Predicting and diagnosing sight loss in children

This is a recorded transcript from a webinar held on Wednesday 22 January with Dr Lola Solebo, Consultant in Paediatric Ophthalmology at the world-famous Great Ormond Street Hospital for Children, and Elizabeth Maxwell. Hosted By Emma Blamont, Head of Partnerships and Research at Fight for Sight.

**Emma:** Good afternoon, everyone. Welcome, and thank you for joining us today in conversation with Dr. Lola Solebo and Elizabeth. In today's Fight for Sight Presents webinar, we'll be talking about Lola's work in predicting sight loss in children, and we'll also be hearing from Elizabeth.

**Emma:** My name is Emma Blamont. I'm the head of research and programs at Fight for Sight. I oversee the research and the social change funding programs. And here today to my left is Dr. Solebo and Miss Elizabeth.

**Dr Solebo:** I'm a paediatric eye doctor, paediatric ophthalmologist based at Great Ormond Street Hospital. And I'm also lucky enough to be a researcher at the Institute of Child Health that sits next to [00:01:00] the hospital. And together we, Great Ormond Street and ICH, form the largest concentration for childhood research in Europe.

**Dr Solebo:** And I've been working in the area of uveitis for a few years now, but also looking into how we improve outcomes for other children who are at risk of blindness because of childhood eye disorders.

**Elizabeth:** Hello, my name's Elizabeth. I was born in 1945. I was diagnosed with juvenile rheumatoid arthritis (JIA). At the age of five and in between 1984 and 86, my sight had faded. And I can't give you a definitive moment because it happened so slowly all my life, basically. So that's it. That's who I am at the moment.

**Emma:** Thank you both for your introduction. Today's webinar will highlight Elizabeth's experience as a child with the JIA, [00:02:00] and how research like Dr Solebo’s is helping give children, today's children, a brighter future.

**Emma:** Before we start just a little bit more about why we are all here in the same room today. Fight for Sight invests in sustainable projects that deliver equity and back science that brings prevention, treatments and cures within reach. Our vision is to save sight and change mind, and to do this we fund the brilliant minds and bright ideas that put change in sight for everyone impacted by vision loss.

**Emma:** Together we're bold, tenacious, informed and optimistic.

**Emma:** We're The UK's only grant giver in both scientific research and social change. And over the next five years we plan to distribute £30 million in grants in these areas. And we really would like to thank our supporters and our donors for helping us realise this ambition.

Today we're pleased to have one such supporter with us, Elizabeth, [00:03:00] who's raised many thousands of pounds for Fight for Sight over the years. We have a short video which beautifully sums up who Elizabeth is and her support for our organisation over the decades.

[You can watch Elizabeth’s story here](https://youtu.be/_1t-uWhBJ_U).

**Emma:** Elizabeth, I hope you don't mind me saying, you're now 79 and you're a veteran fundraiser for Fight the Sight through all the activities you do for us, including baking. You also volunteer for Blind Aid, which has received funding from Fight for Sight through our social change funding programme.

You were diagnosed with JIA, as you mentioned, when you were age 5 and you had your treatment here at GOSH. What are your early memories of coming to GOSH and receiving treatment?

**Elizabeth:** Oh dear, so many memories. I think the first thing I have to say is I was never, ever worried about coming here. Because after all, Great Ormond Street was the second home. I was in and out. All my formative years, probably until I was about nine or ten.

So [00:04:00] I was either in for bed rest and exercise and physiotherapy, or I was at home. But even at home, my mother would do the exercises every day. But other memories, well, do the nurses still wear pink? No. Ah, well pink was, and the hats, I loved the frilly hats. I remember during the summer, it was very warm we used to be wheeled out in our beds to sleep on the balconies. I bet that doesn't happen anymore. And I'm very well aware of a little hat being put on.

Obviously when it got a little chilly. Oh, so many memories. I remember on the balcony one morning I was given a very runny egg. And I decided to squeeze it through the bars and listen to it drop.I was very interested in the sound it would make. I think I was about five floors up in a ward. I wish I could remember its name. And the smell. I mean, the wonderful, I don't, I don't suppose you use that disinfectant anymore. But that was sort of reassuring to be [00:05:00] there when I was never worried. It was just a part of my life, you know, either at home or, in the hospital.

I, could I say I loved it? It was a natural place for me to be, because it was just second nature to be there, when it was necessary, for a period of intensive physiotherapy. Or I had my tonsils out, I remember, I remember asking you, are you sure you're going to wake me up? But of course I did.

It was never a worry knowing I had to go back in.

**Emma:** Okay, so now onto a slightly more serious topic. When did you first realise you were going to lose your vision due to the complications of your condition?

