

Impact Report 2023





Together we are working wonders for children with brain conditions

Our **vision** is that every family that includes a child with a brain condition will have the chance to discover a better life together.

Our **mission** is to listen to families that have a child with a brain condition.

We use what they tell us to inspire the best research and innovation.

Then we help them put the knowledge into practice so they can discover a better life together.

Our families, researchers and supporters go further when they travel together:

Families play a vital role in their children's lives and in everything we do. We want the families we work with to feel valued, listened to and part of our work.

A spirit of enquiry and innovation drives our research teams. The potential for discovery in their work and in the families whose lives they will touch is truly exciting.

We want to inspire people to give, raise funds, and get behind us by not just reminding them of the need for what we do, but also the positive outcomes they could help families achieve.

This report reflects what we achieved together in 2023

2023 at a glance:



948 families got a good night's sleep thanks to our Sleep Service.



Our Legal Rights Service helped 274 families access public services.



We lent 1,195 books and toys to help families learn and play.



Our information resources were downloaded 55,292 times.



Our Innovation Centre helped **266** children discover life and have fun with their friends.



We spent £599,328 on life changing research.

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By 'brain condition', we mean any neurodevelopmental condition that affects the developing brain, including those caused by illness, genetics or traumatic injury. Brain conditions include (but are not limited to) autism, ADHD, Down's syndrome, learning disabilities, cerebral palsy, epilepsy and developmental delay.

















I. We use what families tell us to inspire

the best research and innovation

Research & Information Strategy

We focus explicitly on supporting research to benefit the families of children with multiple and complex needs or rare conditions. In other words, needs characterised by a combination of physical disability, learning disability, development delay, physical and/or mental health problems, genetic diagnosis and/or autistic spectrum condition.

In our experience, this community is poorly understood and provided for within the research environment. Our services will continue to reflect and align with our research ambitions.

Ultimately, through our research and associated services, we want to promote understanding and to see a world where neurodiversity is respected and celebrated, and where children with neurodevelopmental conditions get to fulfil their greatest potential without barriers to their complete participation in societu.

In 2023 we have continued to:

- See research translated into policy and practice at a local, national and international level that will improve the quality of life of families.
- Develop evidence-based resources for families to help them tackle some of the challenges they face and make decisions about what is best for them.
- Promote understanding of neurodevelopmental conditions, particularly rare conditions and associated complex support needs, among professionals and within society.
- Develop the next generation of researchers who will champion the needs of children with neurodevelopmental conditions, particularly those with multiple and complex needs or rare conditions.
- Collaborate more, with universities and other charities, in funding, designing, implementing and communicating research outcomes.
- Leverage more research funding to support research that will benefit the families of children with multiple and complex needs.







Summary of key research in 2023

In 2023 we reviewed our Research Strategy and priorities for the next 5 years and have continued to work in partnership with universities and families in a productive, engaging and collaborative way to find answers to some of the questions and most persistent problems families face.

Read our Research Strategy in full on our website together with more detail on the work of our Research Partners.

Fabricated or Induced Illness Research Report

We published a major new report on Fabricated or Induced Illness (FII). The research report considered the prevalence and impact on families in England, Scotland and Wales of being accused of creating or exaggerating their child's difficulties – an extreme form of parent carer blame.

The report was based on research undertaken by the Cerebra Legal Entitlements and Problem-solving (LEaP) Project based at the School of Law, Leeds University.

Key messages from the report:

- The major finding of the research is one of family trauma. The making of an FII allegation often causes devastating and life-long trauma to those accused and to their children.
- FII allegations against parents o disabled children appear to be widespread and increasing,
- Disabled parents appear to be four times more likely to be accused of FII than non-disabled parents.

- 50% of allegations of FII were made after a parent carer had complained about the actions of the relevant public body.
- Most FII allegations (84%) resulted in no follow up-action or were abandoned and in 95% of the cases the child(ren) remained living with the parent.
- Royal College of Paediatrics and Child Health (RCPCH) 2021 FII guidance is likely to give rise to a very high number of 'false positives' (people being wronglu accused of FII).
- NHS practitioners were the source of most FII allegations, followed by school and then local authority children's services.

