



cerebral  
palsy  
scotland



# Annual Review 2019 • 20



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BOBATH SCOTLAND

**IS NOW...**



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**Stephanie Fraser**  
CEO Cerebral Palsy  
Scotland



**Ian Johnstone**  
Chair of Trustees



## Joint statement from Chair and CEO

**This has been a year both of provision and progression. Across 2019/20 we provided a total of 990 individual therapy sessions for children and adults with cerebral palsy, supporting people to build skills, confidence and knowledge of their condition. We ran therapy-led groups for all ages and stages throughout the year, hosted a national conference and trained health professionals.**

Most visibly, in April 2020, Bobath Scotland changed name to Cerebral Palsy Scotland.

This rebrand is one part of much wider work we are doing to increase awareness of cerebral palsy and enable us to reach everyone affected by cerebral palsy across the country.

There is not enough support and services for families and individuals living with cerebral palsy. We want to raise our game and close this gap so that every person with cerebral palsy can participate and achieve to the best of their ability – this is our key aim.

Bobath Scotland first opened its doors in 1995. Over the years the charity and its ambitions have grown and developed, and it became clear to us that the name no longer captured the breadth of the work we undertake.

Providing therapy using the Bobath concept is still the core of what we do, but we want to make it much clearer that we now do much more, such as providing online information about CP, creating opportunities for people with CP and their families to meet each other and to access learning, supporting families and individuals with their emotional wellbeing, and working for changes in policy that improve the lives of people with CP.

As always, we thank you all for your continued support as we work harder than ever before to provide services for children and adults with CP in these strange times. We trust that this Annual Review will show that the charity, in partnership with the CP community, continues to work towards our shared mission of improving the lives of people in Scotland with CP.





# Celebrating 25 years

**In March 2020 we celebrated our 25th anniversary with a grand silver-themed ball.**

The charity owes an enormous debt to our founding families, a group of parents who campaigned tirelessly to establish a Scottish centre providing specialist therapy for children with cerebral palsy.

It was in 1995 that a group of dedicated families under the leadership of Alan Burns OBE established Bobath Scotland in Knightswood, Glasgow, and the first children with cerebral palsy were seen for therapy.

Following two further site moves, in 2009 Bobath Scotland relocated to the charity's current home in Port Dundas.

In 2011 we expanded our provision by installing a state-of-the-art therapy kitchen in the basement of the centre.

A key development for the charity was the launch of our therapy service for adults with cerebral palsy in 2012.

Over the years our services have continued to grow and develop. These have included the launch of our annual Cerebral Palsy Scotland conference and exhibition in 2013, producing online information about CP and local support services for people in Scotland, introducing a fortnightly baby group for children and their families in 2018 and exploring ways to support mental health and wellbeing for people with CP in 2019.

The growth and development of the charity has continued in 2020, when in April we took the positive step forward to rebrand and become known as Cerebral Palsy Scotland.