**Elizabeth:** I always find that a difficult question because I don't think I was ever told in so many words that I was going to. I think when I was sort of [00:06:00] mid-thirties, I may have gone to a specialist. And asked him very clearly, I'm not leaving here until you tell me, am I going to lose my sight?

By which time I was blind in my left eye, I still had some vision in my right. So and he said, it's more than likely. Now, why didn't I say to him, well, that's not a good enough answer. I want to know a clear yes or no. But I went away thinking, oh, well, it may not, it's not going to happen today. It may not happen tomorrow.

So maybe I was in denial. But that was fine by me because there was never much conversation about it anyway, if any. So nobody ever said, well, this is what is happening. This is what is happening to your eyes. So, I was in blissful ignorance, in a way, and it was okay by me, but would it have made any difference if I'd been told, ‘Yes, you are’? I really don't know. And again, of course, it happened so slowly, really, over the years, [00:07:00] gradually disappearing, and even though I had cataracts removed, I had various operations the sight continued to fade, and fade. How did I feel? I can't answer that. Just I accepted it, actually. I think that's the simple thing.

I just accepted it, because actual fact, I didn't have a choice. I had no choice. And, unlike today, where you can press a button and get loads of information, I had no information. Because nobody gave me any information. They'd look and not tell me. So, I should have asked, maybe. But maybe I didn't want to. I really don't know the answer to that.

**Emma:** So as you know, Dr Solebo's longer research aims to enable earlier diagnosis for future generations. Is there anything you'd like to ask Lola about her research?

**Elizabeth:** Do you work here or do you work in the hospital with the children?

**Dr Solebo:** I work in both places. I first came to Great Queen's Street as a baby eye doctor in 2004/2005 and I remember doing my medical school career and in the first year as a pre-registration house officer (first year doctors) I remember thinking: “I'm never going to be a paediatric, the reasons why it just looks like a lot of work.”

But I got to Great Ormond Street and two things happened. I realized just the amazing, positive power of being, of having the privilege of looking after a child's future and also just, you know, hanging out with children. [00:09:00] I'm the first born of four and they're much younger than me, so I always sat for them.

I used to spend summers looking after children in a nearby nursery. I was always going to be a paediatric eye specialist, I don't know who I was fooling. But I got to Great Ormond Street very early in my career, before you really know anything, and Great Ormond Street is one of those sites where we look after children with rare disorders. You see things you won't see elsewhere. So even quite senior doctors coming to Great Ormond Street can feel really quite, gosh wow, what am I looking after here? But as a very junior doctor, I think, you're used to not knowing anything and just learning, learning, learning. It was a phenomenal experience, a career changing year.

And it wasn't just that, not just being part of the clinical aspect, but also the research aspect. You'd be researching up about a case. reading a paper, reading a textbook, and the person who wrote that textbook would be walking down the corridor of Great Ormond Street. And then also there was a relationship with a researcher happening just next door.

So the Institute of Child [00:10:00] Health has a really close relationship with GOSH, but it's also part of UCL. So it's this great body of research that sits within UCL, and education as well, and teaching. So to be able to be part of that relationship where families have a need and you turn that into a research question, and then you take it to the research side and then discover information that's helpful and then bring it back to the families.

It's just phenomenal. In my role as paediatric consultant ophthalmologist I look after children in clinic. I look after children with uveitis and other inflammatory disorders. And that's two days a week. And then the other three days I'm a researcher. In reality it’s not as clear cut as that because if I got a message from a patient, I’d reply regardless of what day it is.

If they need some medication re prescribed, I'll still do that. And of course, when I'm sitting there as a doctor, my research mind is always ticking. Always thinking, why don't we know that? What would the experiment [00:11:00] look like to enable us to answer that? And by experiment, I'm an epidemiologist, which means I use data about patients to uncover useful information about those patients and, of course, about people who are healthy as well and using that information to feed back into populations who are at risk, or have disorders.

One really useful example is one of the key bits of research that Fight for Sight are funding is seeing whether or not we can use imaging technologies to detect uveitis at an early stage in a child who we know is at risk for developing uveitis.

If you pick it up late. Children tend to do worse. The young people, the adults we go into, [00:12:00] tend to have worse vision. So right now, the routine way that we pick up uveitis is using a microscope. on a desktop called a sit lamp and a clinician like me will look inside that child's eye and we'll try to see tiny immune cells dancing about in the front chamber.

Humans aren't always as good as they should be at spotting tiny white cells floating about inside a child's eye. If you ask two specialists to look at the same child on the same microscope sit lamp they have about a 60% chance of agreeing with each other because humans are humans. So because there's that uncertainty around that diagnostic measure, and also because it takes a really trained specialist to be able to even do it at that level. It means that there's this sort of blockage in getting enough children seen early enough. [And there aren't quite enough paediatric eye specialists like me in the community looking after children.]

