# Look Forward – Spring 2022 (Issue 176)

This edition of Look Forward is packed full of details of our plans for 2022. There is so much going on and being able to get together in person is a big part of that. We hope you’ll be able to join us at one or more of our events – we’re so looking forward to seeing you in person again.

Our [sight loss survey](#_Help_to_shape) is now open. Your feedback is really important to us and we value your input. It has already shaped our work as demonstrated in the images above and it will shape our future work too.

## Weathering the storm (Tina Houlihan)

We’re practically bursting with enthusiasm and excitement about our plans for this year. It’s been such a long time since we were able to meet face-to-face that it feels even more special than normal. More about those later.

Firstly though, I would like to ask for your help. As you have probably gathered from the cover of this edition of Look Forward, we are repeating our [sight loss survey](#_Help_to_shape) this year. You may remember that in 2019 we had more than 900 responses and those insights have informed our work since then.

This is a chance to check that our work is making an impact for you, our community. The survey can be completed on paper (enclosed with this edition of Look Forward), online or, if you prefer, you can phone our office and we’ll arrange for someone to call you back.

Registration for our [Annual and Professionals’ Conferences](#_Register_now_for) is now open and we’re looking forward to being able to welcome you in person or online in 2022, whichever you choose.

We’ve also got some great webinars lined up and a bumper number of [information days](#_Lots_to_look). Finally, we know that meeting others living with similar conditions is really important to you, so we’ve expanded our [local peer support group meetings](#_Local_peer_support) in 2022.

Do please make sure you share your email address with us (if you have one). We can then send you our monthly e-Newsletter as well as Look Forward in the format of your choice.

## Join #TeamRetinaUK

Our essential services, and the medical research we fund, provide support for today and hope for the future. We can’t do it without you – join us in 2022.

### Run!

Run the TCS London Marathon on 2 October 2022 with Retina UK and get your medal! Soak up the incredible atmosphere as you run by Tower Bridge, Big Ben and Buckingham Palace with the crowds cheering you on! Or, take on 26.2 miles close to home in the virtual race.

Registration fee:
£100 (London), £14 (virtual)

Fundraising target:
£2,000 (London), £165 (virtual)

[www.RetinaUK.org.uk/LondonMarathon](http://www.RetinaUK.org.uk/LondonMarathon).

Fancy a city to sea route? Join us for the world’s biggest half marathon! Run from Newcastle to South Shields at the Great North Run on 11 September.

Registration fee: £15
Fundraising target: £400

[www.RetinaUK.org.uk/GreatNorthRun](http://www.RetinaUK.org.uk/GreatNorthRun).

### Walk!

From May to September, take on an Ultra Challenge with Retina UK. With 25, 50 and 100km distances available, find the route that’s right for you. [www.RetinaUK.org.uk/walk](http://www.RetinaUK.org.uk/walk).

### Jump!

With a tandem skydive, the sky really is the limit! Strapped to your expert instructor, you’ll jump from a plane at 10,000ft, freefalling at speeds of up to 120mph before your parachute opens and you slowly descend to the ground.

Booking deposit: £70
Fundraising target: £395

[www.RetinaUK.org.uk/skydive](http://www.RetinaUK.org.uk/skydive).

Want to find out more about joining #TeamRetinaUK? Email fundraising@RetinaUK.org.uk or call Simon on 07736 925174.

## Riding the rollercoaster – a clinical trial experience

David Bureau has been on a clinical trials rollercoaster for the past eight months, but is still feeling positive about his experiences of taking part in the phase 2 trial of a cell therapy for retinitis pigmentosa, developed by biotechnology company ReNeuron.

David first noticed problems with his vision when he was struggling to read the speedometer in his car, and was diagnosed with RP at the age of 30. Now in his early 50s, David was approached in spring 2021 by the Oxford Eye Hospital team preparing to enrol participants in the ReNeuron study.

