Sight Scotland iSight magazine – Christmas 2021 edition

Giving everyone with sight loss someone they can turn to

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# Introduction

Dear Supporter…

Welcome to our Winter edition of iSight. I hope this finds you and your family well. We have been humbled by the support you have all shown to our recent letter that introduced you to Amanda - over £6,000 has been raised so far for our Family Wellbeing Service. Amanda was only 26 years old when she started losing her sight to Stargardt disease. You can read more about Amanda [by clicking here](#_Meet_Amanda).

Our Support Line was officially opened on 22 September by Minister for Public Health Maree Todd MSP. The support line (0800 024 8973) is now open to all those with sight loss and their families to get the help and advice they need. You learn more [by clicking here](#_Support_Line_now).

As always, our Policy, Public Affairs and Research team has been working hard to ensure the voices of people with sight loss are heard by decision makers. Find out about our campaign to get braille labelling on a wider range of products [by clicking here](#_Braille_labelling_on).

Our colleagues at our sister charity Sight Scotland Veterans have been busy analysing the services they offer to veterans and looking at how they can reach more veterans with sight loss –read all about their future plans [by clicking here](#_Sight_Scotland_Veterans:).

Christmas wouldn’t be Christmas without decorations. And after last year, we need bright and wonderful decorations this Christmas. But we need your help! We want to fill our residential services with bright and colourful decorations this Christmas for all those who live there to enjoy. All you need to do is buy or decorate Christmas decoration and send it to us – care of the Christmas Elves at Sight Scotland, 2a Robertson Avenue, Edinburgh EH11 1PZ. We’ll deliver your decoration to the residential service. Find out more [by clicking here](#_Lighting_up_Christmas) or by visiting [sightscotland.org.uk/bauble](https://sightscotland.org.uk/bauble). You can also buy some lovely Christmas cards: visit [sightscotland.org.uk/shop](https://sightscotland.org.uk/shop)

I hope you and your loved ones have a very happy and safe Christmas. From everyone here at Sight Scotland – Merry Christmas. Best wishes, Davina Shiell

### Support Line:

Talk to us on **0800 024 8973**.Now open 9am to 5pm, Monday to Friday

### **Did you know?**

Nearly 90% of those with visual impairment who we surveyed said it was important that both they and their families received support to deal with the emotional impact of sight loss.

### iSight in alternative formats:

To receive iSight in large print, braille or audio CD please contact us on 0131 229 1456 or email <mailto:fundraising@sightscotland.org.uk>

**Sight Scotland** is the operating name of The Royal Blind Asylum and School. Scottish Charity Number SC017167

**Sight Scotland Veterans** is the operating name of Scottish War Blinded, a Scottish Charitable Incorporated Organisation, charity number SC047192.

**Address:** Sight Scotland and Sight Scotland Veterans, 2a Robertson Avenue, Edinburgh EH11 1PZ

# **Support Line now available nationwide**

Your support is enabling people with sight loss to receive advice and support soon after their diagnosis - a crucial time when many need help.

Our Support Line launched nationwide in September! Now, people across Scotland can call us on 0800 024 8937, from 9am to 5pm, Monday to Friday.

This helpline offers people with sight loss, and their families, someone to turn to for information, advice and support. The Minister of Public Health, Maree Todd MSP, attended our launch event on 22 September, along with our Community Workers who operate the Support Line.

We were delighted to welcome Amanda and Charlie too - both of whom are living with sight loss and have received support from and built strong relationships with our Community Workers.

Donations are vital to the Support Line and keeping it running; they also ensure help is only a phone call away for people with sight loss. Thank you to everyone who has helped people like Amanda and Charlie by supporting the new telephone line.

# **Meet Amanda**

Amanda Whitfield is a young mum from Linlithgow. Amanda was diagnosed with Stargardt disease in 2016 – a hereditary condition which started affecting her sight when she was 26. Recently, Amanda has experienced a drastic deterioration in her sight.

“I was heartbroken,” Amanda said.

“It’s a macular degeneration disease and they said it wouldn’t deteriorate until I’m a bit older.