So we need to improve how we detect this disease, not just because [00:13:00] the kit we use could be better, but also we need some kit that doesn't determine, it doesn't need a specialist taking the image or looking into the eye. For example, taking a photograph of the eye and then letting a specialist see it. you know, sort of down the end of the computer line.

And that's the research that Fight for Sight is funding. And that research that we're doing to try and figure out how we can improve detection, that is underpinned, it's supported by what we've learnt about healthy children and healthy children's eyes. And that's because we took this imaging machine to primary and secondary schools around London and we asked for the children's help in letting us image their eyes.

Just to see what could we expect to see on an image of a healthy child's eye.And because of their understanding, because we know that we actually might see a few flicks (the tiny white cells floating around) on this camera, that doesn't mean that child has uveitis. That's just, you know, we've got hundreds of children now who don't have uveitis to know what it looks like not to have uveitis.

That means we can use [00:14:00] that camera. It's called an anterior segment, OCT. We're better prepared to use that camera to say yes. That is a case. So that's one of the wonderful things about being here at the Institute of Child Health, because it's in the name as of child health, looking at states of healthy children and looking at states of children who have diseases, which does two things that allows you to get better at picking up that disease. But of course, healthy five year olds could turn into seven year olds with JIA. So again, it's really important that we have that sort of population aspect to our research.

**Elizabeth:** So you've actually probably answered the next question I was going to ask with was with the illness, is it an automatic thing that a child will lose their sight in later life. I mean, it obviously is not a given because of the wonderful research and also different treatments, I guess, there must be, because when I was a child, there was no research as you are doing, and thank God for Fight for Sight for enabling you to do that, but there was nothing like that.

**Elizabeth:** So Is it a given that it will happen to a child if she's now, they are diagnosed with …

**Dr Solebo:** this condition? So no, fortunately, it's not a given. It's actually quite uncommon for a child with JA uveitis or the other slightly more common forms of uveitis that affect the front of the eye, it's uncommon for them to lose vision to a severe degree in both their eyes during childhood, although of course they can continue to develop problems later on in their life. But even later on, childhood blindness is fortunately not the expected outcome for children with JAUBS, although it happens far too often. And there are three main reasons for that. None of which I can claim [00:16:00] any praise for. Things that have happened over the past few decades. The first one is treatment. So treatment really has changed. I remember just talking to you earlier about steroids starting to come in when you had developed juvenile rheumatoid arthritis, we used to call it, but now we call it juvenile idiopathic arthritis, JIA. So earlier treatment with steroids, first of all, to have short term improvement of disease, but we know we can't use them long term. So the longer term treatment is immune therapy. These are drugs, medications that will help to settle down the immune system and stop the destruction that we know can be happening in the joints..

**Elizabeth:** But the children are growing how does that affect their bodies?

**Dr Solebo:** It's such a great question. One of the things that we do know is what the long term outcomes are for [00:17:00] many of the medications we use, because they've been used so long, we do know about the arthritis. So we know that with those medications, we give those children the best chance of being disability free later in life. It isn't an easy course. It isn't an easy pathway taking this medication. Sometimes for some children, the rest of their lives, but certainly for a few years, they can be orally, but often they're injections. They can be happening every week, every two weeks. There can be side effects and every decision about should that child be on this kind of long term therapy or not be on this long term therapy is a discussion between the child's family, the child and the clinician looking after them.

It always must be the discussion because the second thing that I was going to say is patient empowerment. That is very much a huge part of improved outcomes. Understanding how important it is that you hear the patient's voice in the treatment decisions. That the patient feels that they are supposed to ask questions but the [00:18:00] clinician is looking after them.

Questions such as why am I on this treatment? What else could be on? What can I be on? What might happen to me? What research are you basing your treatment on for me? So that empowerment of the patient's voice and the child's voice as well. A five year old has very definite ideas about what they want the next year to be like.

It's one of the greatest factors for helping to improve outcomes. And the third thing for the eye disorder is early detection. Sometimes it happens when a child is far too young to be able to report there's something going on with their eyes. And sometimes it happens in a silent way, so uveitis can start in JIA without symptoms. The child's going to have a lot of activity happening inside their eyes, damaging activity, without knowing that there's a problem. So in about 2006 or so, one of the consultants who used to look after uveitis at Great Ormond Street called Clive Eggleston, who trained me, and got together, got the Royal College of Eye Doctors together with the College of Rheumatologists, made everyone sit down and agree to a screening or [00:19:00] surveillance pathway.

Watching children who have just been diagnosed with JIA, seeing them within the first a few months of their diagnosis and then seeing them every few months thereafter so we could pick up uveitis at an early enough stage before the damage can start because once this damage starts accumulating it can be really hard then to get that child a good outcome.

