Empowering children, young people and their families living with Usher syndrome

**Fight for Sight:** [00:00:00] Good afternoon and welcome to this webinar. It's really lovely to see you all here and thanks so much for being here.

**Fight for Sight:** So just a little bit about the organization. So we are Fight for Sight, and we fund the brilliant minds and bright ideas. Of those who put change in sight for everyone affected by vision loss. Over the next five years we plan to distribute 30 million pounds of grants investing in researchers at the forefront of tackling vision loss and also We'd like to fund those people and projects who are really changing the lives of those who have vision loss within the UK.

**Fight for Sight:** We're really delighted to be funding Usher Kids UK as part of our programme. They're such a joy to work with and I don't want to delay any more. So I'm going to hand over to Chloe, who is going to give her presentation. Thank you so much, Chloe.

**Chloe Joyner:** Thanks very much, Kerry. And thanks for this opportunity for us [00:01:00] to connect with our community, but also with those who want to know more about Usher syndrome.

**Chloe Joyner:** So we're really grateful for this opportunity. Moment of truth for me to share my screen. So one moment, and

**Chloe Joyner:** I hope now everyone can see the slides that I'm looking at. And just as Kerry said, I will absolutely do my best to read out everything that's on the screen and also describe any images. So just to introduce myself first, my name is Chloe Joyner. I'm the parent of a teenager with Usher syndrome and the founder of this charity, Usher Kids UK.

**Chloe Joyner:** And we're going to be talking to you today about how we work to empower the next generation of families that are living with Usher syndrome. with Usher syndrome. And the perspective that I share is that of a parent. I'm joined in fact, by another parent who's going to talk with us later, Claire. But we know it's also important for you to hear directly from children and young people that are living with Usher syndrome.

**Chloe Joyner:** So we've included quotes and also interviews with them within this session. [00:02:00] I'm joined today by Jessica.

**Jessica Hill:** Hello everyone. I'm Jessica. I'm the events and communications officer at Usher Kids. And today we'll be covering three main topics. The first will be, what is Usher Syndrome? So this will be quick 101 main facts that you might need to know.

**Jessica Hill:** The second will be talking through the typical journey of families and the impact on them of this journey. And thirdly, what does Usher Kids UK offer and what difference do our services make to our community? The

**Chloe Joyner:** time is up to you. Thank you. So I'm going to begin with this very brief 101 on Usher syndrome, just for those who might not be so familiar with the condition.

**Chloe Joyner:** It's a rare genetic condition thought to affect approximately 2000 children and young people in the UK, age 0 to 25. And it affects [00:03:00] three senses. On the screen, I've added an icon to represent each. So starting with the ear, Usher syndrome affects hearing all those living with. Usher syndrome have a level of hearing loss and in most individuals, this is ranges from moderate to profound hearing loss and is present from birth.

**Chloe Joyner:** The next icon I'm adding to the screen is an eye because Usher syndrome also affects vision and the text I'll read out. The vision loss condition that's associated with Usher syndrome is retinitis pigmentosa, which isn't just limited to those of us living with Usher syndrome has some predictable symptoms, which are the progressive loss of vision and This begins with difficulties seeing in dim or dark conditions and then starts to affect peripheral vision so that increasingly it's like looking through a tunnel with various different sort of features occurring within the remaining vision that's left.

**Chloe Joyner:** And for some adults they can find that final element of central vision is then compromised. It's really hard to [00:04:00] predict the age of onset and also the rate of change because there's very little and limited natural history data. But in many cases, the vision loss begins in childhood with noticeable changes by the age of five for some children, and an acceleration of changes often described within the teenage period for many young people.

**Chloe Joyner:** And finally, the final icon that I'm adding is a set of weighing scales to represent balance because for many, but not all, who live with Usher syndrome, their balance system, their vestibular system is affected. And this is most noticeable in infants because they will be the children who are very late to hit those milestones that we're all looking out for.

**Chloe Joyner:** So they're often late to sit, late to stand and late to walk. They absolutely do reach those milestones, but what does remain is a sort of definite sorry, an indefinite effect on their balance system, which means they can appear clumsy. Those who are looking at the images on the screen, you might notice that between each of these different sensors, I've added a multiplication [00:05:00] sign because unfortunately the combined impact of these three sensory losses is not as simple as adding them together.

**Chloe Joyner:** One plus one in this case does not equal three. Deaf children are reliant on their vision to fill in gaps in their hearing. The reverse is true for those who live with visual impairment. People with balance challenges use their vision to help compensate. So having issues across all three senses has a compound impact, meaning that the strategies that are needed to access and navigate life with this Usher syndrome are unique too.

**Chloe Joyner:** On the next slide, I'm going to describe the typical journey of a family receiving this diagnosis. And to bring that to life, I've added an abstract image of a, or a graphical image of a road, a symbol showing a road with a sequence of coloured markers along the top of the road, and some icons beneath which represent the different points in this journey that I'm going to be discussing.