The trial treatment was a preparation of retinal photoreceptor progenitor cells (RPC). These cells have only just started on the path of maturing into fully differentiated retinal cells; you would find them in a developing human eye and they are basically very “young” photoreceptors. Based on encouraging animal studies, ReNeuron scientists were hopeful that these cells would integrate into the retina, where they could provide nourishment and support to improve survival of existing retinal cells, or possibly even develop into photoreceptors to replace cells that had already degenerated. The cells are injected into the back of the retina (subretinal injection) under general anaesthetic. ReNeuron had already undertaken a small phase 1 clinical trial of a conservative dose of the cells, which produced encouraging safety data, so the company felt confident to move forward to phase 2, with a higher dose and more trial centres across the US and Europe, including the one at Oxford.

After a detailed screening process involving a full day of tests at Oxford, David was preparing to travel to the hospital again in June last year to undergo treatment when the trip was called off at the last minute. The evening before surgery, David was told by the Oxford team that ReNeuron had paused the trial after a participant in Spain had suffered an infection – everything had to be put on hold.

This was something of an anticlimax, but by September things had started moving again. ReNeuron had introduced additional checks to guard against infection, and David’s surgery was re-scheduled for October. This time it went ahead, and David became a trailblazer as one of the first ten people in the world to receive the higher dose as part of the phase 2 trial. He received the treatment in his right eye only, which has always been the more severely affected – this is typical clinical trial protocol to limit the risks to the better eye and preserve some vision should things go wrong.

After surgery, David had to lie on his front with his head as still as possible for a week to allow his retina to settle down. “My wife has a photo of me lying on the corner sofa with my forehead on a footstool looking down at the iPad on the floor!” he told us. All was well at David’s post-op check-ups, although he did have to undergo an additional unpleasant procedure that involved injecting steroids into his eye in an attempt to suppress some inflammation.

Over Christmas, he thought he noticed some encouraging signs: “I was stepping into the shower and suddenly realised that I could make out the bathroom cabinet to my right, which I hadn’t been able to see from that angle before” he said.

However, a visit to Oxford in January this year was disappointing. As it turned out, things weren’t going all that well for the trial in general. A number of participants across the globe had experienced unwanted side effects from the more challenging surgery involved in injecting the higher dose of cells. Meanwhile, ReNeuron had followed up with the participants from the original lower dose study and found that the improvements they experienced were usually only transient, lasting less than two years.

On this basis, ReNeuron has very recently made the decision to halt the trial and proceed no further with the development of this treatment. However, it believes that the therapy does still hold potential, and will look for a third party that is able to take it on and address the challenges, perhaps by investigating ways of increasing the impact of the lower dose.

David has taken a pragmatic attitude to these disappointments. “Nothing ventured, nothing gained – my right eye was always rubbish” he told us. “Right now, I think that if I was asked in a year’s time to take part in another trial, and I was eligible, I would still consider it. But of course that might change, we’ll see how things go.” David appreciates the high level of care he has received from the Oxford team, who will continue to monitor him and gather data over the coming months. He feels that, if nothing else, he understands a lot more about his medical history than before.

ReNeuron isn’t the only company that was involved in clinical testing of retinal progenitor cells; the US company jCyte is still going ahead with trials of its treatment, which is applied via a less invasive technique. More information about jCyte is available in the Research News section of the Retina UK website.

## Help to shape our future

Would you like to help shape Retina UK’s future? Do you want to ensure decision-makers understand the impact of inherited sight loss? If so we’d love to hear from you.

By sharing your views and experiences in our 2022 Sight Loss Survey you can help ensure our current and future activities are relevant and that they respond to your needs.

We will also share the findings with other statutory bodies and organisations that can make a difference for people living with inherited sight loss.

In 2019 more than 900 of you completed our survey. The information you provided has been invaluable.

Members of our community have been involved in the development of the survey.

Paula McGrath, Director of Development, said: “It is vital we have an up-to-date understanding of how people experience life with inherited sight loss. This is why we repeat our survey every three years.

“The findings will enable us to set our priorities, measure our progress and impact over the coming years and support our applications to funding bodies. I would strongly encourage all of our community to take this opportunity to make their voice heard.”