**Elizabeth:** It's just, I mean, I'm astonished and I'm so thrilled that the opportunity to have the conversation is now because there was no conversation when I was a child at all. It was just. accepted or, but never discussed. And now I'm of course itching to ask so many questions, I know we don't have time, but it is fascinating to know what is happening, because there was also no treatment when I was a child, albeit, steroids were just coming in. Professor Moncrief who looked after me, just mentioned steroids, and my mother said, Absolutely not, I don't like the sound of that. So I had the very old, very lengthy treatment of [00:20:00] exercise and bed rest and exercise and so on and so forth, but no medication as such.

So I don't know how I dealt with the pain, because it must have been there. No idea. I can't remember it, because I don't remember. The state of pain but it is one that I'm so pleased to know that all this research is available for everybody and you were unable to ask the questions.

**Dr Solebo:** Definitely, I would say that physiotherapy exercise is still a really key part of the treatment plan.

So something else that we're doing within the Fight for Sight funded project. A few years ago. They looked at all the positions for consultant eye doctors. So how many, if a consultant eye doctor job, a vacancy came up, how many of those vacancies are being taken up? And then one year. 73% of those vacancies [00:21:00] weren't taken up. So there's a real shortage of actually all eye specialists in the UK, but in particular, paediatric eye specialists. That's not just in the UK.

I mean, for example, Nigeria, where I was born, I came over to the UK when I was two years old. In Nigeria, there's five, I think, paediatric eye specialists, who I talk with sometimes and sharing knowledge with them. There's. a real shortage. Even in higher income countries like America, there's a crisis of paediatric ophthalmologists.

So we really do have to get smarter in using technologies. And the reason why I bring up the patient voices, it's all very well me sitting in my research office thinking, wouldn't it be amazing if a family could walk across to their high street optician, get a photograph of the eye that the optician would email me and I'd be able to say, yep, that's fine, or no, that's uveitis.

But then we, because we have a lovely patient group who help us design all our research. And then we thought with them, what [00:22:00] happens if you're sitting in the high street and you get the feedback or a letter later on saying your child does have uveitis? And then you're at home, it's that one extra little, you know, you're not sitting with me saying, telling you, you have uveitis, and we discuss what it is and this is what treatment looks like.

You're somewhere in the community with that results letter. Is that the way that we should be communicating results? How would we actually use this technology in a way that would want, make families want to use it? So as well as the sort of standard trial of comparing an expert on the microscope. to an expert looking at the images or anyone else looking at the images.

And we're also interviewing families to find out what would be the best way to roll this out? What would be, how would they want to know the results? What would we have to put in place to make sure that children got seen soon? You know, which I, we think is so important. It's, it's far too easy. Just think there's a fantastic bit of kit off you go, but there is a [00:23:00] really powerful way to do additional research to generate the understanding we need to implement to actually start to use that kit once we find that it's effective.

**Elizabeth:** Is this the only country where this research is taking place?

**Dr Solebo:** In the uk one of the lovely things about paediatric eye doctors, maybe because there was a few of us, we all talked to each other in the uk. The package of work on which everything else sits on, was funded by the National Institute of Health Research.

Which is the research arm of the NHS. Before I started that work I got together with other paediatric life specialists and adult eye specialists who look after children and young people with uveitis. So we formed an interest group so we could share knowledge. And I've already shared my, what we found out about the imaging technique, not just through papers, but also sharing it with other centres.

So we've shared it with Moorfields, for example, who are doing some of this work now with, with a team in Liverpool, for example, are doing some of this work now. So yes, although the work is being driven and [00:24:00] originating here at Great Ormond Street Institute of Child Health. It's just such an obvious thing to make sure that everyone else gets the understanding that they might need to add to the evidence base, because that means we'll be able to see patient benefit faster.

And the other lovely thing is because we're one of the few in the world who's doing it for children, we're also able to talk to other teams in other countries, making sure that we all sort of add our value together. But yes, in the world. This is the first time there's been this kind of trial of this imaging technology versus a clinician looking the standard way.

And it's not just the first time in the world for children, they haven't done it for adults with uveitis either yet. Which again is wonderful for child health and child health research to be leading the way. Because if you take, if you go into an adult uveitis waiting room, and you ask everyone in the waiting room to stand up, If their uveitis started in childhood, [00:25:00] out of a hundred in the waiting room, only one person will stand up.

If you go into the waiting room and you ask only those people who are blind because of their uveitis to stand up, one in ten of them will have childhood onset disease. So it's much less common for it to start in childhood but much more damaging when it starts in childhood. So again, it's just so wonderful to be leading this research that we know, we hope, you can never say we know, we expect to have benefit for children at risk, but also have benefit for adults as well. And this is all funded by Fight for Sight. The trial of comparing the technique that we've worked out is one of the best techniques to take pictures of eye cells in the eye versus the standard examination, that has been funded by Fight for Sight. And the extra interviews that we're doing to understand how we would then roll this out is also being funded. That's wonderful.