# What is cerebral palsy?

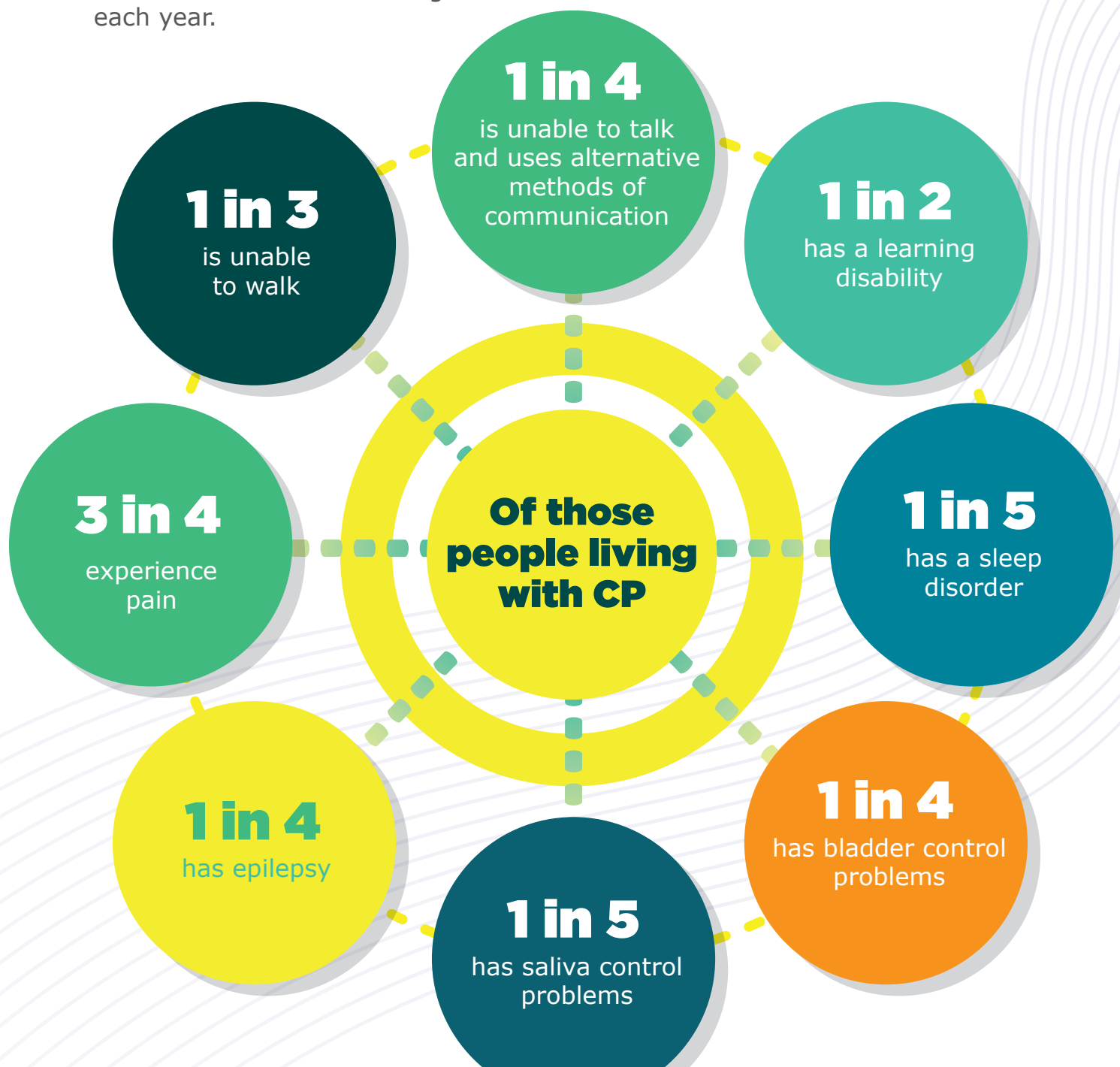
Cerebral palsy (CP) affects a person's ability to control their movement, posture and balance.

The condition results from an injury to the brain that occurs either before birth or during the child's early development.

Cerebral palsy is the most common physical disability in children. Around 1 in 500 births will result in a diagnosis of CP and in Scotland around 150 children are diagnosed each year.

No two people experience cerebral palsy in the same way. How someone is affected will depend on the type of CP a person has and how much of their body is affected.

As well as affecting movement, cerebral palsy can affect other areas of function.



# Who we are and what we do

Cerebral Palsy Scotland's mission is to help people with cerebral palsy build skills, knowledge, confidence and relationships. We advocate for the CP community to have life-long access to knowledgeable, compassionate services and support.

## Our Values



### We see the whole person

We listen to and work alongside the person with cerebral palsy, their family, and others around them. We understand that people with CP are unique individuals and we always adopt a personalised approach.

### We are always ambitious

We enable people with cerebral palsy to pursue achievement at all levels and in whatever way they choose to define it. We aim to open people's eyes to the next opportunity.



### We stay practical

We use our knowledge and expertise to work in practical, direct ways. We create services that reflect what people with CP want and need. Our growth is guided by what's best for the CP community and not what's best for Cerebral Palsy Scotland.