### Take part

The survey is open to anyone living in the UK with an inherited sight loss condition. It can take 40 minutes or longer to complete, especially if you are using accessibility software or devices. It is not possible to stop part-way and resume another time, so only start the survey now if you have time to complete it in one session. Otherwise, feel free to exit and come back when you have more time. The deadline is Tuesday 26 April.

It can be completed:

* on paper
* online ([www.surveymonkey.co.uk/r/SightLossSurvey2022](http://www.surveymonkey.co.uk/r/SightLossSurvey2022))
* over the phone. Call 01280 821334 and we will arrange a time to phone you back.

You can respond anonymously should you wish.

### These are some of the actions taken following the last survey:

### Information provision:

You said: You wanted to hear more from Retina UK on treatment updates, research progress and managing life with sight loss.

We did: We started new monthly webinars and podcasts on a variety of topics.

### Peer to peer support:

You said: You benefit from informal meetings with others affected by sight loss.

We did: We moved our local peer support group meetings online during the pandemic and we’re setting up new ones.

### Understanding genetic testing:

You said: 43% of you told us you were not aware of genetic testing or it was not available to you.

We did: We launched our innovative Unlock Genetics resource, packed with information to enable you to make informed choices.

### Mental health and wellbeing:

You said: Only 8% of you said you’d experienced no emotional or psychological impacts.

We did: We created accessible wellbeing modules for our helpline volunteers, now we’re developing these for our community.

### Approving treatments

You said: More than 900 of you told us how inherited sight loss impacts on your daily lives.

We did: We shared your experiences with decision-makers who agreed to the first treatment for inherited sight loss being available on the NHS.

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## Lots to look forward to in 2022

We are so looking forward to welcoming you to our events this year. There are lots of different ways to access them; our face-to-face events are re-starting and we will continue to provide our webinar series online.

### Information days

We will be holding a number of face-to-face information days this year. More information, including the venue and speakers will be available soon on our website www.RetinaUK.org.uk/info-events and sent via our e-Newsletter. If you don’t already receive emails from us, we would encourage you to share your email address with us.

* Aberdeen - 18 May
* Bristol - 13 September
* Oxford - 14 September
* Manchester - 27 September
* Hull - 29 September

### Webinars

Our incredibly popular free-to-attend monthly webinar series continues. Upcoming events include:

* Thursday 31 March – Medical Images and what they show with Dr Daniel Jackson from Moorfields Eye Hospital.
* Thursday 28 April – ‘Mini-Retina’ – A tool to unlock the future of restored vision in retinal blindness with Avril Watson, PhD student in Professor Lako’s lab.

Register to attend at [www.RetinaUK.org.uk/info-events](http://www.RetinaUK.org.uk/info-events).

Recordings of past webinars are available online: [www.RetinaUK.org.uk/recordings](http://www.RetinaUK.org.uk/recordings). These are available in video format (on YouTube) or audio (via Anchor FM). If you would prefer to receive past recordings on a CD or memory stick, just get in touch by emailing info@RetinaUK.org.uk.

### Local peer support group meetings

Our local peer support group meetings have been really popular so far this year. These meetings offer an opportunity to meet others living with inherited sight loss in your area.

There are also some great speakers with interesting and informative topics.

Forthcoming groups are as follows:

* London (online) - 19 March, 11.00am - 1.00pm
* Hampshire (face-to-face) - 28 March, 10.30am - 12.30pm
* Scotland (online) - 29 March, 7.00pm - 8.00pm
* Manchester (face-to-face) - 23 April, 12.00pm - 2.00pm
* Glasgow (face-to-face) - 16 May, 12.00pm - 1.00pm
* Edinburgh (face-to-face) - 17 May, 1.00pm - 3.00pm

Find out more and register to attend at [www.RetinaUK.org.uk/groups](http://www.RetinaUK.org.uk/groups).

We need [volunteer group facilitators](#_Volunteer_opportunities_with) and helpers in various locations.