“I have a blockage in both eyes for my frontal vision. I can’t read much anymore – I’m having to use magnifiers or take pictures with my phone.

“I didn’t know how I was going to cope with things in the future, with my daughter,” Amanda said.

“I got in touch with Sight Scotland because I can describe to others what my sight loss is like, but they aren’t going through it themselves. It was good to speak to someone that knew about Stargardt disease.”

Amanda built up a relationship with Debbie McGregor, our Community Worker. Debbie spoke with Amanda about ways to compensate for her visual impairment in her daily life.

“Debbie has been an absolute godsend,” Amanda said.

Image shows Debbie meeting up with Amanda for a walk and a chat.

Amanda said: “She has guided me on a few things that she thinks I could potentially need in the future or need now. It’s amazing how just talking to someone can make you feel as if you’ve got a weight off your shoulders.

“I don’t feel as panicked about what the future’s going to hold.”

Debbie has introduced Amanda to several equipment options, helping her to adapt to life with sight loss.

“The future is looking brighter,” Amanda said.

“It sounds silly but it’s knowing I’m not going to do it alone. Debbie is like a friend that’s always there and she’s just been an absolute gem, even just to turn to, to talk to.”

“You’ve always got a friend and you’ve always got someone to help support you.”

### Support Line:

Our Support Line service is for anyone impacted by visual impairment, so that no-one in Scotland has to struggle with sight loss alone.

Talk to us on 0800 024 8973. Now open 9am to 5pm, Monday to Friday

### **Donations keep our Support Line running**

Please help us to help more people like Amanda by making a donation:

• Online at [sightscotland.org.uk/donate](https://sightscotland.org.uk/donate)

• By post using the form at the back of this magazine and the enclosed Freepost envelope

• By phone on 0131 446 3089

# **Meet Charlie and Gail**

Charlie Burns was shocked to learn he had age-related macular degeneration.

He received the diagnosis last year during a visit to the optician.

“At first, I couldn’t believe it,” Charlie said.

“I thought it had just been my glasses. I’d never heard anything about macular degeneration before. It all happened very quickly.

“My sight loss has been a blow to me. Life has changed enormously.”

After the diagnosis, Charlie wasn’t sure what to do next. He faced a long wait for an appointment at the eye hospital.

Charlie said: “No one has ever said to me what to do next after my diagnosis or that I might be able to get support.”

Charlie’s daughter, Gail, found the news of her father’s diagnosis confusing and scary.

“I did some research to find out more, and I felt quite down about it,” Gail said. Then Gail and Charlie called our Support Line.

Charlie said: “Sight Scotland’s support has been brilliant. They have given us advice and ideas that I wouldn’t have thought about.

“Anita O’Reilly, one of the Sight Scotland Community Workers who has been supporting us, has been brilliant. She’s got a good nature, she’s a good listener and she’s very caring. Whether it’s magnifier options or finding social groups, she’s been very helpful.”

Gail said the emotional support Anita had provided her was invaluable.

“Now we’re in a much better place and I think Sight Scotland’s made a massive difference.”

# **Research discovers effective method to test for glaucoma**

Sight Scotland is committed to funding research into eye disease. We know that research can find solutions to change lives for the better.

A study we funded has found that nearly 60,000 people living with glaucoma in Scotland could benefit from carrying out eye pressure tests at home.

Glaucoma is a major cause of blindness. It develops slowly over many years and affects a person’s peripheral vision first. It is caused by a build-up of fluid and pressure inside the eye. The increased pressure causes damage to the optic nerve, which causes gradual and irreversible vision loss.

An eye pressure test can be carried out at home. A research team from the University of Edinburgh set out to establish whether it could be beneficial for people affected by glaucoma to test their own eye pressure with a self-testing kit, rather than visiting a hospital or an optometrist to be tested.

The study found that access to home testing could result in an increased number of eye pressure measurements being taken. Because of this, home testing can provide a better indication of when pressure levels are high and whether treatments are working.