**Chloe Joyner:** So first up, an icon showing a graphic image of an ear.[00:06:00]

**Chloe Joyner:** In ours, and in the majority of families with Usher syndrome, as I've said, the hearing loss diagnosis usually comes first. Most families, like ours, have no experience of hearing loss. This condition is passed on recessively, so usually no one else in the family is affected, and therefore it often comes as a shock.

**Chloe Joyner:** But families tell us that they've quickly felt they could access a path of care and support. And the messaging that they receive on this hearing loss pathway is that as parents, there's so much that you can do to empower your child and your family. You understand the choices that you have. There's a community there for you to belong to.

**Chloe Joyner:** There's information to enable you to make decisions. And there are lots of tools that you're shown that you can help equip yourself with. This means that for many families and young people, they quickly develop a sense of identity around the hearing loss and a sense of agency that they can make decisions to access the things they need to do the things that are important to them.

**Chloe Joyner:** So it's all sounding very positive. What happens next? In the case of a [00:07:00] family, that's going to be received this diagnosis of Usher syndrome. The next aspect is the. Genetic testing that now happens increasingly early. So because of advances in genetic testing, families of a child identified as having hearing loss will be offered genetic testing, meaning that this diagnosis of Usher syndrome can happen now at a very young age, while the child is still a baby, and often long before symptoms of vision loss might in fact be noticeable.

**Chloe Joyner:** So families with Usher syndrome receive this second diagnosis not long after finding out that their child is deaf. A second shock. But this time, the experience they tell us about on this journey is very different. There's no pathway of care or support which is designed for those with Usher syndrome.

**Chloe Joyner:** And the messaging that they're receiving is also very different. They're often told there's nothing that we can do and there's nothing that you can do. We'll just measure your child's vision loss each year and look out for changes. The child is fully sighted at this point, so many services are [00:08:00] geared, that are geared for families with vision loss, don't feel appropriate or relevant.

**Chloe Joyner:** And yet the impact of the family of this diagnosis has already begun. As the child or young person gets older, the family then shifts into different scenarios in which their child and they need new and different types of support and information. For example, when they move into education. And here I've added a logo of a pile of books with a.

**Chloe Joyner:** Graduating hat, I forget what that's called, but it's to represent education. The majority of kids with Usher syndrome are in mainstream settings, and they'll likely be the only child in that setting with even a single sensory loss, let alone multi sensory loss. The supports and the strategies that are needed are wide ranging, and they're often pieced together by the family in the absence of specialist support or best practice.

**Chloe Joyner:** As the child becomes a teen, their own adjustment and acceptance of this diagnosis becomes a key focal point for families. And here I've added in a graphic icon, which [00:09:00] shows. It's the side profile of someone's head with circles indicating, the thoughts of that person. And then also a heart in the middle, representing their emotions.

**Chloe Joyner:** And really this is just to draw attention to the emotional impact, which particularly can be very profound within that teenage period when not only the family is reacting to the diagnosis, but this young person is becoming increasingly independent and developing their own reaction and relationship with this news.

**Chloe Joyner:** The young person at this point is trying to work out what this condition means for their future, for their sense of who they are, or who they thought they were, and what lies ahead. And they're trying to learn how to live well in the day to day, in spite of this knowledge, the parents are often in the situation of having to try to support really complex emotional reactions without any guide as to how to do very few specialist services exist, which address the needs of those given an early diagnosis of progressive conditions so families can often feel on their own during these stages. As a young person transitions into [00:10:00] adulthood. And here we have an icon of a stick figure and then with an arrow pointing to a larger stick figure who's wearing a tie.

**Chloe Joyner:** So I guess recognizing this young person is becoming an adult and they're transitioning into new settings and scenarios. Maybe they're considering moving away from home, moving on to further education, starting employment, navigating new relationships. Transitioning to adult services and at each of these junctions, they have lots more to consider and adjust to than they're typically sighted and hearing peers, the journey that these families are on mean that they will pass through times when they need more or less or simply different types of support.

**Chloe Joyner:** Families and young people tell us that the challenges of being on this journey of continuous change and adaptation, while having to piece together all of the support that they need themselves with services simply not designed for this combination of experiences. Often the professionals that are surrounding us don't know how to support and that lack of best [00:11:00] practice can make families feel even more fear, isolated and fearful.

**Chloe Joyner:** So on the next slide, I wanted to share a couple of quotes, giving families and young people's own words so that we can understand some of the impacts of this journey that they're on. So first I'm going to read out a quote, which is given to us by a parent of a child with a young child at this point with Usher syndrome, and what they told us is I lost my peer group overnight with this diagnosis.

**Chloe Joyner:** One moment we were comparing weaning stories, and the next I'm trying to work out how and when to tell my deaf child that their vision is going to be affected. No one that I know has experienced that. And just to reflect on this, in my view, parents make the weather in their homes. So if they are feeling isolated and fearful, this is the atmosphere they create and pass on to their child, even before that child knows about this diagnosis.

