




epilepsy scotland

Annual Review

2021 / 2022

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Our Mission

Epilepsy Scotland works with people living with epilepsy to ensure that their voice is heard.

MESSAGE FROM CEO



Leslie Young

The last few years have posed challenges to every one of us. The resilience and strength demonstrated in the unprecedented times should not only be celebrated but used as the foundation for what we do next. It would also be remiss not to say, as did Albert Einstein, “in the middle of difficulty lies opportunity”.

This sentiment held true for Epilepsy Scotland and we chose to grasp every opportunity presented and work with it. Our dedicated team of colleagues, volunteers and supporters were instrumental in facilitating the continuation of support to the epilepsy community, ensuring the voices of people living with epilepsy are heard not just in good times but especially in more difficult and challenging times. As we move forward, we have an opportunity now, to build on how we adapted and grew over the last few years. We can take our learnings and use them to shape our work and grow even more as an organisation.

The pandemic motivated us in many ways, and we knew we needed to become more accessible. We recognised the increased reliance on digital platforms and saw the need to update our website. We now have a more accessible platform which will better serve the needs of our community not just now but in the years to come.

In addition to our in-person services, we realised the value of moving online. Our Wellbeing, Youth, and Welfare Rights teams now offer a hybrid of online and face-to-face services. This will continue to ensure we reach even more people than ever before.

In September we launched our new SPIFOX Wellbeing Garden, gathering together as an organisation for the first time since the beginning of the pandemic. I was delighted to share this with the First Minister of Scotland, Nicola Sturgeon MSP, who opened the garden and stayed to chat with our services users, staff members, Trustees and other invited guests. The atmosphere was relaxed, happy and all those in attendance enjoyed it thoroughly.

None of this would be possible without the dedication of the Epilepsy Scotland team and volunteer Board of Trustees which I have the great privilege of working with. The individual talents and collective agency to support those living with epilepsy is the reason we can enter this new year with anticipation.

I will close by thanking all our supporters. Your commitment and generosity, through volunteering, fundraising and donations, especially in the most challenging of times, serves as an inspiration to us all.

I believe our 2021/22 Annual Review is a testament to our hard work. I hope you enjoy learning more about our year.

DEDICATED COMMUNICATIONS

Our NEW website

In August we launched our new website. It is a more accessible platform which better supports our community to access our resources. Since its launch, we have seen an 86.4% increase in users.

National Epilepsy Week

For National Epilepsy Week, we ran our #BeyondCovid campaign. We gained PR coverage in The Glasgow Times, The National, The Scotsman and The Courier.

Purple Day 2022

To celebrate Purple Day, 50 buildings across Scotland lit up purple to raise awareness. These included the RRS Discovery, Glasgow Science Centre and St Andrew's House. Motions were submitted in UK Parliament and Scottish Parliament, they were supported by 32 MSPs and MPs collectively. We also secured TV coverage on That's TV Scotland, radio coverage and PR coverage in newspapers including the Edinburgh Reporter, Shetland News and the Aberdeen Live.

Social Media

All our social media channels have seen an increase in engagement over the past year. Our Instagram followers increased by 17.4% and LinkedIn by 13.9%.

The #TalkEpilepsy Podcast

We produced four podcasts this year which reached over 453 listeners from the UK, USA, Australia, Germany, Canada and South Africa!

86.4%

increase in new
website users



"Thank you for everything you do, and all of your posts, it's made a hard to navigate situation so much easier! Thank you so much."

- Social Media Follower -



"I just wanted to thank you, I've had epilepsy for a little bit and it's kind of ruined my life, but with the education that you provide I've learned a lot and I can see that I won't always feel this way. So, thank you for being there."

- Social Media Follower -

453

podcast
listeners

Our Facebook
posts reached
1,471,613
people

WELLBEING

81

participants

Thanks to the generous support of the National Lottery Community Fund Scotland we have been able to provide our Wellbeing Service for the last four years.

Our aim is to support the emotional wellbeing of people with epilepsy as holistically as possible. We provide a bespoke programme of one to one and/or group support using counselling, breathing techniques and peer support. These empower participants to deal with the challenges of their diagnosis and its impact on their emotional wellbeing.

This year we have grown our service, reaching more participants than ever before. We began offering a hybrid service of remote and face-to-face.