### Sight Village

We will be attending the Queen Alexandra College (QAC) Sight Village events in 2022 as follows:

* Birmingham - 28-29 June
* Leeds - 21 September
* London - 8-9 November.

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## Could your employer support our work?

Retina UK relies entirely on the generosity of our wonderful supporters. We could not provide information and support to our community, or fund ground-breaking medical research into potential treatments, without you.

This year, we want to expand the number of businesses supporting our work, and we need your help to identify opportunities. Companies are more likely to choose to support Retina UK if an employee makes an approach to explain who we are, and what we do.

Some of the different ways in which businesses can support our work include:

* Nominating Retina UK as ‘charity of the year’. Fundraising at work is a great way to help others and get to know your colleagues. We can provide a fundraising pack to help get you started.
* Payroll giving, a simple and tax-effective scheme, allowing employees to donate to Retina UK via a monthly, direct deduction from salary.
* Match funding, where some businesses very generously match whatever you raise for a charity.

Our Corporate and Community Fundraising Officer, Fiona Leahy, would be happy to provide more information or help you approach your employer. Contact Fiona on 07736 958207, or email fiona.leahy@RetinaUK.org.uk.

## Register now for 2022 conferences

We are excited to announce that this year’s conferences will be held both in person, and online, and that registration is now open!

The venue for the conferences is the Macdonald Burlington Hotel on New Street in Birmingham. The hotel is directly opposite the exit from New Street station, and a short walk from both Snow Hill and Moor Street stations. There is also a tram stop outside.

We know that travelling to our Conferences is not feasible for everyone, so a hybrid approach will offer the best of both worlds. The Conferences will be streamed via Zoom directly from the venue in Birmingham, including the ability to ask questions†.

*†If you are attending remotely, it will not be possible to ask your question in person.*

### Professionals’ Conference – Friday 8 July

Our Professionals’ Conference will be held on Friday 8 July and will look at what our community has told us they need in terms of support from the charity and health sectors.

You will hear the outcome from our sight loss survey and hear from members of our community about the support they have received from Retina UK following a referral by professionals.

#### Outline programme\*

10.00 Welcome and Introduction to the day: Tina Houlihan

10.15 Retina UK audience insight survey (inc Q&A)

10.55 Break

11.10 Mental health: Dr Mhairi Thurston

11.35 Living with sight loss – Looking after your mental wellbeing

11.50 Q&A

12.00 Networking lunch

13.00 Panel session

14.00 Break

14.15 Condition specific session

15.15 Q&A

15.30 Thank you and close

*\*Note that this programme is subject to change.*

#### Continuing Professional Development (CPD) points

We are really excited to announce that this year we will be able to offer CPD points for delegates attending the Professionals’ Conference, whether it be in person, or online (the number of points awarded are currently under discussion).

Register now at: [www.RetinaUK.org.uk/prof-conf](http://www.RetinaUK.org.uk/prof-conf).

### Annual Conference – Saturday 9 July

Our Annual Conference will be held on Saturday 9 July. Hear the latest news in medical research and clinical trials, and explore gadgets from technology companies, including what the future might hold in technological advances and learn how to better manage your wellbeing.

#### Outline programme\*

10.00 Welcome and introduction to the day: Tina Houlihan

10.10 Clinical trials and research update

11.45 Break

12.10 Technology for everyday living

13.10 Lunch

14.10 Introduction to the afternoon: Tina Houlihan

14.20 Mental health: Dr Mhairi Thurston

14.45 Living with sight loss – Looking after your mental wellbeing

15.00 Q&A

15.15 Retina UK audience insight survey: Tina Houlihan

15.40 Thank you and close

*\*Note that this programme is subject to change.*

Register now at: [www.RetinaUK.org.uk/annual-conference](http://www.RetinaUK.org.uk/annual-conference).

We are pleased to announce that Dr Mhairi Thurston will be joining both Conferences.