**Chloe Joyner:** These parents and families face unique challenges, and they need a peer group to be able [00:12:00] to learn from and lean on, and a support system which understands the journey that they're on. The loss that these families are trying to accept hasn't happened yet. Which is very different from the deafness which has been a part of their lives forever.

**Chloe Joyner:** I can vouch that it's very hard to accept something that hasn't yet happened. Many conventional forms of support don't work. And so families on this journey need tailored emotional support. And next I'd like to share a quote from a young person who talked to us at the age of 17 years. What they said was, losing your sight after what you believe to be a fully sighted childhood is huge.

**Chloe Joyner:** It is an enormous adjustment and can really rock your sense of who you thought you were and who you believed you were going to become. You weren't born without sight. You didn't lose your vision as an infant. It didn't happen overnight. No one can say exactly how quickly it will progress and at this point there is no cure.

**Chloe Joyner:** There are a lot of unknowns. And this is what we hear within our community at Usher Kids [00:13:00] UK. Young people who are on this journey have lots of questions which they or their families don't know how to answer. And so again, young people need their own network of support and trusted places to turn to help them navigate and feel confident about the journey ahead.

**Chloe Joyner:** Now that we've looked at what Usher Syndrome is and the typical journey and the impact on families, I want to talk to you about the work that Usher Kids UK does, which is in direct response to what we hear from our community about their experiences. Our mission is simple. It's to empower children, young people and their families who live with Usher syndrome in the UK.

**Chloe Joyner:** And we want to challenge the messaging that families so often hear, that there is nothing that you can do. Whilst that might be medically correct at the moment, in fact, there is so much that we can all be doing to empower children, young people and families with the tools, the skills and the community that they need to thrive.

**Chloe Joyner:** And that's what we're here to do. I want to point out that there are lots of organisations [00:14:00] who address different aspects of our community's needs at different stages in their journey. And we really enjoy and are grateful to work in partnership with them. We're not here to replicate those services, but instead to focus on the unique and the specific experiences, impact and needs associated with Usher Syndrome that we've just talked through.

**Chloe Joyner:** I'm going to hand over to Jessica, who will tell you more about our services.

**Jessica Hill:** We at Usher Kids UK concentrate on four main service areas. The first of these is information. So we create trusted resources through collaboration with experts, tailored for our community of families and professionals. On the screen, under the word information, we have a small poster with a picture of a young boy who's sitting on his father's shoulders with the title Usher syndrome, as well as a QR code at the bottom of the poster, which links to our newly diagnosed information pack.

**Jessica Hill:** When we talk of the provision of information, we mean we [00:15:00] work with a team of experts to create resources which address the common questions and concerns that families have in the early stages following a diagnosis. Families and professionals can download our information pack directly from our website and we can send posters and business cards to professionals to raise awareness within their own services.

**Jessica Hill:** Connecting families with quality information. helps them build knowledge and confidence as they embark upon this journey. And our ASHA specific resources, for example, regarding educational strategies, reassure them that they can access best practice advice and guidance for every step along the way. The second service area we concentrate on is support.

**Jessica Hill:** Wherever families are in their journey, we are always here with support. On the screen, under the word support, there's a photo of a group of adults sitting on comfy chairs in a large indoor space. One person is [00:16:00] facing the camera and is wearing a yellow Usher Kids UK t shirt and is smiling at the others in the group.

**Jessica Hill:** We know one of the biggest questions families face in the early days is how and when to talk to their child about their diagnosis. We've created a series of resources focused on this topic. including a video by a clinical psychologist, along with advice from other parents who reflect what did and didn't work within their own family.

**Jessica Hill:** When families get in touch, we can offer the opportunity for them to speak to others with lived experiences and access other tailored support focused on their individual needs. Our third service area is connections. So we create opportunities for our community to share experiences. And meet with others who understand on the screen under the word connections, there's an image of young children playing together on the floor with lots of toy [00:17:00] cars.

**Jessica Hill:** So we offer a program of virtual and in person connections, which enabled children, young people and families who may have never met another person with Usher syndrome to connect with each other at our annual summer camp. Young people living with Usher syndrome, 11 to 25 years old, connect with peers and role models, having fun together, building amazing friendships, skills and confidence alongside others.

**Jessica Hill:** who really understand the journey that they're on. At our spring family social event we bring our community together for a brilliant day of fun and relaxation so they can get to know others in our community and build their own network of support. Toward the end of the year at our Autumn Information event, we enable families to hear from expert speakers and access workshops as well as having another opportunity to connect with each other.[00:18:00]

**Jessica Hill:** Our program really ensures that no one has to feel on their own, on their journey and access what is most helpful to them, depending on their current priorities, which of course is very different for everybody. Finally, our fourth service error is advocacy. We harness insight from our community to amplify their voice, champion their priorities, and improve outcomes.

**Jessica Hill:** Under the word advocacy on the screen, there's a photo of Clary, who's here today, standing with a young person with Usher syndrome. They're both smiling at the camera, standing in front of Big Ben, after a very productive day in London together. An example of some of the advocacy work that we do is working with partners in the NHS and other sectors to develop a care and support pathway for families with Usher syndrome.