### We are kind

We are unapologetic about putting kindness and compassion at the heart of our work.



### We build relationships

We want to reduce the number of people who "know no one like me". We build relationships with people with CP, their families and professionals. We enable the CP community to network, share and collaborate. We work positively with health and education professionals, organisations and government to get the best outcomes for people with cerebral palsy.

# The year in numbers

Between April 2019 and March 2020 we:

- ▶▶ Provided individual therapy for **137** children and **51** adults in the centre and through outreach. A total of **990** individual sessions supported people to build skills, mobility, confidence and knowledge of their condition.
- ▶▶ **176** attendances at group activities including: Kitchen Craft, holiday clubs, adult AAC (Augmentative and Alternative Communication) users group, and babies group.
- ▶▶ Published regular e-newsletters for **1,700+** people
- ▶▶ Online information reached **7,691** visitors (a 38% increase)
- ▶▶ Continued to host a peer support Facebook group for **232** adult members.



2019  
2020

- ▶▶ Around **300** people and **41** exhibitors registered to attend our free, specialist conference to share learning and best practice and to build relationships between families, adults with CP, carers, and professionals."
- ▶▶ Professional training and qualifications for **41** allied health professionals ranging from short courses to six-month long qualification to enable more specialist support within communities across the country.
- ▶▶ Offered regular volunteer placements for two adults with CP to ensure their voice is fully represented in communications.
- ▶▶ Developed a new name, brand and website to help people find support more easily.



# Support for children and adults

## Therapy

Providing therapy using the Bobath concept is at the heart of what we do at Cerebral Palsy Scotland. Our team of specialist physiotherapists, occupational therapists and speech and language therapists work together to provide individual therapy sessions that are tailored and personalised to suit individual needs. Between March 2019 and March 2020 we worked with 137 children and 51 adults in the centre and through our outreach programme.

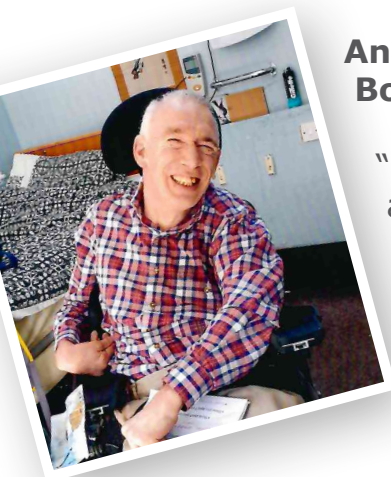
Cerebral Palsy Scotland's outreach programme enables us to provide specialist treatment right across the country. Thanks to the National Lottery Community Fund, this year we continued our outreach Right Start programme for 2-6 year olds. In partnership with local NHS teams and schools, Bobath-trained therapists from Cerebral Palsy Scotland delivered therapy in the Grampian region to children, as well as providing training and support for families, health and education professionals.

In another outreach project, Cerebral Palsy Aberdeen funded our therapists to continue a programme of work for adults in the Aberdeenshire area. Using the newly built facilities at Orchard Brae School in Aberdeen as a base for this work, the project focused on identifying and working towards individual therapy goals.





# Ewen, Ann and Donald



## **Ann discusses the family's longstanding connection with Bobath therapy:**

"Ewen, soon to turn 60 years old, whose life has evolved around his challenge of athetoid cerebral palsy, currently enjoys a fully supported and active lifestyle at Capability's Scotland's Upper Springland in Perth. However it took the family much too long to discover the added bonus of Cerebral Palsy Scotland – where currently now Ewen so greatly enjoys the treatments which have become both crucially helpful and happy features of his life.

"Throughout all his early years, Ewen had the good fortune to travel regularly with us from our home in Los Angeles, California, to visit Scottish grandparents and also - of supreme importance - to spend a week of each summer in London receiving treatment from Mrs Bertha Bobath founder of this therapeutic approach which continues to play a crucial and beneficial role in the lives of Ewen and many others with cerebral palsy.