Her work focuses on the social and emotional effects of acquired sight loss. She is interested in wider issues surrounding disability, equality and inclusion and is strongly committed to making a difference to policy and practice in the field of counselling and vision impairment. Mhairi lives with retinitis pigmentosa.

Mhairi is a senior lecturer in Counselling at Abertay University with over twenty-five years’ experience in education. She is also a Registered, Accredited Counsellor with the British Association for Counselling and Psychotherapy (BACP).

## A vision of hope – remember us in your Will

As many of you will know, last year I turned 80. It’s often the case when you reach milestones like these, that you take a moment to look back and reflect.

Retina UK, or the Retinitis Pigmentosa Society as it was known when I first founded it in the 1970s, has been such an important part of my life. I embarked on this adventure with one aim – I wanted everyone living with an inherited retinal condition, like me, to have access to safe and effective treatments to prevent the loss of their sight.

Over the decades since then we have come so far, and the very first treatments are starting to emerge thanks to the tireless efforts of many of our community to drive progress and invest in pioneering medical research. Retina UK has also developed a range of vital information and support services.

When I made my Will, I included a gift to Retina UK. After I’m gone, I want to know that I will continue to make a positive contribution to future generations of people living with inherited sight loss.

Charitable bequests like mine are vital to the charity, and they’re so easy to arrange. Just speak to your solicitor when making or updating your Will, or contact the team at Retina UK for more information. You can email them at fundraising@RetinaUK.org.uk or call Deborah on 07841 004564. And if you haven’t yet made a Will, Retina UK is pleased to offer a free Will writing service, just visit [www.makeawillonline.co.uk/RetinaUK](http://www.makeawillonline.co.uk/RetinaUK).

Join me, and our legacy will be a world where no one needs fear the loss of their sight – a brighter future, and a vision of hope.

**Lynda Cantor MBE**Founder and Honorary President

Legacies are an important source of income for Retina UK. Over the last four years, gifts in Wills and in memory totalled more than £2.5 million

## Thanks to you

* 2021 finished in festive style with Worksop’s Got Talent, organised by James Clarke. Thanks to the support of the hundreds of people who came to the show and the incredibly talented acts who performed, £14,988 was raised.
* Jackie braved the Whitby Boxing Day Dip, raising an incredible £1,070!
* Clair Pritchard held a Mini Christmas Fare, raising £915 in aid of Retina UK, in memory of her mother, Linda Pritchard.
* Castle Lodge 6657 hosted a Ladies Night, raising an amazing £8,736.60! Thank you to everyone who made this event such a success!
* BritAsian Beauty Pageant, chose Retina UK, as their charity partner for their 2021 awards. The event, which showcased new talent, raised £387.
* Jas took on a swim challenge, completing a breathtaking 10km in three and a half hours and raising a fantastic £4,645!
* Euroglaze supported Retina UK as their charity of the year. They raised £10,273.

We are so grateful to everyone who supported our appeals last year. Together, you raised:

* Spring Appeal - £20,865
* Christmas Raffle - £16,285
* Big Give Christmas Challenge - £53,772
* Stamp Appeal - £506

Thank you for all of the imaginative ways you’ve fundraised so far in 2021/22. Send us your snaps to fundraising@RetinaUK.org.uk – we’d love to see them!

## Volunteer opportunities with Retina UK

Are you interested in volunteering with us but not quite sure which role would suit you? We are holding a Volunteer Introduction meeting online on Wednesday 6 April. Contact Clair on volunteering@RetinaUK.org.uk for more information.

* With the return to face-to-face meetings later this year, we need volunteer facilitators to run local peer support group meetings and/or helpers in Belfast, Berkshire, Brighton, Cardiff, Kent, Manchester, Merseyside, Milton Keynes, Somerset and West Midlands.

If you live in these areas and would be happy to volunteer for a few hours, three or four times a year, please get in touch.

* We need a younger generation of talk & support volunteers. Are you aged 18-30? Would you be happy to help a newly diagnosed person talk about what it all means and provide emotional support?
* Are you the parent of a child diagnosed with an inherited sight loss condition? We need someone to talk with other parents who have received a diagnosis for their child.