**Jessica Hill:** We'd really like you. to hear directly from our community of children, young people and families about the [00:19:00] real difference these services make to them. First, one of the children who regularly attends our events tells us what it means to her. Thanks

**Chloe Joyner:** Jessica. I'll move on to the video and just to dig at the description of what you'll see on screen is there's a young girl who's standing inside a large colourful room.

**Chloe Joyner:** She has a white t shirt on and a pink, a pair of pink A headband which has a pair of pink fluffy ears on top and she's wearing glasses and looking at someone who's interviewing her in front of the camera. I'll move on to that video now.

**Fight for Sight (2):** Why do you like coming to Usher Kids UK

events? I like to come to Usher Kids UK events so I can meet people who are like me and click together easier because we're related to each other.

**Fight for Sight (2):** That's lovely. And what events have you come to with Usher Kids

UK? I've come to lots of [00:20:00] events including doing dancing and arts and crafts. Would you like to tell

**Fight for Sight (2):** me about what you did with your teddy bear today?

Yeah, when, with my teddy bear I got to have my own cochlear implants fitted on it and he had his own hearing test.

Oh, there. I think he enjoyed that. I think Thank you.

**Chloe Joyner:** Okay, we'll move on to another short video now, and this time you're going to hear from a young woman who is a member of our community and lives with Usher Syndrome. So on screen Ah! Apologies. Okay, now on screen what we have is a white background with the Usher Kids UK logo and the main person that you can see is this young woman that I've described, who is facing directly to the camera.

**Chloe Joyner:** She has a dark green hoodie on, which just actually has the logo for our summer camp slightly hidden from view she has long dark hair and wears glasses. And then in the small corner [00:21:00] of the screen, you can see the interviewer, who's Jessica that's here with us today. And Okay, so I'll play this video now.

Sorry for coming to our event UK. Had you met anybody previously with Usher syndrome? I actually hadn't. So the family day, the family information day, was actually the first time I'd ever met anybody else with Usher syndrome. And it was really weird for me, knowing that all these people were out there.

Somewhere out there in the wilderness and it was only at this information day that I'd actually been able to meet other people like me for the first time. What was that like? It was really emotionally overwhelming in a way. When me and my mum were on the train home, I was I had this rush.

I was like, oh, that was the most amazing feeling. I got to stand there and talk about my personal experiences. But I also got to meet all these other amazing people who were just like me. That feeling of meeting other people that know what you've been through and what you're going through without you having to say a single word about it.[00:22:00]

It feels really fulfilling really poignant, actually, you've filled a little missing part of you, and it's, it sounds really cheeky, but it's true it's really nice to just feel understood for the first time. I think then, moving on from that, our next question is, how would you say being able to meet other people?

with Usher Syndrome. How has that impacted you? I think it almost validates your experience. So like for me personally, I had grown up knowing that I was deaf, but I never really felt like I fitted in very much. I felt too deaf for the hearing world and too hearing for the deaf world. So I was in limbo.

But then when I met these other people with Usher Syndrome, I felt like I'd found my community of people. And I felt like all of my experiences leading up to that moment. Had been validated by these other people who had been through similar things and who had similar experiences. What differences would you say that having those connections, how has that impacted your journey with Autism [00:23:00] Syndrome?

I think even though by the time I had come to the Usher Kids UK event, I had very much come to terms with my diagnosis. I was still learning things and I was still, I still had questions and other people, ultimately, even though we have the same diagnosis, they still have different experiences.

So I think seeing other people's experiences and hearing other people's experiences, it opens your mind up to the things that you might be capable of, things that you might also experience, things that you'd perhaps not considered. And, some of the people that I've met have done some absolutely incredible things.

Their hearing is worse than mine or their sight is more progressed than mine, and they're still doing these incredible things. So it makes you a little bit less afraid of the future. You're looking forward to the next crown. I cannot wait.

**Chloe Joyner:** Okay, so I hope that's helped to bring to life some young people's experiences and the difference that it makes to be able to access the kind of community that we have and [00:24:00] accessing others that understand the journey that they're on.

**Chloe Joyner:** The final video we just wanted to share is a shorter one and it's a father talking about his experiences. And so let me move. To that video.

So when we first had the diagnosis that both our children had USHA, that was really quite an isolated thing, quite they're already the only deaf kids in their school, so to find out they had this rare condition was very We felt quite alone when we reached out to Russian Kids UK.

It was really nice to have lots of, find out that there are lots of other families out there going through what we're going through to be able to share stories, get information from them, and it helped us all feel like we were not on our own with it. And that's really, can't really quantify how helpful that was.

All of us. Much more positive approach after that. And then quickly we accessed all the other services that Flushing Kids provide. And now we feel very much part of a community [00:25:00] of people. And it's the events that they put on are the highlights of the children's year. And it feels an awful lot better now that we know that we're not alone in going on the journey of Usher syndrome.