The research report calls for:

Urgent revision to the RCPCH (2021) FII guidance including:

- to address its failure to recognise the harm to parents and children caused by allegations of FII
- to address the danger that its 'alerting signs' may have an unlawfu discriminatory impact on disabled parents
- to acknowledge that its 'alerting signs' (of FII) are unsupported by any peer reviewed research.



Professor Luke Clements said:
"The evidence suggests a significant increase in the numbers of parents — especially disabled parents — being inappropriately accused of FII. These allegations have a devastating and ofter life-long impact on families — including their children: the very people the system is supposed to protect. There is an urgent need for a radical overhaul of policy and practice in this field".

The full report can be downloaded from our website.



Lifestyle interventions during pregnancy improves child neurodevelopment

The Cerebra funded research team at the University of Barcelona, published the results of a clinical trial showing that structured interventions during pregnancy, such as those centred on a Mediterranean diet or mindfulness-based stress reduction, can improve child neurodevelopment by the age of two.

The study represents the first randomised clinical trial aimed at evaluating the impact of lifestyle interventions, particularly those based on the Mediterranean diet and stress reduction, on child neurodevelopment. The studu:

- Paves the way for potential revisions in current pregnancy monitoring and control protocols.
- Demonstrates that modifying a pregnant woman's lifestyle can effectively decrease pregnancy complications and enhance the health and development of the baby, without necessitating pharmaceutical or alternative forms of treatment.

Authors of the report conclude:
"These results provide a clear and
empowering message to mothers and
families. It is possible to positively influence
pregnancy and the future baby's health
with relatively easy-to-implement
measures".



Tailored behavioural sleep interventions for children with neurodevelopmental conditions.

We began a project with researchers at Aston University to understand how practical and effective behavioural sleep interventions are for children with neurodevelopmental conditions.

The project will examine whether tailored sleep interventions improve children's sleep, daytime behaviour, and caregiver wellbeing.

Why do we need a project examining sleep in children with neurodevelopmental conditions?

Sleep plays such a vital part in children's mental and physical health, development learning, and behaviour. Children with neurodevelopmental conditions often experience poor sleep, which can negatively impact their mood and behaviour, as well as causing increased anxiety and stress in their caregivers.

Research is needed to determine which strategies are effective in improving sleep outcomes.

What difference will this research have for children with neurodevelopmental conditions?

This project will help us to understand how effective behavioural sleep interventions are for children with neurodevelopmental conditions, as well as understanding caregivers' experiences of these and possible barriers to completing them. This may help to identify areas in which changes can be made within the Cerebra Sleep Advice Service and other sleep support services to improve their accessibility and effectiveness.



The project is being led by Dr Georgie Agar a Lecturer in the School of Psychology and Institute for Health and Neurodevelopment at Aston University. Her PhD was funded by Cerebra, and she is thrilled to be working closely with the Sleep Team on this exciting project.

Barriers to Breakthroughs:

In June 2023, we hosted our conference at Birdcage Walk, Westminster on "Barriers to Breakthroughs: The positive impact of our collaborative research for children with complex needs and their families".

Attendees were treated to a host of talks from world-class academics who are undertaking research funded by Cerebra.

Key topics included:

- Pregnancy identifying interventions to help prevent and/or minimise childhood disability
- Bright ideas for brilliant kids innovative, bespoke products to help disabled children discover and engage with the world around them
- Interventions research to improve the lives of individuals with learning disabilities and/or severe or complex needs and their families
- Legal entitlements helping families to access their legal rights.

100% of delegates reported that they had found the conference useful

"I loved how interesting the topics of presentation were today as well as how knowledgable the presenters were. I'm amazed by the impact Cerebra has had and feel that today has been an incredibly motivating experience. Thank you for putting on a very informative and successful conference".

All of the presentations from our conference are available to view on our website.



2. We provide families with the highest quality evidence-based information and support

From physical and mental health, dealing with social services, financial and legal affairs and education, all of our Information Resources offer expert advice and research-driven strategies to help families deal with issues we know they may be facing.

All of our information resources are free to download from our website.

82% of users who gave feedback rated our guides as excellent.