1,356

one-to-one
sessions

160

groups

100%

of clients said the
supportive service
helped them meet
their goals

95%

of clients said their
mental health
improved

"I didn't expect to meet so many friends, I didn't think there would be a place where I'd be able to open up about the things I was feeling."

- Wellbeing Client -

"I didn't expect to feel as empowered as I do. My wellbeing worker is my strength on my weak days. She helps me find light in situations when it's dark and she is the only person I can be 100% open with about epilepsy and actually feel like I'm not losing my mind."

- Wellbeing Client -

"This service helped me through an extremely dark time and for that I will be forever grateful. Every person I dealt with was honest, supportive and extremely attentive. You are all amazing."

- Wellbeing Client -

NHS Lothian

We have been delighted to work with NHS Lothian's Neuropsychology Clinics where patients can opt-in to a 6-12 week programme of one-to-one work and optional breathing and relaxation groups. 27 of this year's participants have come through this route and we think the outcomes are proving the effectiveness of direct partnership between the NHS and ourselves.

Dumfries House

In partnership with Dumfries House, part of The Prince's Foundation, we delivered an online wellbeing programme to people living with epilepsy. We offered advice and information on managing epilepsy, mental health, food, sleep and finance. It was well-received and we hope to continue our link with the organisation this year offering something similar, this time face-to-face!

Going Forward

As we go into the next year, we are excited to welcome a new Wellbeing Worker to the team and develop our support to people with epilepsy using the newly opened Spifox Wellbeing Garden.



HELPLINE & INFORMATION

Our Helpline and Information team have continued to adapt to support the changing needs of the epilepsy community.

Our Check-in Service

After the success of our new Check-in Service introduced during lockdown, we conducted a major review which now allows us to offer support to many more people. We provide a weekly call for 10 weeks to check in on physical and emotional wellbeing.

Our Publications

We have had a busy year reviewing, updating and writing new information.

- With the introduction of new Scottish benefits, we have written three new leaflets on [Child Winter Heating Assistance](#), [Child Disability Payment](#), and [Adult Disability Payment](#).
- With the valued advice from the Glasgow paediatric epilepsy team we produced a new [guide for parents](#). We also produced a brand new [student guide](#) to help students with epilepsy navigate university life.
- We updated our [Driving factsheet](#) and had it checked by the DVLA for factual accuracy.
- We reviewed our popular [Seizures explained](#), [First aid for seizures](#) and [Stress and epilepsy](#) factsheets to ensure they held reliable and up-to-date information.

Our Support Group

Recognising the need for ongoing support throughout the pandemic we set up a monthly online support group. It allows people to share experiences and meet others. This is in addition to our online information events and epilepsy chat sessions, which help raise awareness of epilepsy and our services. It also offers the opportunity to discuss specific topics such as sleep or memory in more detail.

"I feel like a changed person since joining. The weekly chat we have has made me feel much more relaxed and has allowed me to tackle all the challenges this pandemic has caused. I felt everything was getting on top of me last year. Getting the chance to discuss this with you has been fantastic. I thank you for that."

- Check-in Service User -

29
check-in
clients

7,610
publications
distributed

20
online events

"Thanks for talking to me. I was quite nervous about calling as I haven't really discussed having epilepsy with that many people. You have provided me with more confidence and I know I have nothing to be ashamed of."

- Helpline Caller -

1,823
helpline enquiries



POLICY & CAMPAIGNS

It was an exciting year for our Policy Team, expanding our influence, sharing the voices of people with epilepsy and launching three new campaigns!

Influence

We supported people with epilepsy to understand the roll-out of COVID-19 vaccines across Scotland. We influenced the Scottish Government to change vaccine guidance to ensure children with uncontrolled epilepsy were protected.

We organised three Cross Party Groups on Epilepsy, with speakers including Professor Tom McMillan who presented research on women with brain injury in prison, and the Director of Scotland's Centre for Employment Research who presented our new research on epilepsy and employment. We were also joined by Minister for Just Transition, Employment and Fair Work.

We contributed to five consultations and engaged with our community for all of them, ensuring we represented the needs of people living with epilepsy. These covered topics including the development of a new National Care Service for Scotland and the role of a Patient Safety Commissioner. We also completed a submission to the Scottish Medicines Consortium's consideration of the medication cenobamate. It was subsequently approved for restricted use in Scotland.