**Elizabeth:** I was going to ask you about [00:26:00] the future, but I think we've probably talked about that a bit. Is there anything else you want to add? I mean, how is this going to go forward? And it's presumably never going to stop. I mean, the more knowledge we have, the more sight is going to be saved. So how do you see the future?

**Dr Solebo:** I want in the future to be sitting in my consultation room and I want to be able to tell a child newly diagnosed with uveitis, and I want to see fewer children uveitis first thing, I want to be less busy seeing children with the new disease, but I want to be able to tell them that their disorder tends to look like this. If we use this treatment, this is what might happen. If we use this treatment, this is what might happen. This is how often we might need to see you for this year and next year. This is what we think your future is going to look like. This is the extra tools that I can give you to help you keep safe. [00:27:00] I want to be able to give them a more predictable disease journey because it's a rare disease, so there's so many reasons why this is such an impact disorder.

There's the disability that might happen. Of course that's such a huge part of it. There's also the unpredictability as well. Yes. And there's the fact that it's so rare that you can't have meaningful conversations that many people, you say uveitis and they say, what's that? Because there are so few people affected.

So it's rare, which means there's isolation there. It's invisible childhood. Eye disease all too often is invisible. If there's a child with a really obvious disability, or a child, for example, in a wheelchair, people know that child needs additional support. People can sort of visualize how that child might need support.

But if a child has vision loss, or is at risk of vision loss, or has a disorder that might put them at risk, It's, it seems to become this sort of hidden disability that people don't, don't instantly say, this is the support that child needs, this is what might need to happen for that child. So that rarity, [00:28:00] that invisibility, and then the complexity and unpredictability all mean that it's just so much for families.

**Elizabeth:** I think nowadays perhaps children will be able, can and do voice how they're feeling. So they will say I'm in pain or I'm sure they are more confident in actually saying this is how I feel. Even, even small ones. I mean, I, I don't remember ever tripping up. I used to trip up my legs didn't work properly, but it was never ever talked about. I think children now can communicate and the parents then have more say and how about going about to find out what is actually wrong. So maybe there's a chance that diagnosis is sooner than it was when I was small.

Because of the research, probably, and things that you can look out for and rheumatologists can look out for. [00:29:00] to make a much earlier diagnosis, which must be helpful in the treatment.

**Dr Solebo:** What two of the things that have been really impactful for the JIA, away from the eyes, but for the JIA in particular, are the positive impact made by patient led organisations.

**Dr Solebo:** So I think there's juvenile arthritis research and then there's children with arthritis or CCAA, that really helped to. empower families, but also just to spread the word. To make JIA a more visible disorder amongst health practitioners.

So I'll mention two other bits of research we've done over the last five years.

One is a study called unicorns, which is just has been wonderful. It was looking at information for children newly diagnosed with childhood uveitis. And we got all our friends in the other eye centres across the UK that I was talking about to share information about children newly diagnosed, so we could start to put together the, what does it look like to have uveitis in 2020, for the first [00:30:00] time in 2020, 2021.

What does it look, how do you get into the eye clinic? How you looked after, what treatments do you have? And one of the early findings that we found was just how long it was taking children to get their diagnosis and therefore get their treatment. I'm sure it is true that patients are more vocal, they might not have things happening, but all too often, especially with the eyes, People don't know what to look out for. And even if they do know what to look out for, the clinicians they're seeing don't know what they're looking at. So we were finding that, particularly if you went to your GP, who, you can understand, GPs are hardly, very unusual for them to see a case of uveitis, or they were going to community care. The uveitis was being misdiagnosed as conjunctivitis and they were given some topical antibiotics or wetting drops to use.

So by the time, this is 2020, 2022, so by the time they got to us in the eye clinic there was already damage in the eyes from the uveitis. [00:31:00] So one of the things we did is we approached the British Journal of General Practice and we said, can we, this is what we found from unicorns, can we write a piece for you to make uveitis more well known to GPs across the country? And they said yes. And we wrote that piece to help educate general practitioners. But that's one of the early outputs from the Unicorn study, and we'll expect there to be more that will really help us to understand what care looks like, what can be improved, and other areas of research.

And another thing that we did as well over the past five years is how do we support children, especially the young children, young people, in reporting what's going on in their lives.

When you're trying to describe what's going on with your eyes, Iit's really hard sometimes to find words that match up to what you want to say or what you're [00:32:00] feeling. And what you think the child can actually hear. And, and listen to, and not be fearful that, I mean, that's really important.

And also even the first time a young child sees me, I know they're shy of me. Often the young type, first time a child, particularly JIA comes to see me, they've had needles in their knee, they've had needles in their arm. They're like, what is Dr. Lola going to do to me in the eye clinic?

