over and head butted the door basically. So dad then ended up down A&E to have stiches.

Alice: It was literally the day that Alexander had his line put in so these were midnight IVs and dad had gone to bed about half an hour before and I basically tried to walk out just to be sort of out of the room type of thing and my mom had kind of tried to stop me be like 'no, no sit down' and we my parents have like a bond conversion, so they've got big wooden slats on the bottom of the door.

So I passed out into that. And then I just remember my mum shouting up the corridor being like 'Brian quick, we're go to A&E' and he was like, 'oh gosh, what's happened now.'

Lucy: And Alex, you would have been there with your hands kind of like this when you're like 'I'm sterile. I can't touch anything. Everything's sterile.'

Alex: Yeah, yeah I was I was. I literally had a syringe attached to my line at the time and I was like, 'What do I do?'

Lucy: When Alex started Kaftrio, Alice, what was that like for you as a sibling, the reality of CF, had that ever hit you and how did that change.

Alex: Has always very very aware growing up I filled my CF, haven't you. You've been really really in tune and, and really alert. I mean, obviously, you know, as I said, being with CF is just the standard things, you know, like during COVID everyone's thinking about don't touch certain services or thinking about certain behaviours in that sense.

Well, that's normal for us. But I mean Alex has even been very aware of that even from a young age, from the age of five even, like she said, about being careful if she's not very well not to come too close to me in case she makes me unwell and all sorts of things. So.

Alice: Yeah and I think that that's pretty much all down to our parents, like I had so many questions because I'm a scientist you know, it's kind of carried on since I was a little kid. They would always be really upfront, really explain everything to me in great detail. And so I from yeah, from when I was maybe like five or six I've known pretty much everything about CF. And

so it was really nice that especially because it was the pandemic, but also our father works away in South Korea and then I'm doing my PhD in London, and so we're almost never all together.

Christmas is sort of a one time of the year we're all together and it was so lovely that he actually got his Kaftrio when we were all there and so we were all sat around the dinner table when he took his first tablet.

And it was such this like, I'll always remember it it was honestly it was like one of those moments like that you will always remember and the next 48 hours were crazy. It was like watching him go through, what you guys are calling the purge, was nuts.

It was it was and then the first thing that we all said notice was the silence. Like just watching TV, there's no coughing or he's laughing and he doesn't have to like take an extra breath or he doesn't have a coughing fit while he's laughing. And that was the first thing that we really noticed in those first 48 hours, was the silence.

It was really really fascinating to watch actually. I mean, coming from a scientific perspective, but also it's somebody that I really love as well and who's so important to me so it was a it was a it was really interesting in between for me to be both sides.

mini interlude with slurping sounds

Lucy: If we touch on your research a bit Alice. First of all, tell me a little bit about what what you do. Obviously I know the decision of why you chose to focus on CF, more about that.

Alice: Essentially, I'm currently a final year PhD student at Imperial College London and so I am situated with Professor Jane Davis who is pretty well known to the community in her Strategic Research Centre for studying *Pseudomonas aeruginosa.*

I had always sort of grown up you know, having a sibling with CF, you understand so much about infection that most people don't. And so it was something that had kind of always interested me. And so I decided to go to university to study microbiology for my undergraduate degree.

And it was during that time that I realised I wanted to get some work experience, you know, boosts the CV, another really prominent researcher in the field is Eshwar, Professor Eshwar Mahenthiralingam. He does a lot of the Burkholderia research and he's actually situated in Cardiff University. And so that was ideal for me because I could live at home in the summer you know, these work experiences are unpaid in academia and things, so I could just drive in have some experience. And that was sort of my real first taste of what research was like, what cystic fibrosis research was like.

And then I graduated with my undergraduate degree and then I went to back to Cardiff to do my master of research degree. And I linked back up with Esh and I did my whole Master's

project with him. And that was my first proper project where I really managed to get in on doing the research of trying to sort of model.

So I'm a microbiologist, I don't know if I said that before, trying to module the microbial communities found in the lungs of people with CF in the lab so that we can kind of understand how they're all interacting together to sort of create what we're seeing in the clinic. From that Master's then that was how it really helped me get my PhD with Jane, because I already have the CF experience.

And so now I'm essentially. Basically everyone I think, in the community is aware of P*seudomonas aeruginosa* and you know how it causes the large proportion of pulmonary infections with people with cystic fibrosis, particularly between the teenage and adult years. What happens is, you know, there's a association with a decline in lung function, but what also happens is that there's a decline in the diversity of all the bacteria found in the lungs as well.