This improves eye doctors’ ability to determine the risk of worsening sight loss from glaucoma and the types of treatment the patient should receive.

Consultant Ophthalmologist Dr Andrew Tatham, who led the research team, said: “Glaucoma is a major cause of blindness, but as it usually develops gradually, many of those affected are unaware that they are slowly losing sight.

“Thanks to the funding from Sight Scotland, our research has shown that it is now possible for patients to measure their own eye pressure accurately at home. This can provide many more measurements and allow more close monitoring of responses to treatment.

“Home monitoring has been incredibly useful in other diseases such as high blood pressure. It has the potential to reduce sight loss from glaucoma, reduce the number of hospital visits needed, and give patients more control over their disease.”

# **Influencing change at the highest levels**

Our Policy, Public Affairs and Research team has been working hard to influence change this year. Below are two projects we’ve been working on.

## Braille labelling on more retail goods

Currently, medicines are required to be labelled with braille, but foods and other consumer goods are not – not even cleaning products. This leaves braille users at a disadvantage when they are identifying packaged foods and other products they wish to purchase.

We are working with Disability Equality Scotland to urge the Scottish Government to consider new requirements for retailers to provide braille labelling on a greater range of goods. Responsibility for labelling legislation was previously a matter for EU law, but it is moving to the Scottish and UK Governments’ responsibility. We have written to the Scottish Government calling for new legislation which makes braille labelling a requirement for a much broader range of retail goods.

We are pleased the Scottish Government has indicated it will be reviewing policy and legislation on labelling.

## **Fair rail, across Scotland**

People with sight loss deserve equality of access to rail travel, wherever they live in Scotland.

But there are discrepancies across the country. Some local authorities provide free or discounted rail travel for people with sight loss and their companions, while others don’t.

We are calling on the Scottish Government to work with local authorities to establish a national policy, so it doesn’t matter where you live, everyone will have the same access to inclusive rail travel. This will make rail travel much simpler and easier for people with visual impairment.

### **Get involved:**

If you support our campaign for a national policy, visit [sightscotland.org.uk/FairRail](https://sightscotland.org.uk/FairRail) to sign an open letter to the Minister for Transport.

# **Lighting up Christmas for Amy and her friends**

Amy adores Christmas. Decorating lush green Christmas trees is her favourite activity each December.

Amy, aged 17, grew up in the countryside, west of Glasgow. She has been learning at the Royal Blind School since she was 7 years old and stays at our residential service on weekdays. Amy was born blind and has no light perception. But she loves throwing crackly tinsel on the branches and wrapping trees with strings of Christmas lights. She loves the smell of pine and feeling the shapes and textures of decorations as she hangs them on branches.

Every Christmas, Amy also decorates her own 1-foot-tall tree in her bedroom at her residential home. Amy’s mum Gillian tells us that one year, she decorated the family tree while Amy was away. When Amy returned to her family home for Christmas, Amy’s first comment when she discovered the decorated tree was: “Hey, decorating is my job!”

Last Christmas was an especially difficult time in our residential accommodation. This year we are making a real effort to make Christmas 2021 particularly memorable for the children and young people at the Royal Blind School and Forward Vision.

Chelsea Chalmers, our Care and Nursing Services Manager, says, “What often brightens my day is seeing children and young people enjoying their regular therapy sessions. Physio, rebound therapy (trampoline-based therapy) and hydrotherapy in the school pool can be so much fun. Along with speech and language therapy, these can make a huge difference to a visually impaired child’s development.”

Chelsea says: “We tailor our sessions to the specific needs of each child or young person. We would love to use some new sensory light equipment to create some interactive experiences for children.

Amy loves to hang up Christmas lights and feel the warmth of the lights in her fingers, even though she cannot see the light. Some of Amy’s housemates can sense light and different colours and love to interact with the sensory light equipment.

This winter, we hope to provide new sensory light equipment to the children and young people who live in our residential services. The children would use the equipment every day for stimulation and enjoyment, supporting their development.

If you have recently made a gift to Sight Scotland, please can we add our thanks for your wonderful generosity. It is so comforting to know that you care as much as we do!