Epilepsy Consortium
Scotland
Chair

3
cross-party
group
meetings

5
consultation
responses

Neurological
Alliance of
Scotland
Vice-Chair

Campaigns

2021 Election Campaign: We launched a manifesto for the Scottish Parliament election to encourage better policy making for people with epilepsy. The five main political parties supported our manifesto and epilepsy policy commitments were made in Scottish Labour's manifesto.

#StudentSeptember: We campaigned to increase awareness of epilepsy in further and higher education. With the help of our volunteer University Ambassador, Orla, we engaged with universities and shared advice and the experiences of students with epilepsy. We hosted an Epilepsy and Learning Webinar and launched our new Student Guide.

Employment Campaign: We commissioned new research from the Scottish Centre for Employment Research. The research found that epilepsy and employment is not well researched or understood in Scotland, and the employment gap for people with epilepsy is over 44%. We developed a campaign which aimed to increase awareness of epilepsy in the workplace and engage employers with information to better support people with epilepsy. As part of our campaign, epilepsy and employment was debated in Scottish Parliament!

Cross-party
manifesto
support

Press Coverage
All our campaigns were
covered in national
newspapers

Parliamentary
Debate

THE SPIFOX WELLBEING GARDEN

Our new garden opened in 2021 as a space for parents to catch a minute to themselves, a place to display artwork and celebrate the creativity of the people in our community and a safe space for our Youth and Wellbeing Groups to explore new hobbies or learn new skills.

The development of the Wellbeing Garden was funded by SPIFOX (the Scottish Property Industry Festival of Christmas) and donations in memory of Eloise Morris.

Special thanks to the Rt. Hon. Nicola Sturgeon, MSP First Minister of Scotland for opening the garden.



"The creation of this inviting, stimulating outside space will play a huge part in enhancing the service Epilepsy Scotland can provide to young people, children, and families of people with epilepsy as well as the wider community. The garden will be a tranquil space for some, a stimulating space for others and open up possibilities for a wide range of activities."

- Lesslie Young, Chief Executive -

YOUTH SERVICE

Our dedicated Youth Service provides support and social opportunities to young people with epilepsy in Scotland. This year we have delivered a mix of on-line and face to face activities.



Purple Pandas Primary Age Group

This year we launched our youth group for those aged 8 -12, meeting weekly online. The group is a space for children to share their experiences of living with epilepsy, meet others for peer support, have fun and socialise. We do activities like dancing and games. People have spoken about bullying, times in hospital and how they feel about living with epilepsy. There is a closeness in the group despite being miles apart!

Youth Ambassadors

Meeting monthly, the ambassadors aim to be a voice for young people in Scotland living with epilepsy. This year they have created campaigns to bust epilepsy myths and raise awareness of seizure response facts, met with a trainee Clinical Psychologist from Royal Holloway, University of London to input into a study on young people's mental health and led on "Spotlight sessions" with our Purple Panda's group, supporting the next generation of our Youth Groups! The group is also supported by a volunteer, Kayleigh, who has been massively encouraging of their ideas and plans for future projects. The group hope to soon receive accredited awards for their volunteering efforts.

Youth Group Gathering

Our Glasgow and Edinburgh groups finally met in person at the Zoo after socialising online for so long. There was a lot of laughter and chatter. It was great to see the bond between people grow from the connections made online to deeper friendships in person.

- Happy Mail -

Our new service sends monthly letters and specially selected activity packs to young people with epilepsy all across Scotland. We have 79 recipients from Peterhead to Dumfries!

"It is so exciting for him when it comes in and he loves seeing what is inside - you really do make it very special and he feels like he is getting a personal delivery from you with your handwritten notes!"

- Happy Mail Feedback -



- Ryan -

Youth Ambassador & Purple Pandas Volunteer

Ryan is the perfect role model for the Purple Pandas. He inspires them to be confident in living with epilepsy and to not give up.

We love Ryan's dedication and positivity and are delighted that he has been selected by the National Youth Link Awards as a finalist for Volunteer Youth Worker of the Year!