"It was in the summer of 1962 that we had our first week-long visit with Mrs Bobath – and her husband Karl - and, what a remarkable partnership that was for there were no bounds to their passion for helping people with cerebral palsy! And so, for a week of each summer for some twenty years, we had the good fortune for Mrs Bobath to give of her utmost to try to teach and guide our little family in the many different therapeutic techniques that would help our Ewen.

"On my geologist husband's retirement from teaching, our small three-some family returned to our native Scotland to have Ewen benefit from living with Capability Scotland here in Perth. This was an excellent move but it was only after my husband died some ten years ago now that Ewen and I discovered Bobath Scotland and that Ewen was to begin to experience the good fortune of working with the skilled and patient Philip Vervaeke, senior physiotherapist at the charity's welcoming Glasgow centre. We both greatly benefit and enjoy our visits there.

"For Ewen as an adult – the goals and the benefits from therapy certainly succeed in slowing the progress of further deterioration in the physical well-being of a middle-aged adult as well as with the object – as far as possible - in slowing the pace of further deterioration. Ewen does not suffer pain in any way, in general, and has a respect for himself thanks to all the wonderful work that he receives from generous helpers. And indeed, I am confident that Dr and Mrs Bobath would have cheered on the decision to change the name to Cerebral Palsy Scotland. It is the quality of the work and its spirit that is so uniquely beautiful and if it can be spread and followed more widely – then that is indeed a blessing."



# Groups for all ages

During the year we ran a variety of free-to-attend therapy-led groups, providing opportunities for people with CP to develop life skills and to mix with their peers in a friendly environment.

## Babies and young children

Thanks to the support of The Grocers Charity and others, 17 children and their families were welcomed to our Babies group which ran fortnightly throughout the year. We continued to deliver our successful Buddies groups for primary-aged children during the October school holidays and again in the February break, the latter focusing on children who use Augmentative and Alternative Communication (AAC). Our aim for these groups is to ensure a mix of fun social interaction and specialist therapy support.



## Teens and young adults

As older teens with CP start to think about what independent life may mean for them, our work with young adults in 2019/20 centred on building key life skills. A joint pilot project with Kelvinside Academy's Innovation Studio saw two young people with CP being supported by our therapists to participate in the NuVu design programme alongside Kelvinside pupils. Unfortunately, coronavirus restrictions forced a pause on this project, but we hope to resume this work in due course.

Our first Kitchen Craft group fostered independent living skills for young adults with CP. Supported by the Morrison's Foundation, four young adults worked on developing their kitchen craft, including knife skills, oven and workspace management. Participants also developed a better understanding of how to manage their own weight and eat healthily and had the opportunity to socialise and cook for friends and family. The group have stayed in touch independently and continue to share recipes and tips with each other on social media.

Supported by the Scottish Government's Section 10 funding grant, our adult AAC (Augmentative and Alternative Communication) users' group took part in a mixture of group and individual sessions. Sessions focused on technical support, developing communication skills and co-creating fun projects.



# Rachel

**In 2020, Cerebral Palsy Scotland partnered with Kelvinside Academy to support their NuVu initiative. Two young people worked with Kelvinside students to help them understand more about cerebral palsy and develop products to support people with physical disabilities. Rachel, 16, was one of the young people involved. She explains more:**

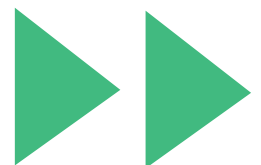
"NuVu is a project run at Kelvinside Academy, which enables students there to develop new skills in many different areas. It is a full-time innovation school with no courses, no classrooms and no grades. It teaches students how to navigate the creative process and relies heavily on collaboration between students.

"I was asked by Sandra McKay who works as an occupational therapist at Cerebral Palsy Scotland if it was something I was interested in being involved in. I said yes because I wanted to see a new way of learning. I knew I would be able to give first-hand feedback as I have cerebral palsy myself.

"As well as helping the young people at Kelvinside Academy understand what daily life is like for a wheelchair user I also helped them understand what things could be invented to help wheelchair users with everyday activities.