**Chloe Joyner:** Okay. And I missed the visual description. So just to describe what was in the screen there, and this father was standing directly looking at the camera and has a checked shirt on and short very short hair. And in the background, what you might've been able to hear is that other families and young people who are in the same space as him, because that was during our information day.

**Chloe Joyner:** I'll stop screening, sharing screen at this point. And we'd like to invite another parent to come and chat with me before we open up for questions. I stopped sharing and invite Claire Lumet is a parent just like me a different stage in her journey. And I thought it'd be really nice to be able to have the chance to hear from Claire and hear another parent's experience.

**Chloe Joyner:** Thank you very much for coming and joining us, Claire. [00:26:00] I wonder if you would begin by letting us know, Your experiences perhaps prior coming to our events. Had you ever met another family? Where were you at in your journey? I guess when you first came to one of our events.

**Claire, parent:** We have never met another family with ushers. So my daughter was diagnosed with deafness when she was born and We were involved with our local deaf children's society for nine years. Then we received the diagnosis of ushers. As I said, we'd never met anybody through the Deaf Children Society with ushers and our consultant hadn't met anybody with this condition either.

**Claire, parent:** So it did feel quite lonely at that point.

**Chloe Joyner:** And what was the impact of you or what has been the impact on you and also your kids of being able to have those connections with other people?

**Claire, parent:** It's given all of us such a confidence boost. It's been so [00:27:00] lovely to meet other families that are deaf. just like us.

**Claire, parent:** For my sons to meet other siblings that are in the same situation as them the questions, uncertainties, it's just so reassuring for them to know they're not on their own. And for my daughter, she's not on her own. She sees other people just like her. As a family and as a parent to know that I'm not on my own and there's other people that I can lean on and have that support.

**Claire, parent:** That's

**Chloe Joyner:** good to hear. And I know you've also come along to our virtual parent support group, so that's available for any parents or carers. In fact, wherever they are in the world, they can come and join us at that virtual session, which really gives a chance to connect and tap into that sort of network of support and net network of expertise actually.

**Chloe Joyner:** 'cause I think often it's. parents who might hold the best sources of information for us all about, strategies to use in the home. So I'm really glad that you've been able to access [00:28:00] those. And just thinking about some of the information that perhaps you've accessed what kind of difference does that make or what impact does that make in terms of that information support that's available?

**Chloe Joyner:** Sorry, Claire, I think it dropped off for a moment. Did you hear the question or should I repeat? Could you repeat, sorry. So I was just wondering about if you've accessed any of the information that we provide and what kind of impact that has or whether it's the support that you receive in that parent group just thinking about that.

**Claire, parent:** It's everything. The information that we've received and obviously the support from other parents and professionals we really feel so much more confident and empowered. I think sometimes when we read things on the internet, it can be quite daunting. And because it's so rare, the information is also quite limited.

**Claire, parent:** So [00:29:00] when we've been along to the in person days, meeting the professionals and other parents just gives us that much more accurate lived experience. So there's practical hints and tips that can make our daily life that little bit. easier and it feels just so much more personalized and helpful.

**Chloe Joyner:** And I guess just thinking overall about the kind of difference that makes in your journey, being on this journey, is there anything else that you. you'd share or say about that?

**Claire, parent:** Just knowing that we're not on our own. We're part of a very unique community that's so supportive and to feel that we don't need to explain ourselves.

**Claire, parent:** We're with other people that just get it. That is so valuable to us.

**Chloe Joyner:** Thanks so much. At this point, we are very happy to open up for [00:30:00] questions. And I know Claire said she might be happy to hang around for that as well. And Jessica's available as well and can share information about our services. So we're very open to any questions from the audience at this point.

**Fight for Sight (3):** Hi there. So it's Kim from Fight for Sight over here. I'll be reading out any questions that come in. From the floor, I've got a question. Can children from all parts of the UK access your service?

**Chloe Joyner:** Yeah, absolutely. So the names on the tin in terms of Usher Kids UK and absolutely, these services are available to anyone in the UK.

**Chloe Joyner:** I recognize that sometimes, for our in person events, that can be challenging, but we do have people that travel a long way to come to our events. We actually have a young person from the Falkland Islands that comes from summer camp. I know that isn't possible for everyone, but that's why we always try to make sure that there's virtual opportunities as well for people to connect.

**Chloe Joyner:** So there's the virtual sessions for parents. Those take place every third Thursday between 8 and 9 p. m. With the exception of summer. months and December. [00:31:00] And it's a really informal chance to connect with other parents. So that's available virtually if distance is an issue. And like I said, we have families joining from all over the world.

**Chloe Joyner:** In fact, we run them across two different times so that we can really cover the globe. And what's wonderful about that is when you have a rare condition, it doesn't matter where best practice sits. If there's a strategy that someone's using in Texas or in Australia, that can be so helpful and connects families with the kind of, just like Claire said, those practical adjustments that you can make that perhaps none of the professionals that you're working with know about, but are going to make a huge difference in your day to day life.