Maybe it has been a little while since you last made a donation? Then you may be interested in helping us to raise funds for this sensory equipment for Amy and all those who live in our residential service.

Simply visit our website to make a donation at [sightscotland.org.uk/bauble](https://sightscotland.org.uk/bauble)

Whatever you do, please do get involved and make this Christmas a really special one. From everyone at Sight Scotland we are wishing you a very Merry Christmas and thank you for supporting us!

## Decorate a Christmas bauble

This Christmas we are on a mission to give Amy even more decorations to hang up at her residential care house – but we need your help!

We would love you to help make Amy’s Christmas extra special by decorating a Christmas bauble that Amy and her friends can hang on their tree. You can even include a special Christmas message for Amy and her housemates. Our care staff will be delighted to read out your messages to everyone in the run up to Christmas and describe the wonderful design on each bauble. Each decoration we receive will help to make a fabulous display.

# **Our precious and precarious world**

Royal Blind School pupils have created some fantastic artwork for an exhibition inspired by the COP26 climate change conference taking place in Glasgow!

The artworks were displayed at the Parish Church of St Cuthbert’s exhibition in late October and enjoyed by scores of members of the public.

Art teacher Helen Cole said each pupil’s artwork was based on the environmental issue that concerned them the most.

“We listened to video clips about animals becoming extinct, deforestation, plastic waste, fast fashion. And through talking about it, the children decided what they’d like to create,” she said.

“Bo made the polar bear which lives on a shrinking artic ice floe. Rebeka made the tiger because it’s an endangered species, and Samantha made the dolphin after learning about how much plastic there is and how much ends up in the sea. Amy made a mobile with three things most precious to her: bees, trees and stars.”

Image shows a polar bear sculpture titled “The Shrinking Arctic, made by Bo, which was inspired by endangered animals and the impact of humans on nature.

Image shows Rebeka with her sculpture tiger of a tiger head. The sculpture is titled “Semi-Retired from Complaining, Wants to Save the Earth”. It is made with Modroc plaster, faux fur and buttons.

Image shows Samantha’s dolphin model, made from Modroc plaster and found objects. The dolphin’s belly appears to be full of rubbish – crisp packets, plastic bags and aluminium cans. The sculpture is titled “Choked”.

# **Paralympic star writes new book**

Libby Clegg MBE, a former Royal Blind School pupil, has written a new book about living – and winning – with her guide dog.

Libby Clegg MBE wins gold medals, dances on ice skates, and now, she’s a published author too! We are so proud of our former Royal Blind School pupil, who graduated in 2008.

Libby is one of the UK’s most popular Paralympic athletes. In her sprinting career, she won nine major gold medals, including two golds at the 2016 Paralympic Games in Rio. Libby is also known for her ground-breaking appearance as a finalist on Dancing on Ice, where she was the first registered blind person to ever appear on the TV show.

Libby’s new book “My Life with Hatti: Six Years with a Dog Who Does Everything”, tells of her close relationship with her floppy-eared friend. It is also available as an audiobook.

Libby said: “With the athletics, I’ve had a very successful career, one with ups and downs at times, but my personal life’s probably more interesting than my athletics success and failures. But focusing on Hatti just gives a different perspective because she’s been dragged around everywhere with me, the poor thing!”

Libby talks honestly in the book about her initial reluctance to have a guide dog because she was in denial that she needed help, even though her eyesight was deteriorating. She talks about the difficulties of introducing her partner Dan’s guide dog Elmo to the family; about the depression she plunged into after winning two gold medals - something experienced by many top athletes - and how Hatti helped her through it.

In the pair’s two-way relationship, Hatti enables Libby to live life to the full - but Libby still has to carry the Labrador Retriever cross on travelators, as Hatti has a phobia!

“They don’t come more special than our Hatti,” Libby said.

Libby retired from elite athletics in September 2021 after winning two silver medals at the 2020 Tokyo Paralympic games. These days, she lives in Leicestershire with her husband and son – and Hatti, of course.