"Additionally, I helped the students to develop a second prototype of their idea which was to make something so that it was easier to do buttons on a cardigan or school shirt. I did this by trying out their first prototype and telling them what improvements could be made. I also answered any questions the pupils had.

"I liked how, through this project, I was able to help people understand how cerebral palsy affects people differently and I also felt privileged to be asked to be involved in this project. I feel it has benefited me as I met lots of new people and now feel more confident about educating people about cerebral palsy."





# Building knowledge and relationships

## Cerebral Palsy Scotland Conference 2019

As part of our commitment to building knowledge and relationships within the CP community, the sixth annual Cerebral Palsy Scotland conference and exhibition took place on 1 October 2019. More than 300 people registered for the event at Hampden Park, which included workshops and seminars from academics, people from the CP community and health professionals. Over 40 exhibitors also attended to showcase their services to delegates. The event was made possible through the support of Digby Brown Solicitors and over 20 volunteers from the Department of Work and Pensions (DWP).

## Policy and Campaigning

We advocate for the CP community to have life-long access to knowledgeable, compassionate services and support. We want to make sure that the voices of people with cerebral palsy and their families are at the heart of decision making at both national and local level.

In November 2019, CEO, Stephanie Fraser, was appointed Chair of the Scottish Government's National Advisory Committee for Neurological Conditions (NACNC). In December the government's Framework for Action for Neurological Conditions was published.

## Mental health and cerebral palsy

This year we are particularly proud of our work looking at the state of mental health support for people with cerebral palsy and how the use of Clinical Psychology could add to existing support services being offered by Cerebral Palsy Scotland. Thanks to funding from The Joan Strutt Charitable Trust, Dr Joy Nisbet, Chartered Clinical Psychologist, was able to work closely with staff and service users to build up a picture of what mental health supports are currently in place for people with CP across Scotland, as well as consulting about developing a more "psychologically informed" approach to Cerebral Palsy Scotland's own services.

To start to address this, our therapy team undertook training in the Individual Recovery Outcomes Counter (iROC), an evidence-based outcome measurement tool created by partner charity, Penumbra, in order to measure the mental health and wellbeing journey for people who use our services. The iROC has now been used routinely with service users since December 2019.

This is the first time that services for adults with cerebral palsy have been included in this way and we hope that this is the first step to ensuring the provision of specialist services for everyone with cerebral palsy wherever they live in Scotland.

Cerebral Palsy Scotland is also represented on various collaborative groups such as The Neurological Alliance of Scotland, the NHS's CP Network, the National Postural Care Strategy team and the AAC Collaborative.



## Training

In September 2019 17 NHS therapists from across Scotland completed the Bobath Foundation Training course, which was fully funded by Cerebral Palsy Scotland and Baillie Gifford. This work has led to an increase in the number of community-based NHS therapists who have specialist knowledge in the treatment of children with cerebral palsy. We continue to be committed to working positively in partnership with paediatric NHS services in ways that will enhance specialist service provision for children and adults with cerebral palsy.

In October 2019 Cerebral Palsy Scotland was also successful in bringing the BOHA (Both Hands Assessment) training course to Scotland for the first time, enabling 24 therapists from across the UK to train in this new assessment of bimanual performance in children aged 18 months-12 years who have bilateral cerebral palsy.



# Fundraising

Fundraising is our most important source of income, and the work we do supporting children and adults with CP simply wouldn't be possible without the help of our donors. We would like to thank all of the charitable trusts, local fundraisers, businesses, volunteers, online community and the many individual donors who support us from month to month.

During 2019/20 fundraising made up 86% of our income and enabled projects from cookery courses and the baby group to take place alongside individual therapy and the annual conference.

More than half of the support we receive comes from charitable trusts, without whom new projects and central support would not be able to grow and develop to meet the needs of the CP community each year. Thank you to the many trustees and decision makers for the critical support these grants provide, which during 2019/20 included: Scottish Government's Children, Young People and Families Early Intervention Fund and Section 10 Alternative and Augmentative Communications programmes.