**Chloe Joyner:** Similarly, I'd say the information resources, We have a small charity so there's, we're working through the kind of information we want to share and one of the first priorities was having the newly diagnosed information pack, so that from the point of diagnosis onwards, families and professionals who are not familiar with this condition can access really good quality information, but also images of young people and families who are thriving, because I think in the absence [00:32:00] of being able to access that kind of information, our brains fill with the worst kind of fears, and they're not accurate.

**Chloe Joyner:** But if you don't have access to a community and information, and that's where your mind can go. So newly diagnosed information pack is a really good resource for any professionals, but also for families and perhaps for wider family members as well. I know families tell us that it's really helpful to share something with.

**Chloe Joyner:** well meaning people in your support network. And it just takes one less job off you having to explain this diagnosis to other people who want to help. This can give them a way of understanding something about what's just landed in your family. And then also information resources around education, for example.

**Chloe Joyner:** And as Jessica touched on the emotional support. So I direct people who might not be able to come physically to our events to have a look on the website and absolutely to get in touch with us. We know that there's still lots of gaps and we work really hard to try and address those, but we want always to respond to the priorities of the community.

**Chloe Joyner:** So just get in touch, it will be literally the people you [00:33:00] see here, Jessica or myself responding to your email. So we're not a faceless organization, let us know and we'll respond and do our best. I just

**Jessica Hill:** have one thing to, to add to that, if I may. One thing when I, still relatively new, but one thing that I thought was fantastic when I joined, was that when we provide events, they're provided across the UK.

**Jessica Hill:** There's not that thing where everything always happens in London, which so often happens. And if you're so far up north, that's such a distance to travel, especially as a family. And so I think it's great and really important. That we do move those events around, so we might be in Birmingham, we might be in the Lake District, we might be in Essex, we might be in London, just so that it's not always the same family as having to travel a great distance.

**Jessica Hill:** I think that adds an element of accessibility to those events.

**Chloe Joyner:** Thank you. And just to finish off on that point the [00:34:00] next event that people could come to it's a free one day event and it's on Saturday 26th of April, and we will be in the Midlands Blackwell Adventure Centre, and the sign up for that will be opening really soon so keep an eye out for that on our social media.

**Fight for Sight (3):** That's lovely. Thank you. So actually following on from the sort of, you mentioned, Australia, and the US international I've got a question here. And maybe, Katharina, you can let us know if we answered you, but I've got Katharina from Greece. Unfortunately, here we don't have specific services for parents or children with Usher syndrome.

**Fight for Sight (3):** How would you recommend us to help a family with a child who has just had the diagnosis?

**Chloe Joyner:** Yeah I can imagine and most families find themselves and professionals find themselves in the same situation. So you're not alone in Greece. And it would be good actually to know, is Katarina's background in education or in healthcare, just to tailor the answer.

**Chloe Joyner:** I wonder if she could mention that. I think, I guess I'd turn back to the point. That I mentioned in terms of, the information that we're all [00:35:00] seeking doesn't really have boundaries or borders. Because much of what we want to know and the best practice is universal. So I'd really encourage you to access the information that we share.

**Chloe Joyner:** And if you find that there are gaps in your knowledge, feel free to reach out and we can help direct you to other resources. Like I said, there are other organizations that feel really important parts of the jigsaw here. And we could signpost you to other organizations. Catherine answers, I'm a social worker.

**Chloe Joyner:** Social worker. Okay. Yeah. I think really important thing to recognize is what you said is that it's working with the whole family because actually this impact is not just on the child or on the parents, it's on all of them, and they will have Very different needs at different stages in this journey.

**Chloe Joyner:** And I think if the child is young, then I would say working with the family. Often we hear services saying to us, when should we start working with this family? Because their vision loss hasn't begun yet. And I'm like yesterday, because there's so much that we can be [00:36:00] doing, even if that's just with the parents, helping them understand the journey that they're on, what are the things that other families find helpful, which thing could they be addressing first?

**Chloe Joyner:** Is it, do they need to focus their energy on. the hearing loss and actually what's the communication choice for this family going to be and help them become really confident and successful in their choice in that area. What do they have the energy for next? It's tempting to throw everything at them, but actually that's not helpful for family.

**Chloe Joyner:** It's overwhelming. So understanding what their biggest question and concern is, and then finding good quality sources of information to respond to that. Having a professional that's willing to go on that journey with them. Most of us will encounter professionals that don't, haven't worked with Usher syndrome before.

**Chloe Joyner:** And I, I personally always feel much more trust when they're happy to say that to me. And I don't expect that they have all the knowledge, but what I love to see is when they're willing to listen to and observe and understand our experiences and our questions and then go [00:37:00] on a journey with us to learn themselves.

**Chloe Joyner:** and expand their professional understanding and build their knowledge to support us. So I think don't worry if you don't have all the answers but just showing that you're opening to learn, open to learning is really powerful.