And to give that support, we got together with families and young people and children who were affected by uveitis. We did some lovely study to try and develop a tool that would help children, young people and families of very young children to report symptoms and sensations in the eye. So for the very young children, the parents will sort of fill it in.

And for the older children, they'll report themselves. So we sat down with family saying, what did you notice? What did you see? And we sat down with them down so they could talk to each other, which is so important. When they're talking to each other, I'm just talking to me and they could [00:33:00] share experience and contrast experience.

We had to listen in and transcribe and then try and analyze what all these families are telling us. And then we also did the same with children and with young people as well. What's it feel like? And one of the phenomenal things that happened during one of the really early on was they started to draw what it felt like.

They started to draw what their eyes felt like with uveitis and show each other pictures and there was so much. Yes. That's what it feels like that one of the things we started to, we used now in the tool, their images, they can select an image of this is what my feels like. So, you know, if there's a squiggly line and I was thinking, how am I going to make one into a tool?

A tool that doctors can understand what they're talking about. But there is a way through my lovely, wonderful other scientists that I work with at Child Health, who do things like academic psychology, develop how to talk science, how to measure things and how to use that measurement. We could take that information, that powerful information directly from the families and young people and make a tool that was not just reliable and worked well, but also was really [00:34:00] true to what they were telling us.

And it was able, that tool was able to to flag when a case of uveitis was active. So just really, there's a great bit of research to be part of, to lead.

**Elizabeth:** Well, it's so heartening because I think, while you're talking, I was thinking, my goodness me, I, as a child, felt isolated. Because there was no information, because it was never discussed, so it was my, I just accepted it as part of my life.

But the opportunities now are just amazing. I'm very heartened by that. Lucky children. There's much more to do, much more to do.

**Emma:** I just want to ask one quick question before we move on to the Q& A from the online viewers. [00:35:00] And you mentioned, you know, some of the Fight for Sight projects and, you know, the value that they've added in terms of the research, but how instrumental do you think the Fight for Sight funding has been in terms of supporting your career and allowing you to flourish as a researcher?

**Dr Solebo:** I've been really fortunate to be supported by other funders throughout my career who've really helped me to get to this position. So, in our chart that I mentioned the Academy of Medical Scientists and now with a Wellcome Award as well. But the thing that the Fight for Sight funding has been able to give us is, so number one, it's funding this trial that we're doing right now and the power of being able to say that we're doing this trial, that will then have findings that will be so powerful when it comes to using this tool in clinical practice, to be able to tell that to, you know, researchers who I talk to in America or into other centres. [00:36:00] It speeds up their research, which is phenomenal.

There's more than enough space for everyone to build up the evidence. It pushes them on to do good as well, but, and also, you know, it gives me that platform to start talking to them, encouraging that research to grow and grow and grow. So the funding of the trial, phenomenal. Fight for Sight also funded an associated small grant.

I've mentioned that it took sort of five years of work to get to the stage of doing that trial, five years of work funded by an NIHR, looking at these immune cells, trying to figure out how we'd use it to detect uveitis. Pfizer also funded a smaller grant that we are starting the journey for specific complications that can happen in uveitis, but also in other childhood disorders, like childhood cataract, so cloudy lens inside the eye. That can happen in Uveitis, but it can happen in children without Uveitis. And other disorders where the child is at risk of getting damagingly high pressures. inside the eye and often these damaging high pressures or glaucoma are happening in [00:37:00] a secondary way.

They're happening because of the other eye disorder rather than because the child has a has a primary cause for the glaucoma. So can we be better at detecting and predicting those children who are going to develop that secondary problem of eye pressure because of their other eye problem. And Fight for Sight funded a small grant that allowed us to start to say, how would we take these images of children who are at risk?

How would we develop the bigger study that would allow us to dig down into what glaucoma risk there might be in the images we're taking of the children? So that is going to be now taken forward over the next few years, the finding that we know about how to create the best quality image. of the certain parts of that child's eye that we want to look at and how we can use those findings now to predict the glaucoma.

I think it'd be great. And probably because of what we've learned in the last five years, it won't be another five years where we can roll out something that we can then use, which is wonderful. So yeah, really grateful for funding.

**Emma:** We've got first question for Elizabeth and it's: how well did you feel your disease cause and treatment was monitored by the hospital? Was the treatment plan clearly laid out?

And then we've got a secondary question, which was, what's your favorite cake to bake for fundraisers?

**Elizabeth:** Gosh, which one do you want me to answer first? Maybe the cake one. Let's do the cakes first. At Christmas it's tradition for me to make a whiskey dundee cake. So which I recommend you have a very strong piece of cheddar to go with. But that's the cake that I normally bake. There's another one which is a Creole cake, which I have to say is full of an extraordinary amount of different alcohols, but it is particularly yummy.