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**COMMUNITY  
FUND**

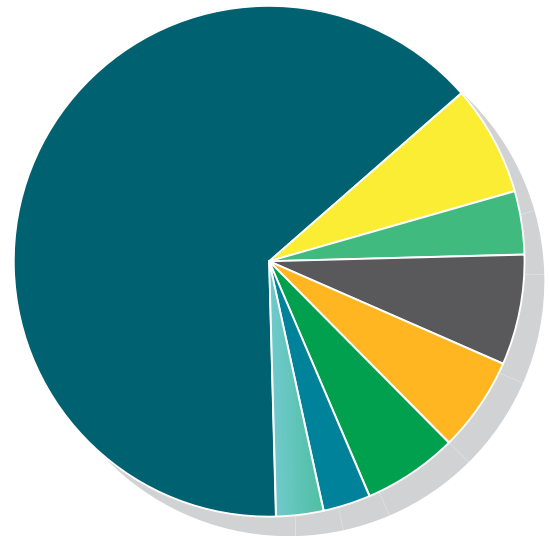
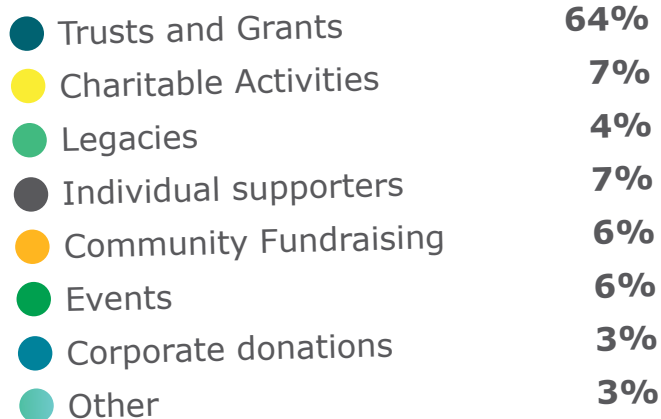
# Financial Review

We remain committed to ensuring access for as many people as possible who need our vital services. We continue to work to bring down any barriers for people to find us, understand how we can help and to ensure that need rather than ability to pay determines access to services. However, we cannot offer lifelong support for people with cerebral palsy without funding and this year over 86% of our income had to come from our own fundraising efforts.

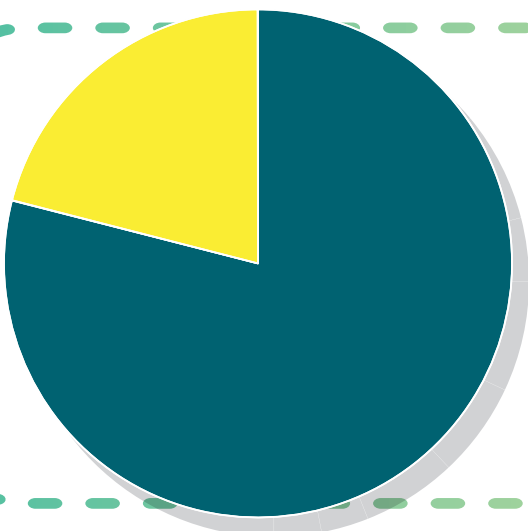
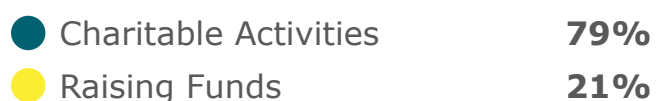
During the year our gross income was **£747,948** whilst total expenditure was **£807,813**. We therefore reported a planned deficit for the year of **£68,360**. The total funds at 31 March included our planned pre-payment of **£62,288** for the completion costs of the Bobath Training Course for NHS therapists delivered between March and September 2019.

We continue to keep a tight rein on costs although this year we have included one off costs for the planned rebranding and relaunch of our website and online resources. Over 79% of our expenditure is on our charitable activities.