**Fight for Sight (3):** That's great. Thank you, Chloe. I have another question from someone asking, can your charity support families from ethnic minority community communities to connect with each other?

**Chloe Joyner:** Yeah, everyone is obviously welcome at all of our events and we do make efforts. If a family contacts us and has, perhaps the English isn't their first language, for example, and they want to connect with another family, we will do our best within our private Facebook group within social media or within our network that we can try and connect people.

**Chloe Joyner:** With whatever kind of community is most helpful for them. We're a tiny national charity. We don't have specific programs that, that actually address specific elements of our community. We [00:38:00] hope that people feel welcomed and included within all our events. And we'd love to hear about it.

**Chloe Joyner:** If people have needs that we need to consider. We make sure that we can. do our best to offer those within all of our different service areas.

**Fight for Sight (3):** That's great. Thank you. Can, I've got a question from someone asking if people can support events as volunteers and what background is needed?

**Chloe Joyner:** Yeah charities always need volunteers, don't they? And we're no exception. And I think. A unique feature of the legacy that we're trying to leave really is helping professionals build their knowledge and gain insight into the experiences of families. So we welcome volunteers from related sectors.

**Chloe Joyner:** So we, at our summer camp, for example, we have a team of approximately 15 volunteers and they all come from disciplines such as genetic counselling, audiology, we have QTVIs that come along we've had habilitation workers in the past and All of that is so that they can bring their skills and, have a fantastic week with an amazing bunch of children and gain insight into [00:39:00] the lived experiences and the day to day experiences of these young people so that they can take that away into their practice.

**Chloe Joyner:** And you tend to see them filling up through the course of the week because they are just. Their mind is blown by a how brilliant these kids are and amazing and all the preconceptions they had about a young person with this condition are blown out of the water, but they also go away really inspired and much more knowledgeable and motivated to go back to their professional network and their services to think, are we addressing the needs and how could we do better to support these young people.

**Chloe Joyner:** So we hope that leaves. That kind of lasting legacy. We do have actually a waiting list for volunteer places for our summer camp in particular, because it's such a wonderful experience. You might not see us going out with calls for volunteers, but if you've got a particular interest and you work in a related sector, we'd love to hear from you because there are lots of different opportunities to get involved.

**Chloe Joyner:** Our one day events that we mentioned, but then also helping us to spread the word. And [00:40:00] raise that all important money. So there's lots of different ways that you can support us. And we love to learn from professionals that have a different angle to share with us. And then we can also hopefully share really useful information.

**Chloe Joyner:** So feel free to get in touch.

**Fight for Sight (3):** Thank you. I've got a couple of questions. One from a parent, and possibly another one from a parent, but is the sequence of events always the same, i. e. hearing, sight, then balance?

**Chloe Joyner:** In the vast majority of cases, it's always hearing first and balance would also present if it's present balance would always present.

**Chloe Joyner:** at the beginning as well. So those two elements would be there. There are some subtypes of Usher syndrome in which the hearing loss is progressive as well as the vision loss being progressive, which means that the hearing loss could present later in those cases, but they're in the minority and the majority would have hearing loss.

**Chloe Joyner:** from birth. And then if balance is relevant within their subtype, that would also be present from birth. The vision loss aspect is the, always the [00:41:00] thing that comes later in terms that it wouldn't present necessarily straight away. But the important point to notice the diagnostic testing capability could pick up.

**Chloe Joyner:** The vision loss well before that young person is starting to experience any functional changes. So whilst it might not be noticeably affecting them, there could be changes in that can be detected on tests. So that, that can be picked up as I've said really early and importantly, the genetic diagnosis and the clinical diagnosis is needed to be able to give a diagnosis of Usher syndrome.

**Chloe Joyner:** So both the genetic testing and the ophthalmology testing is required.

**Fight for Sight (3):** That's great. Thank you. And this is from a parent. Our child has moderate hearing loss and has been diagnosed with RP with the highly suspected ushers awaiting genetic results. How and when would you advise us to start talking about this with our child?

**Fight for Sight (3):** She currently knows she has poor eyesight and hearing loss, but nothing else.[00:42:00]

**Chloe Joyner:** Other parent expert here on this call, Claire, and I'm happy to hear anything that you'd say on that. Certainly a huge question we receive, Jessica can vouch for that. It's something that you notice cropping up. In our chat on the private Facebook group, for example I would definitely suggest having a look at the website, the emotional support pages and watching both the video by the clinical psychologist, which really addresses this specific question, but also looking through the tips from parents.

**Chloe Joyner:** For parents, because I think what you'll see from that is that there isn't unfortunately for any of us a really clear answer as to when and how, but I think some of the things that the common features I'd say that families say tend to work is this is not going to be about one big kitchen table moment where everyone everything stops you sit down and deliver this news.

**Chloe Joyner:** This is about finding language that you as a parent or carer feel comfortable with. Feels natural to you and and you feel ready to have those conversations. And if you don't, [00:43:00] I'd say it's really important to address your own needs at this stage and to get yourself in a place where you feel like at least you've found your feet might not be ready to accept what's happening.