WELFARE RIGHTS

"I could not have got through this without the help from my WRO."
- Welfare Rights Client -

"It was an incredible service that made a huge difference to the process. I had accepted refusal before, but knowing Epilepsy Scotland would help me appeal gave me so much more confidence. The help with the initial application meant that we were given DLA first time and it has changed our lives."
- Welfare Rights Client -

Our Welfare Rights service has continued to work tirelessly to maximise household income for people with epilepsy and their family members. We support clients to complete the forms, prepare and gather evidence for mandatory reconsideration and provide representation at appeals.

None of this work would be possible without the very generous funding for this project from the Bank of Scotland Foundation and we have been extremely grateful for their ongoing support in improving the financial wellbeing of our clients.

"I am a carer for a person with dementia as well as epilepsy, Epilepsy Scotland gave me full support and confidence to claim Carers Allowance enabling me to have financial support and peace of mind in my carer's role."
- Welfare Rights Client -

3,371
individual contacts

229
clients

205
cases

100%
client satisfaction rate

£1,644,090
generated in client financial gain

Disability Benefits

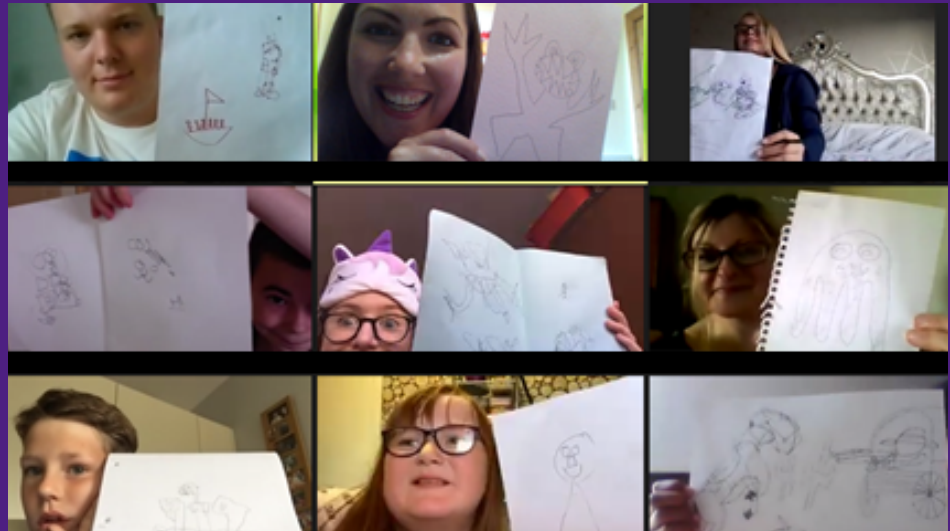
We have worked with Scottish Government as they progress the transition from Disability Living Allowance to Adult Disability Payment. We have welcomed these opportunities to work closely with government over the past year to influence improvement in disability benefits and ensure the needs of people with epilepsy are at the forefront of the new system.

Information Sessions

We delivered information sessions to Epilepsy Specialist Nurses (ESNs) to improve their knowledge of the benefit system, the challenges clients face navigating the system and how medical evidence provided by ESNs can influence the decision makers in reaching a fair decision. This evidence can increase the possibility of a successful outcome.

Our Team

We have been delighted to welcome Janine Cook, as Welfare Rights and Training Administrator, to the team. Part of Janine's role is to provide support to the work of the Welfare Rights Officers and she is likely to be the first person you'll speak to with a Welfare Rights enquiry. Welcome Janine!



TRAINING

This year we trained over 1,500 people across a total of 76 courses. These courses generated around £77,000 to help support the collective work of Epilepsy Scotland.

Our Courses

We mainly used online classrooms and virtual platforms with some in person sessions. A highlight from our year was definitely returning to face to face training and being able to get out on the road once more.

Our Trainees

We were delighted to work with an incredible array of organisations, who have all overcome enormous challenges through the COVID-19 pandemic. Hearing their stories and training their staff has been inspirational and truly rewarding.

Our Volunteers

This year, we invited volunteers to join us on training courses. The volunteers shared their stories with care staff, to enhance their empathy and give them a fresh perspective on what it means to live with epilepsy. Their input is so valuable!

76

courses ran

1,500

people trained

£77,000

income generated

"The feedback I received from staff on the training you delivered was some of the very best I have had in a long time."