## Income



## Expenditure





CEREBRAL PALSY SCOTLAND'S

**RESPONSE  
TO THE  
CORONAVIRUS  
PANDEMIC**



## Our response

The rapid spread of the COVID-19 epidemic and Scotland's ensuing "lockdown" on 23 March 2020 led Cerebral Palsy Scotland to close our therapy centre, in line with national guidance. Unable to deliver hands-on therapy sessions and therapy-led groups meant we had to quickly refocus and adapt our services to support the CP community during exceptional circumstances.

As people with cerebral palsy were identified by both Scottish and UK governments as "vulnerable" early in the crisis, we recognised the real concern within the CP community for their health and wellbeing and the requirement to find new ways to meet people's needs. We provided support in the following ways:

# 01

### Online guidance about coronavirus and cerebral palsy

We launched an online Coronavirus and cerebral palsy guidance page on our website, summarising key information on risk, advice on managing carers and support workers in the home, accessing Personal Protective Equipment (PPE), hand-washing advice for people with reduced mobility, and staying well.

During the first two months, over 12,000 people visited our coronavirus guidance, with 8,000 of those visiting during the first four weeks of the crisis.

# “

**There has been minimal intelligent comment about what to do – especially for people with cerebral palsy. Your site is full of intelligent, practical advice that is CP-related, on dealing with the coronavirus. I am so delighted that I came across your website – it really helps.**

# ”



02

## Weekly lockdown email updates to the CP community

We sent out weekly updates to around 1,500 subscribers throughout the lockdown period between March and August 2020. These highlighted national guidance updates relevant to the CP community, useful information and support from other organisations and updates on new services that we were able to offer during lockdown.

“

**Thank you for all your brilliant, informative and kind emails over lockdown. They have been a great source of information and support.**

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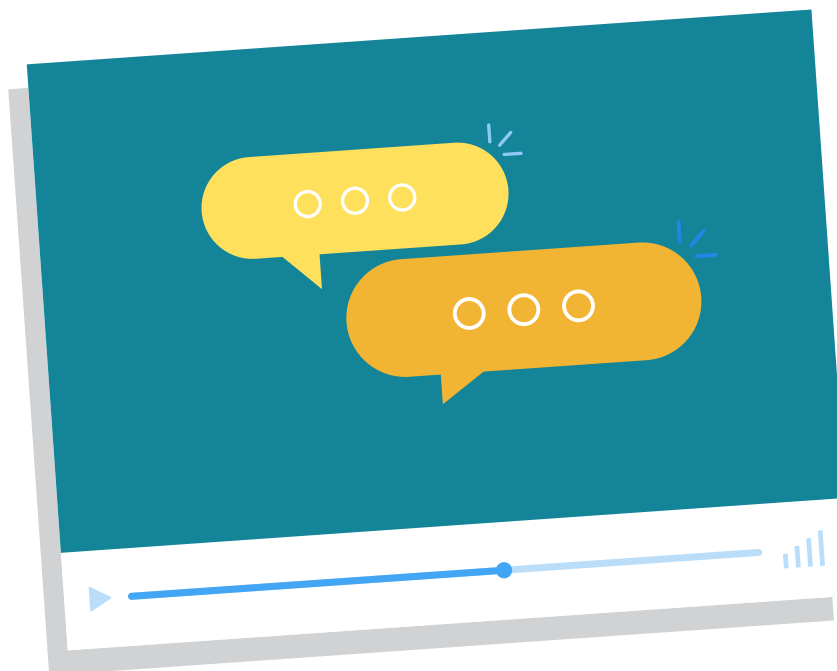


03

## Virtual therapy consultations

Due to the restrictions, children and adults with cerebral palsy experienced a reduction in the therapy and other support they would typically receive both in the community and at hospitals. Most in-person appointments were cancelled and NHS support was offered principally via phone or through virtual consultations.

Cerebral Palsy Scotland delivered virtual consultations on request to anyone with CP throughout Scotland, at no charge, thanks to funding from the Scottish Government's Wellbeing Fund.



## Virtual therapy sessions

### Wren and family

**Cerebral Palsy Scotland's virtual therapy sessions have provided support to people and families across Scotland during the pandemic, including two-year old Wren.**

Wren and her twin brother live with parents Katy and Conor in North Uist. Wren's cerebral palsy affects all four of her limbs, and she also has a severe visual impairment, epilepsy and gastrointestinal difficulties.