**Chloe Joyner:** Maybe we never do, but we can find our feet and look after ourselves so that when we have those important conversations with our children, we feel like we are able to respond to their questions. And we're not also channeling how we feel about it. So I'd say no big. one off moment in which this is handed over.

**Chloe Joyner:** If the child is young, then actually there's an opportunity to start to build their knowledge of some of the terminology before they even know about that this is something that's relevant to them. It could be, just as we do around hearing loss awareness, it could be, Oh, look, do you know why that person.

**Chloe Joyner:** Feels underneath the pedestrian crossing for something that can tell them it's time to cross. Or do you know why that person's got a dog with them? Interesting conversations, which after all is what a child wants to have, which just fill in pieces of their knowledge so that as, and when. You come to a point where you [00:44:00] might want to explain, that there's differences in your hearing or we've understood that actually there might be differences in your vision as well.

**Chloe Joyner:** This might affect the way that you see. And I think a lot of parents have also said that they find it easier to talk about changes than talk about some kind of end state. And for many, they find the word blind, for example, to be quite emotive. And also it's people's perception of what blindness is often.

**Chloe Joyner:** not accurate if you don't have any experience of it. And so it can give everyone a false impression that there's going to be this moment at which all vision is gone. And this young person only sees darkness and it's not accurate. So again, helping to dismantle some of those perceptions that.

**Chloe Joyner:** People might have can all put you all in a different place. So that as, and when you start to talk, about specifically that child, they don't feel quite as fearful or perhaps about the information that you're sharing. And I, the final thing I'd say before I ask Claire her thoughts is that I know in our home, what really worked was talking about, this is a young person who's already got a lot of [00:45:00] experience about how they.

**Chloe Joyner:** Do the things they want to do with a sensory loss. So utilize that. It's a real strength they've got. So in our house, we just talked about, we know there might be changes in your vision. You know how we do things differently as a family because of your hearing loss. That's what we'll do. You will find ways to do all of the things that you want to do.

**Chloe Joyner:** And we will support you to do that. And that was a way in for us that made those conversations feel easier to have. Clare, is there anything you'd add?

**Claire, parent:** Really just to echo what you've said definitely feeling confident in yourself. before you share the information, just to know that, like you say, you've got your feet on the ground.

**Claire, parent:** And sometimes the questions that you answer aren't the questions you expected. They go off on their own little tangent and that's fine. But also, your own child. I think it's really important that every child is [00:46:00] different. They all require a different language or a different level of.

**Claire, parent:** information for them. So go with what your child needs at the time and that can be built on or gone over at a later date. I know my daughter really loves playing with her Barbie dolls. So the fact that we've now got blind Barbie with a cane and there's already the Barbie dogs out, she loves playing and reenacting things.

**Claire, parent:** Just those little things making everything very normal in our household really helps.

**Chloe Joyner:** That's brilliant. And this is something that, little and often I think is the way that we probably all approach it, dipping in and out, listening out for questions that they might have. But definitely tuning into your own needs to, and sometimes you do, that does show to the child, but just.

**Chloe Joyner:** Giving yourself pat on the back, really, for [00:47:00] everything you're processing as a parent. It's it's a lot to be dealing with your own reaction and then also trying to pivot and work out how to support your child and, absolute kudos to everyone who's busy doing that. And just give yourself, if you've had a difficult conversation, allow yourself time for a cup of tea and just to catch your breath and just recognize you're doing something pretty special in, in supporting them around these, their understanding of this.

**Chloe Joyner:** Yeah, we're all here for you. I do, we'll share the link for that emotional support page, but yeah, I hope that you would find that information useful.

**Fight for Sight (3):** So here up on the screen right now. is some get in touch information from Usher Kids UK and just a reminder that these slides will be available, they'll be sent in an email

**Fight for Sight:** And huge thanks to Claire and Jessica and Chloe for sharing your presentation and your experiences. It really is great to hear about the impact of Usher Kids UK and I'm really [00:48:00] delighted that we are continuing to fund you as well.

**Fight for Sight:** Just before we all go, if you did enjoy this webinar, we would love you to join us next week for our next one. And that's going to be with Dr. Amy Gerrish, who is a research scientist at the Regional Genetics Lab in Birmingham. And she'll be spotlighting her research leading to better childhood cancer diagnosis.

**Fight for Sight:** She's also going to be joined by Fight for Sight Ambassador Katie Elliott, who herself was diagnosed with a retinoblastoma. At the age of four, and she's going to be talking about her treatment and her memories and experiences of her diagnosis and how this has shaped her life as an influencer, ambassador and advocate.

**Fight for Sight:** And if you'd like to join us for that, you can sign up through our website. But apart from that, I'd like to thank you all again for coming, and we really hope that you enjoyed the webinar today. If you could just take a couple of moments when this finishes [00:49:00] to answer a couple of questions just about our webinar series and this webinar, that would be really helpful for us as well.