While their circumstances may be unique, Libby and Hatti’s story will be reassuring and familiar to any dog lover. Libby and Hatti are a devoted pair helping each other through life.

“My Life with Hatti” by Libby Clegg is available from several bookstores, include WH Smith. E-Books and Audiobook versions are available from the publisher at [quercusbooks.co.uk/contributor/libby-clegg](https://www.quercusbooks.co.uk/contributor/libby-clegg/)

# **Thank you for tackling sight loss with us!**

Thank you to everyone donating and raising funds to help people with sight loss!

Cheers to all the teams who took on the 2021 Kiltwalk on 26 September. What a great day out!

Images show pairs and groups of fundraisers out at the Kiltwalk in Glasgow, wearing Sight Scotland T-shirts and holding their Kiltwalk medals.

# **Sight for Sight challenges**

Sight Scotland invites you to tackle a fundraising activity inspired by your favourite Scottish sight to support people with vision loss.

Every ‘Sight for Sight’ fundraiser can help make a difference to the lives of people with vision loss. All you have to do is think of a fundraising challenge that involves your favourite Scottish sight. [Click here for to visit our website for ideas to inspire you](https://sightscotland.org.uk/get-involved/fundraise-us/sight-for-sight-scotland).

## Building a library with Lego

Stewart Lamb Cromar, a life-long Lego fan, created a model of the University of Edinburgh library for his ‘Sight for Sight’ challenge.

Image shows Stewart holding up his Lego models. Stewart, who has sight loss, said: “Sight Scotland do an incredible job empowering people with sight loss and blindness, but they also raise awareness of what can be a hidden disability. My Sight for Sight fundraiser was a fantastic opportunity to make a positive out of my own sight loss, have fun along the way and connect with some fantastic new people!”

## Climbing Tinto Hill for Sight Scotland

Image show a fantastic team from Morgan Sindall Group, who climbed over 700 metres to summit Tinto Hill for their Sight for Sight challenge.

# **Christmas cards and stocking fillers!**

It’s never too early to order your Sight Scotland Christmas Cards. This Christmas, help us tackle vision loss by sending a Sight Scotland Christmas card to your friends and family.

Our Christmas cards feature scenes of Edinburgh in the snow and a beautiful penguin card designed by a pupil at the Royal Blind School. Please use the order form enclosed to order yours in time for the festive season.

We also have stylish water bottles and handy notebooks that will make ideal stocking fillers or a great Secret Santa gift.

## **Christmas cards delivered to you**

Order your Christmas cards:

* By post using the form that came with this magazine
* Online at [sightscotland.org.uk/shop](https://sightscotland.org.uk/shop)
* Call us on 0131 446 3089

# **Sight Scotland Veterans: Reaching many more veterans with sight loss**

Our sister charity Sight Scotland Veterans recently launched its new strategy, which will help it deliver on our shared ambition to reach many more people with sight loss in Scotland.

Since 1915, Sight Scotland Veterans has been supporting and empowering veterans, helping them to regain their confidence, live independently and connect with each other. At the moment, this support is provided mainly to veterans with significant sight loss through activity centres in West Lothian and Paisley and its outreach service.

But there are many more veterans – especially those at an earlier stage in their sight loss journey – who could also benefit from its expertise and support. Early intervention can make a huge difference in terms of slowing down the impact of sight loss. Friends and family members of veterans could also benefit from the information and advice Sight Scotland Veterans provides.

The strategy was created with this in mind. Sight Scotland Veterans staff and service users were invited to share ideas and feedback on what works well, what could improve, and how its services could develop in the future. They identified four key goals for Sight Scotland Veterans for the next three years: To enhance the support it provides; remove barriers and become more accessible; to understand what success looks like and look for ways to improve; and to use its resources wisely.

Putting this strategy into action will allow Sight Scotland Veterans to build on its rich history and ensure that many more veterans with sight loss can live fulfilling, independent lives.

# **Yes, I would like to help people with sight loss.**

To help people with sight loss, please donate at our website: [sightscotland.org.uk/donate](https://sightscotland.org.uk/donate)

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