For more information or to chat about any of these volunteer roles please contact Clair on 01280 821334 or email volunteering@RetinaUK.org.uk.

## Annual General Meeting notice

The AGM will be held on Saturday 9 July at 4.00pm at the Macdonald Burlington Hotel in Birmingham and online.

Online, postal and telephone voting will be held in advance of the AGM, meaning all members who choose to do so can exercise their right to vote at a time, and in a format, that is accessible to them. All members with voting rights will receive information on how to vote.

We will present the results of the vote at our hybrid AGM meeting which members can join in person or online. All are welcome to attend the meeting where there will also be the opportunity to hear from our Chairman and Treasurer and to ask them, the Board and the Chief Executive questions.

Register to attend the AGM at [www.RetinaUK.org.uk/annual-conference](http://www.RetinaUK.org.uk/annual-conference).

### Agenda

1. Welcome
2. Apologies
3. Approval of the minutes of the previous AGM (result of online voting)
4. Presentation of the Annual Report and Accounts for the year ended 31 December 2020 and 2021
5. Presentation of Retina UK activity in 2021 and 2022
6. Adoption of the Annual Report and Accounts for 2020 and 2021 (result of online voting)
7. The appointment of the auditors (result of online voting)
8. The appointment of trustees (result of online voting)
9. Any other business

## Let’s talk about tech: Amazing and liberating tech

Recently I have been thinking about how amazing and liberating technology can be for anyone who is blind or visually impaired. By Jonathan Abro

I had the pleasure of an audio described visit to the Postal Museum and to ride in the Mail Rail, a train that used to carry post from Paddington to Liverpool Street, all in the effort to ensure that our letters got to their destinations. So, while not instantaneous as receipt of messages are expected to be today, this really was the original social media and got me to thinking about all the forms of communication and entertainment the incredible technology brings into our lives.

Added to that, audio description (AD) is truly brilliant. There are so many ways of experiencing this wonderful window into entertainment and I highly recommend you try as many different apps and services as you can to find all that you like.

### · **TV and streaming channels –**

whether free or pay services, they provide AD with quite a lot of programs so try apps such as BBC iPlayer, ITV Hub, My5, All 4, UK TV Play, Netflix, Amazon Prime, YouTube, Disney+, Sky Go.

### · Art and culture –

whether in person or online, being able to experience the pleasure of theatre, museums, galleries and heritage sites through this beautiful form of description is wonderful. Visit [www.vocaleyes.co.uk](http://www.vocaleyes.co.uk) where you can see what’s on and subscribe to their newsletter.

### · Social media and communication –

while very few people write and post letters these days, hence the demise of the Mail Rail, that is not to say we do not communicate with each other, we just do it differently. With social media and digital communication there is a myriad of options to send a message, photo, video or voice message and know that, unless the recipient has gone off grid for any period of time, it is likely they will receive it the moment you send or post it online. We can also have digital face-to-face conversations with family and friends or join in on a webinar or discussion regardless as to where in the world or which time zone everyone is in. Apps from an ever-growing and endless list of others either already or will soon be available to try include WhatsApp, Twitter, Facebook, Instagram, TikTok, Clubhouse, Zoom, Teams;

### · Radio, music, reading and podcasts -

today reading does not mean just a physical book, newspaper or magazine but has extended into the digital world of audiobooks, talking newspapers and magazines, podcasts and so much more. From the public libraries to the newsagent and music shops, smartphones mean that whether we are lounging at home, going for a walk or run, or sitting in our favourite coffee shop, we can enjoy this entertainment anywhere and everywhere. As with everything else there is an endless list of apps, these are just some; Dolphin Easy Reader, Libby, Calibre, Voice Dream Reader, Audible, Kindle, BBC Sounds, Radio Player, Deezer, Downcast, Apple Music, Google Podcasts, Amazon Music, Spotify.

There truly are no limits to how we communicate and get our entertainment. I hope this will find you some new and fun ways of partaking. Please remember that neither I nor Retina UK recommend or profit from your use of any of these apps, it is just me sharing them with you and hoping you take pleasure from them.