So the pathogen essentially dominates that environment, but we don't exactly know how that happens. And so one of the potential mechanisms we're thinking of is that it's, it's something called secretion systems. So bacteria are actually really cool and they encode these weapon systems is what their called. It's called bacterial warfare, bacteria sort of use these systems, they've evolved to, you know, inject toxins into each other to try and kill each other to sort of win out and, and be the dominant bacteria in that niche.

And so we're thinking that this might be sort of a potential way that *Pseudomonas* is able to dominate the environment, but the systems can also be used against host cells. So also potentially, you know, enabling it to survive the immune system and things.

And so part of my PhD has been kind of validating the presence of some of these systems in the bacteria and then trying to see, does are these system active and do they allow the bacteria to kill other bacteria and so to sort of infer that this is a mechanism that it's it's able to use to sort of dominate the environment. So that's kind of where my research is at the moment. I'm just about finished my PhD at the end of June. So yeah.

Lucy: I mean, I think for anyone with CF when they hear the word *pseudomonas*, they shiver and like like, oh, IVs it is then, so I think it is like a really important researcher field and it is probably, correct me if I'm wrong, but the most common kind of bacteria that we grow, it's likes the damaged, wet lungs we have, I guess.

Alice: Yeah, so it's the most common, it's also the problem is is that it's sort of found everywhere in the environment from soil to drinking water. So it's something that's easily picked up and it doesn't affect anyone that doesn't have some kind of underlying health condition. But generally it's you hear *pseudomonas*, you automatically think cystic fibrosis.

Lucy: And I guess where do you want to go with this afterwards?

Alice: So I am going to continue on in academia in a postdoc position. So I'm looking at still studying *pseudomonas*, but a little bit more on gene regulation in the bacteria as opposed to the human. We know that certain systems that enable the bacteria to dominate the environment, not just the secretion systems, but other virulence factors as well.

They are regulate, their genes are tightly regulated, and so we don't understand, you know, the whole mechanism and interplay of all of this gene regulation to to equal what we're seeing on the plate or in the lab. And so that's something that I'm particularly interested in, it's the sort of how, when, why, these systems are switched on or switched off when they are. So, hopefully looking a little bit at that kind of regulation. interplay with the genes.

Lucy: And research and what you're doing is fundamentally important to kind of the Cystic Fibrosis Trust, to people with CF because it can lead to treatment and it can lead to understanding you know, since Kaftrio, many doctors say that they're kind of ripping up the old CF book. And so there's so much research needed on on what changes how bacterias how *Pseudomonas* changes with Kaftrio.

It's just such an interesting pool and, and a lot of what the fundraising community do and and the fundraising team at the Trust and volunteers, what they raise money for, goes into the research and things that that we need. So it's such an important field.

Alex, how do you feel that your sister kind of chose CF as the thing because personally with CF and doing that, I'd be like too much too much CF. So I say, well, how do you feel Alex that she's chosen that?

Alex: I'll be honest, first of all, I mean, just, I mean, I'm in awe of her and what she does, but I'm trying to say this with a level of calm voice now not to get too emotional about it. Because we don't talk about we talk about practicalities and what she's doing quite regularly as family, but I don't think we talk about the emotional side of it too much. And so I mean, I'm so so proud of what she does, and I am absolutely in awe of the research she's taking part, in her knowledge is just utterly phenomenal. And also, being completely honest, I also think is really, really humbling.

That she's chosen a career that's dedicated to my life. So that's that's how I feel in terms of emotionally and I mean, the other thing is touching back on what you just said, about informant treatments and linking to clinic. One of the things obviously this probably links back to my acceptance levels throughout throughout my years of growing up, but even now, a lot of the time I'm like, why am I taking this medication? What does it actually do because especially when we're taking prophylactic meds, sometimes like I'm taking this I'm fine, I'm well, why am I taking these things? So a lot of the time Alice has been able to actually explain things from a completely different and in a completely different way to what I would experience in clinic.

Obviously clinic, I mean clinic has been absolutely fantastic. The team that I'm under phenomenal and I really can't praise them enough for the quality of the service that they actually provide me with. But sometimes I want to ask more questions when I've gone away from the clinic and actually Alice is able to be able to bridge that gap or explain things in a

completely different way and then when I see the real point in, for example, a prophylactic treatment, we I'm okay, well, I'll take it and actually more accepting of the reasons why I'm given these medications to take.

When ultimately, I think we're going back to discussing about when I've said the acceptance has mainly been one of the biggest issues psychologically, even now maybe I'm not that accepting of a lot of medication, but I will take it because I understand them. I see the reasons behind why I'm being asked to take it.