- Training Organiser -

"I just wanted to say thanks so much for your talk this morning. I have someone in my life whose memory has deteriorated drastically since they developed epilepsy (four years ago). It really is reassuring to talk to adults in their situation and to understand why it happens too. I'll certainly ask about a memory clinic when they is next at the neurologist. Thanks so much again, we feel so lucky to have found you all at Epilepsy Scotland."

- Training Participant -

FUNDRAISING

It was another challenging year with so many national fundraising events cancelled, however, the fundraising team were encouraged by how many people took on virtual challenges, donated, held their own events or joined up to our virtual events.

John Ferguson's Tractor Run

The community support was phenomenal for the Tractor Run in August. It raised over £18,000, and the streets were lined to watch all 157 tractors begin their run through the back roads of Stonehouse and Strathaven.

The Ladies Lunch

Epilepsy Scotland's flagship fundraising event, the Ladies Lunch, saw a triumphant return in December. Our favourite host Edward Reid took to the stage to woo the crowd and help raise over £10,000.

Halloween Firewalk

The Halloween Firewalk was the first event to be hosted in the new SPIFOX Wellbeing Garden. All the participants were so brave!



Ladies Lunch Host, Edward Reid with Ruby Walters



Our Firewalkers

"I'm raising funds for Epilepsy Scotland as they're such a critical service for those of us in Scotland living with epilepsy. I have received support from Epilepsy Scotland for several years now, particularly when I was at university and my epilepsy was flaring up and I was also struggling with depression. I love to be able to give back to Epilepsy Scotland to allow them to continue to provide vital services— and what better way to do that than to burn my wee tootsies!"

- Rosie, Firewalk Challenge Participant-

THANKS to all who helped make this happen



Special Events

All those who took on a challenge
All those who held events
Everyone who attended the Ladies Lunch
Those who bought artwork at our Lifeworks art auction
Everyone who attended the Patter Merchants Comedy Clash
Everyone who donated a raffle or auction prize for our events
Our event committees

Youth Service

Cruden Foundation
Mugdock Trust
Scottish Children's Lottery
Gordon Fraser Charitable Trust
Shared Care Scotland - Better Breaks
The National Lottery Community Fund - Awards for All
The National Lottery Community Fund - Young Start
Kellie and family who donated books for Happy Mail
The Morrisons Foundation
Aviva Community Fund
John Watson's Trust
Hedley Foundation
Children in Need
R S Macdonald

Core/Corporate

CAF Resilience Fund
Cecil Rosen Foundation
Morrisons Foundation
E C Hendry Charitable Trust
The Robertson Charitable Trust
The JTH Charitable Trust
Ann Jane Green Trust
The Institute of Directors
Paterson Tax Services
Baby Bakes Glasgow
Coal Competitions
Cumbernauld Library
Ferrier Pumps
Diageo

Individual Giving

Our Volunteers
Legacy Donors
Regular Monthly Donors
Raffle or lottery participants
People who bought merchandise
Those who held a collection
Payroll Givers
Members

Wellbeing Service

The National Lottery Community Fund
Glasgow Nursing and Medical Relief
The Glasgow Community Mental Health and Wellbeing Fund
CAF Resilience Fund
James Weir Foundation
TillyLoss Trust
Spifox

Welfare Rights

Bank of Scotland Foundation
Scottish Government - Income Maximisation
Miss Isobel Harvey Trust

Community

Queens Park Supporters Club
Dumbarton Harp Social Club
Livingston South Community Church
The Kindergarten Scotland Ltd Huntly
Kirkliston Bowling Club
The Funky Natz Committee
Glasgow Bowling Association
Inverness Royal Academy
Nairn Dunbar Golf Club
St Columbas Church
The Circle, Dundee

Policy

Arvelle

Helpline & Information

Eisai
Northwood Trust
Haywood Sanderson Trust
The Meikle Foundation
MEB Charitable Trust
Mrs M A Black Charitable Trust
The James Tudor Foundation
The Leng Charitable Trust
Alexander Moncur Trust
Swinton Paterson Trust
Hospital Saturday Fund
Northwood Trust
The Appletree Trust
Thistledown Trust
A M Pilkington
Zogenix

get in touch

Freephone: 0808 800 2200

Text: 07786 209 501

Email: contact@epilepsyscotland.org.uk

epilepsyscotland.org.uk



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Head Office
48 Govan Road
Glasgow
G51 1JL
Tel: 0141 427 4911

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