But the Dundee cake is whiskey [00:39:00] based and it has to be good whiskey and not cheap and nasty. So that's that. Does that, I think that, that's enough for now. Enough alcohol for now. And. What was the one about treatment,

**Emma:** and the plan, and? So it was, how well did you feel your disease course and treatment was monitored by the hospital, and did you have a clear, was the treatment plan clearly laid out?

**Elizabeth:** Well, I wouldn't have known that, you see, because again, there was no discussion. Professor Moncrief used to have a lot of discussions with my mother, and I just understood that when I came next door, when I went to, into the ward, I knew what was going to happen, the routine was very, very clear. Very set.

The, the plaster casts were taken off about three times a day. And I had the routine of the exercises and bed rest. And I can't remember anything else, actually. That was the routine. Now, whether or not I dare say Professor Moncrief had the plan but I didn't know anything about it. [00:40:00] So I can't really answer that properly.

I'm sure that's not very helpful, but I'm sure the clinicians knew, but I certainly didn't. But I was very, very young. Would it have made any difference to me? I just went with the routines it was every day. And then if I wasn't in hospital, next door, or if I wasn't in Great Ormond Street, then I was home.

And the routine had to be kept up at home as well. Mummy was very good about doing the exercises at least three times a day, which I often didn't want to do at home, because it must have been painful. And I can just think, oh, I used to say, oh no, please, not now. That must have been because of pain. But anyway, in hospital, I never complained about it, because that's how it was.

**Dr Solebo:** What do you remember about the different medications that are used for your eye or for arthritis?

**Elizabeth:** As far as the arthritis is concerned, I don't [00:41:00] remember having any medication at all. So I don't know how they dealt with the pain, because there must have been a considerable amount of pain. In all my major joints. So it, it, you know, it was complicated, but I don't remember. But how did, sorry, what was the first bit? Oh no, just what medications you remember for your eyes or your Oh, the eyes. Well, I think drops, simply drops. I think they were steroid drops, I take it. But that's about all I I, there wasn't anything else.

I didn't take anything. Well, as I said, no steroids. It was only, presumably, steroid drops, if I had conjunctivitis or a flare up of what the other related. Troubles are with the eyes, but just drops.

**Dr Solebo:**. So they may not have been steroid drops. So around the time when you would have been a 5 to 10 year old with the uveitis, the [00:42:00] treatment at that point was dilating the pupil up to try and sort of paralyze the iris muscle in order to help there not be inflammation inside the eye. Right, well. Steroid drops in the way that we use them now, they haven't figured out how to use a steroid in a drop formation that was safe for the eye. So it might not have been steroid drops.

**Elizabeth:** Well, I, I don't know. But it was only that, and no other medication at all.

**Emma:** Thank you, Elizabeth. So we've got a couple of questions for Dr Solebo. And the first question is, what's the average age of uveitis onset in children in JIA? And how common is onset in adults?

**Dr Solebo:** And just to say, one of the things we know from unicorns is that childhood uveitis, which can affect the front of the eye, the middle of the eye, the back of the eye, or all the eye, it most commonly affects the front of the eye. We call that an anterior uveitis. And that's about 80 to 90 [00:43:00] percent of cases.

And out of those children who have front of the eye problems, about one in less than one in ten of them will have JIA. So there are a lot of children with uveitis that don't have JIA. But if we focus only on JIA, uveitis JIA tends to happen in what we call a bimodal distribution, which just means there are two big times when it can happen. Two to five year olds and then 11 to 14 year olds. Those are the two sort of hits. of juvenile idiopathic arthritis and those children who will go on to develop a uveitis with their JIA, they tend to be in the two to five year old group. But we can get some really young children. So one of our patients developed uveitis when she was 18 months old and with the JIA.

So when they were 18 So it can happen in really really, really, really young, and it can happen in the older adolescents, of course, as well. So there's a wide range, but it tends to be those two big humps. And those are similar humps for all sorts of, all the sort, all the other different sorts of uveitis, particularly the sort [00:44:00] that affects the front of the eye.

So one hump at two to five, and then another actually quite bigger hump for the non J uveitis, a bigger hump at 11 to 15, which is. You can imagine, can't you? You're sort of a young child trying to take independence, first time you're going to secondary school, trying to discover the world. You might, you know, have your first phone, don't get too close to a phone, but you're stepping into independence and becoming your own person and then this disease falls in on your life and it's not of course just a diagnosis, it's all the time away from school, it's all the time away from work.

**Elizabeth:** That's right. And the continuing source of pain and not being able to play sport. I wasn't allowed to play sport in case. I was knocked and my knees were knocked or, you know, I just couldn't do it. And that, I, that upset me actually because I wanted to be one of the crowd. But I, I was sort of separated in a way from them, so it was a strange feeling, you know, but it had to be because they were, [00:45:00] my joints were very painful.