Lucy: Yeah, I mean, I think we all need an Alice in our lives. And and also I think a lot of people you know, they have CF, but they're actually never told what it means, what it is and you know, unless you ask the doctors the questions in clinic or unless you research which sometimes can be can be too scary if you just find websites that aren't the Trust that explain it in a good format.

You know, if you've not, if you don't really know how it works or like Kaftrio some explaining that to me about like my gate opening and my something or other going through and the sodium channels and I'm like, wow, I didn't know I had gates in my cells, like, you know, the explanation of things makes you want to take the tablet.

So Alice, what from your perspective very quickly, why would you say research is so important?

Alice: I mean, Alexander has already said that, you know, the medical teams are so amazing with what they do and dealing with the conditions but at the same time, the doctors can't do what they do without the tools, and research makes the tools for the doctors to be able to treat people with CF, you know, as effectively as possible. So if we don't have research, then we're not going to get advancements and people living CF with CF living life unlimited. So yeah, research is incredibly important for for that aspect.

Lucy: Well, it's CF week. And I know its Wear Yellow Day on the Friday the 16th of June. What do you guys typically do on CF week or what are you going to be doing this year?

Alice: It varies. I mean, last year, I was actually at a conference presenting my work so I was there wearing yellow and I put a slide in about CF awareness week. But yeah, it depends I think we we always try and remember to wear yellow as well because we know it's CF week but sometimes your like 'oh which which days it again?'

Lucy: Yeah, I mean, yellow is my favourite colour. So I do love the fact that it's the charity's colour too. So I think it's I mean, I think I'll be on my honeymoon when it is where yellow day so I'll be repping in Corsica in bright yellow.

That's just been so interesting and the connection you two have, even though like you are so far apart in age and kind of been brought up like different times and different countries, etc. I think it's really it's like a really special bond you've got and I think the whole overarching feel from the podcast is that everyone needs an Alice.

I just want to thank you both for coming on the podcast today and chatting all about your experiences and know it is incredibly emotional when actually you're face to face or virtual as we are, but by expressing that kind of emotion and feeling to someone and kind of someone you don't know as well. So yes, thanks for being so open.

It was lovely having a catch up with Alice and Alexander – thank you both so much for joining us on the podcast and speaking so openly about your work and CF journey.

Izzie: A big thank you to Lucy, Alice and Alexander for sharing their expertise and stories. Now we are going to be finding out a little bit more about the importance of funding our research here at cystic fibrosis Trust.

My names Izzie and I'm content lead at the Trust and I'm joined by Paula who is our head of research.

Paula please could you tell us a little bit about the research we are currently funding at the Trust?

Paula: We fund a very wide and balanced portfolio of research at the Trust and the research we fund is informed by the questions that were developed by the CF community in the James Linds Alliance exercises. So all the research we fund is awarded and reviewed by our research grants review committee. So that's an external body of people and it consists of academics, clinical scientists, members of the clinical team, and then people from the CF community which includes people with CF and parents of children with CF. And they ensure that the research we fund is not only excellent, but also of high strategic importance to people with CF.

And we know that everybody's CF is different and so we really try to ensure that we fund a wide portfolio of research that meets everybody's unmet needs. For example, we fund research into CFTR which is the protein channel it's defective in cystic fibrosis. And we try to understand more about that.

We fund work that then tries to fix the CFTR protein and that's work that I guess is of high strategic relevance to people who are not able to benefit from the modulators. We fund research that deals with the symptoms of cystic fibrosis. So we fund that research. We fund research into cystic fibrosis related diabetes, and we also fund research around infection. So from very basic research that tries to really understand why bugs like to live in the CF lung to research that is actively developing therapeutics for infection. So it really is a very wide and balanced portfolio.

Izzie: And I guess within that, obviously, as you said, funding is very important, but why is it so important for the research that we do?

Paula: I think funding is vitally important and it's really important that we as a Trust, support and develop CF researchers. I mean, if you think about it, less than 200,000 people with CF in the world, amongst all the billions of people on the planet, and it's really important that we as a charity, highlight research and try to really bring it up to the fore.

Izzie: And for people listening, where can they go if they want to donate?

Paula: So on our website, if you go to the work we do, you can have a look at all the different types of research that we fund and that gives you sort of an idea of sort of breadth of our research portfolio. And there's various ways on those websites that allow you to donate.

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

Paula: Pleasure.

Lucy:

Thanks so much Paula and to Alice and Alexander for sharing their experiences and to you 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 enjoyed listening to CForYourself, don't forget to subscribe, rate and review. And please join us in wearing yellow on Friday the 16th of June. Well, that's all from me, but look forward to speaking to you as soon as season two of CForYourself will be back and coming to you this summer.