**Dad Conor said:** "She likes the feeling of movement. So, lots of bumpy rides in her buggy, being thrown up in the air and getting lots of cuddles. Of course, she's in pain quite a lot but she goes through periods when she is quite happy and she loves hearing people talk."

A team of local therapists and other health professionals support the family, but during the pandemic in-person support has been more limited. The family had several virtual sessions with Cerebral Palsy Scotland physiotherapist, Philip Vervaeke:

**Conor explained:** "We found the most valuable thing was the access to their expertise in cerebral palsy – how children with cerebral palsy develop, what kinds of things they like, how to support them to grow, how to protect their posture."

**Katy said:** "The benefit of the remote sessions, in particular, is that they can see Wren in her home environment. They could see all of her equipment and help us adjust it, and Wren is obviously much more calm and relaxed so she was able to tolerate therapy too."

"For us to go down to Glasgow where Cerebral Palsy Scotland is based requires that we go on a plane, which she doesn't really like. It's getting quite hard to transport her because of her size and age now so she's usually not in the best of moods when she gets to a session but here, she's much happier.

Cerebral Palsy Scotland also helped the family access training material for a new care worker for Wren and those who support her in nursery when she returns.

The couple hope Wren will continue to make progress.

**Katy added:** "We've been pretty amazed by some of the things she has been able to do because the prognosis when she was born was so negative. Mostly what I want for her in the future, is to be comfortable and happy."



## 04

### Gathering evidence on life for people with cerebral palsy during the pandemic

In May 2020, Cerebral Palsy Scotland undertook an online survey of the cerebral palsy community in order to gather evidence on the impact of lockdown.

The results were widely shared with Scottish Government and the NHS, university studies and umbrella bodies including the Neurological Alliance of Scotland and the Health and Social Care Alliance. Within the charity, Cerebral Palsy Scotland used the findings to inform and guide the development of our coronavirus services.

In September, Cerebral Palsy Scotland conducted a second survey of the CP community, in order to build up more robust evidence and track the impact of the restrictions for people with cerebral palsy over time.



## 05

### Bringing the CP community together online

A weekly 'virtual coffee' session for adults with CP ran between April and August and built up a regular group of attendees, many of whom felt socially isolated throughout this period. The informal chats enabled peer support and information sharing, as well as a place to ask questions of Cerebral Palsy Scotland.



**I have virtually attended the group most weeks and it is a real boost for me, obviously it isn't the same as meeting people face to face but it is a great alternative.**

**The zoom meeting has been something to look forward to every week. I would like the virtual calls to continue on a regular basis, even when life gets back to some kind of normality. It is so important to have communication and support available to people who need it- Zoom is now a new way that we can do both.**





## 06

### Therapy tips videos

To complement our offer of virtual therapy consultations we produced a series of five videos containing therapy tips for different ages and stages. Topics covered include: therapy tips for lockdown, moving with your baby with cerebral palsy, and advice on moving and playing with children with cerebral palsy in the home.



“

**Thank you for the latest video - delightful and of great interest. I so very, very much appreciate all that you are doing to keep all of us on track as best as possible in these current difficult times. Warmly and with deep gratitude for all that you're doing to support us and our families.**

”

## 07

### Re-opening the centre

Our centre in Glasgow re-opened on 13 July 2020, in Phase 3 of the Scottish Government's Route Map for the easing of coronavirus restrictions. We have felt it is essential to be available to provide in-person support, albeit within very strict protocols and risk assessments and with restricted availability of appointments. Phone and video consultations continue to be available as long as they are needed, allowing us to continue to support people who cannot access the Glasgow centre.





## Trustees

I Johnstone

D Reid

E Boyd

N Lapping Resigned 26/03/2020

J McPhail

P Morris

M O'Neill Resigned 14/05/2019

K Colquhoun

K Campbell Appointed 14/05/2019

A Matthews Appointed 17/02/2020

G Craig Appointed 17/02/2020

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