**Elizabeth:** So yes, I think knowing, knowing a little bit more about it might have been helpful.

**Dr Solebo:** So, so adult uveitis is more common, as in, so child uveitis think that the frequency is, if you look at how many new cases are you going to see in the UK over the next years?

We think it's like up to five per 10, 000, really low frequency of new cases of uveitis. But for adults, it's much more common. Uveitis in adulthood is the most common reason why someone will walk into an eye casualty hospital in the UK. So it is a more common diagnosis for adulthood.

**Emma:** So we've got another question again for you, which is what level of [00:46:00] ophthalmologists can give a definitive diagnosis of uveitis based on the images you'd receive? Would it only be consultants or would it be specialty trainees as well?

**Dr Solebo:** So on the images received. So we're not currently using the imaging technology in routine clinical practice.

And that's. Getting to that stage will require the research that Fight for Sight is funding. But if you're talking about looking through a microscope slit lamp, the routines of a machine that you'll see when you walk into an eye clinic where a doctor sits with you and has a look in your eye through a microscope, the level of seniority is important.

Because if you get two highly trained consultants to look at the same child, you might get between 60 and 80 percent agreeing within a reasonable range of error within the same child. For example, if you're going to GOSH and you see one of the three of us consultants work together, so it's got the two phenomenal colleagues who worked at GOSH, you've got a really high chance of agreeing within the three of us.

And the lower you [00:47:00] go down with regards to training, the wider that gets, that difference gets between two people looking at each other. And when it becomes, when you're talking about the very early stages, so the time when you really want to pick up uveitis, you just want to see a few immune cells. You don't want to see the scarring that can happen if you leave the uveitis by itself for too long.

So the scarring. Very junior ophthalmologists can see that scarring that's happened and they can make a really good diagnosis of uveitis because they can see all the damage uveitis has caused. That very early stage. It took me, I'm trying to remember, when I was a baby doctor, I think I didn't really see cells the first, like, four months.

It took me quite a while just to reliably see them, let alone to see them in very early, subtle cases. And that's for adults. Think about a wiggly three year old, a wiggly, what, 18 month old on the sit lamp. That, arguably, you'd really need a very senior, even, not just a consultant, but a really trained paediatric consultant who looks after uveitis a lot.

**Emma:** So thinking about the new technique that you've developed and [00:48:00] do you think this was where something like AI might be able to help in future informer diagnosis?

**Dr Solebo:** That's a really exciting thing. So I mean if I take the previous question before about what level of seniority you'd need to look at the imaging machines.

A member of the public can see the cells on the image. We know that because we did a citizen science study where we asked members of the public to look at the images for us to label them up. And we asked them to label them up. Oh gosh, I'm going to get it wrong. More than 20, 000, tens of thousands of people giving up their time to label these images for us.

The reason why we did that is we wanted lots of images labeled because we wanted to feed that in to an AI system to create an algorithm that would be able to automate the analysis. We know that's where it will need to be eventually. But the challenge in that is that we need to know just how much information we need to get from the AI.

AI has a horrible carbon footprint. So you want to know that all the [00:49:00] trees you're burning for the AI are worth it. And how can you limit the amount of work you're giving the AI to do? So is it worth it? And also, how can you just really minimise, how many images from the front of the eye, for example, do you need to take, how big does the window need to be, what sort of algorithms is the most efficient way of saying, yes, that's uveitis, no, that's not uveitis.

So imaging and the data we're collecting for this trial is going to be another phenomenal tool to do that work. And that's one of the reasons why it's so important that we share our findings internationally, that I can use the trial to really push work internationally because the more data and images we get, the better and more efficient eventual AI will be very exciting.

**Emma:** That's brilliant. I think we're going to have to wrap up now with the Q& A. This has been a really, really informative webinar. I hope you've enjoyed it at home or wherever you're viewing from, your office. There's some more resources available online. These will also be in the email that you've received post webinar, [00:50:00] which will give you access to the link and our survey.

**Emma:** You can join us as well for our next webinar if you liked what you saw today. Which is on empowering children, young people and their families living with Asher Syndrome, which will be on Thursday the 27th of February at the same time. And really I'd like to say one big final thank you to you both for

**Elizabeth:** Well, thank you.

**Elizabeth:** I have to say thank you to Lola because I've been waiting, I've waited 80 years actually, to ask all those questions.

Thank you!

**Emma:** So, thank you both, and thank you. Thank you again to Elizabeth for sharing her favourite cakes with us. I think, you know, we'll, we'd be wobbling around the fundraiser if we'd had one of those cakes.

**Emma:** And it's, it's been really, really interesting to hear about, you know, the difference really between your experience as a child and how things have changed thanks to research [00:51:00] over the years. So yeah, thank you all and thank you for joining us. Thank you.