QUOTE: “I find it fantastic that, even though I cannot see, with the aid of screen readers I can use a smartphone that has a flat glass screen with no tactile markings and a computer regardless as to whether the screen is on or off!”

## How do I get a guide dog or buddy dog?

If you’d like to apply for any of Guide Dogs’ services, either for yourself or for a child/young person, the first thing to do is to pick up the phone as described in this special feature by Guide Dogs UK.

Our Guide Line is the best place to start for those interested in how we can help, and is available on 0800 781 1444 from 9.00am to 5.00pm, Monday to Friday.

If it’s a guide dog you’re hoping for, our friendly advisers can check if you meet our criteria, and we can arrange a visit to tell you about Guide Dogs’ services in general and the different options available to you.

As part of this visit, we’ll complete a Health Risk Assessment to identify any issues that might affect your ability to get around and, if appropriate, seek advice from your GP or other relevant specialists.

Depending on the outcome of this visit, we may then organise a time to assess and record your current vision, abilities and situation. With you, we’ll explore:

* How well you can confidently and safely move around indoors and outdoors,
* What mobility aids you currently use (if any),
* Any training or services which might be helpful to you to meet your goals, including those provided by local or national partner organisations.

Assessments are completed by one of our highly trained adult orientation and mobility specialists (or children’s habilitation specialists). Once we’re confident a guide dog would match your needs, and that you’re physically able to get out and about enough with a guide dog’s help, you’ll be progressed on to the guide dog assessment. This focuses specifically on the skills, abilities and attitudes you need to form a successful guide dog partnership.

If successful, you’ll then be placed on our ‘awaiting training’ list and trained with a guide dog once we’ve found a suitable dog for you.

Russ, who lives with choroideremia, wouldn’t do anything on his own before Sparks came into his life. He qualified for a guide dog eight years ago and almost two years to the day after qualification, he was matched with Sparks.

The close bond between Russ and Sparks is evident. Russ said that he has given him his ‘independence and freedom’. Sparks is almost 10 years old and is due to be retired in the spring – he will stay with Russ as a much loved pet. Russ no longer qualifies for a guide dog as his route to work has changed since his initial assessment but should things change in the future, Russ would apply again.

Nationally, 68% of people waiting for a guide dog are matched within two years or less.

If you’re speaking to Guide Line about a buddy dog for a child or young person with sight loss, the next step is for us to invite you to a Discovery Webinar. This is where parents/carers can find out about eligibility criteria, what a buddy dog is (and what it isn’t), and can highlight the realities of dog ownership. After that, you complete an application form which leads to a phone interview and a home check. We then invite you to a Development Day (or these days, it might be a webinar), where parents/carers can learn more about dog care, and your local Canine Assisted Partnership Specialist can get to know your family.

If everything goes smoothly, the next step is an Experience Session, which is another chance for parents/carers to learn about dog behaviour, care and welfare. After that, we’ll do our best to find the right buddy dog for your family.

Thomas, who lives with Usher syndrome, and his family welcomed buddy dog Chipper into their lives eight months ago and they haven’t looked back. Chipper is a Labrador Retriever with a sunny disposition. He’s quite the local celebrity, particularly at the school gates! Thomas had been anxious at night because he struggles to see well after dark. He was also reluctant to go downstairs alone in the morning. Chipper has helped enormously and Thomas describes their relationship as follows: “He protects me and makes sure I don’t get hurt”.

The family had been looking into getting a family dog but it was a comment by a support worker from Sense who suggested a buddy dog from Guide Dogs. It took around seven months from application until they were matched. He is part of the family forever now and is devoted to them all. Hannah (Thomas’ mum) said she “would recommend getting a buddy dog for a child living with sight loss to anyone”.

Visit [www.guidedogs.org.uk/gettingsupport/](http://www.guidedogs.org.uk/gettingsupport/) for more information.

## We are so grateful for all donations to our work

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