Our top 10 downloaded guides and factsheets for 2023 were:

1. Disability Living Allowance Guide	18,679
2. Sleep Guide	5,108
3. Sleep Tips	3,304
4. Accessing Public Services Toolkit	1,943
5. Sleep Cards	1,513
6. Sensory Processing Guide	764
7. Anxiety	974
8. Managing Challenging Behaviour	963
9. Money Matters	742
I O. Toilet Training	527

Parents told us:

"Your charitable help and guidance is outstanding.
The information, advice and guidance is of real and effective help which parents can use in practice! Thank you so much



We published 3 new guides and factsheets:

Mental Health in Children with Rare Genetic Conditions

Looking after your own wellbeing as a parent/carer of a child with a brain condition and My Wellbeing Plan

Child Disability Payment Scotland Our Sleep Cards were downloaded 3,190 times

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Our Sleep Advice Service offers a range of information and support to help children – and everyone in the family – get a good night's sleep.





How Our Sleep Service Helped:

In 2023:

We helped 781 families on a one-to-one basis

We held 4 online sleep seminars and 18 face to face workshops

167 families were helped through our seminars and workshops

5,108 Sleep Guides downloaded

3,304 Sleep Tips downloaded

1,513 Sleep Cards downloaded

Parents told us:

"The different strategies suggested by the Sleep Team and the constant support made a massive difference – Z now falls asleep within 15 minutes".

"The Sleep Service has given us help and advice on how to improve my child's sleep. This has made a huge difference. G is now only waking around twice a week and his overall mood and behaviour have improved as a result of him getting more sleep".

"Our son sleeps anywhere between no sleep to 4/5hours each night. We received telephone advice from the Sleep Service. It has helped with smali changes in sleep and helped us look at the sleep problem from an entirely different view." "Cerebra's Sleep Service - It was just simply amazing! There was great communication and I felt very well looked after. Hugo did manage to improve his sleep and I just wanted to say that you're doing an amazing job"

"Sleep is such an emotional subject for parents struggling with children who have neurological issues. This service is amazing and the Sleep Team were understanding, reassuring, experts in their knowledge but most importantly treated all of us as individuals too"

Short and disrupted sleep is common in children with brain conditions and specialist advice is needed to overcome the complex challenges they face. Our Sleep Advice Service is unique in being able to provide the tailored support that children with a brain condition need.





Our Legal Rights Service provides families of children with brain conditions with help when facing difficulties accessing support services they are entitled to.

Social care

SEN provision

21

Disabled Facilities Grant

Health services

12

School transport

Safeguarding/child protection

Housing

Welfare benefits

Continence services

Discrimination

Family Law

Clinical negligence

We helped 170 families with specific information:

In 2023:

Our Accessing Public Services Toolkit was downloaded 1,943 times

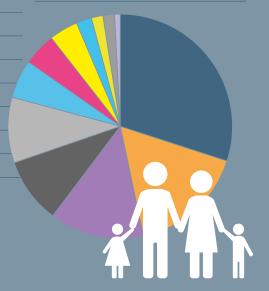
Our legal rights template letters were viewed 1.782 times

We held 12 Problem-Solving Accessing Public Services Toolkit Workshops

A total of 104 people attended

84% of attendees reported that after attending the workshop they now had the confidence to try this at home

94% said the workshop improved their knowledge on how to access public services



Challenging Local Authority Policy — How Our Legal Rights Service Helped

"I can't thank Cerebra enough for their advice which has allowed us to challenge the LA's policies. I dread to think what situation our family would be facing without their help and I am certain that we would not have succeeded in securing the support that we need (and are legally entitled to) without it.

I first got in touch having tried to understand the legislation about the social care support for my son and ourselves as carers. I was struggling as I could not understand how the LA policies aligned with the guidance we were signposted to by other organisations. My son had received a social care assessment significantly outside the statutory timescales which identified needs, but which social care said we did not qualify for support with due to their thresholds, which did not appear to align/correspond with the statutory policies or advice guides.

The LEaP team were the first and only people who listened and tried to understand our situation to give tailored advice rather than signposting me back to the same legislation. They grasped the key issues and gave clear logical and

highly knowledgeable advice. Were it not for this advice I would not have had the confidence in my understanding of the legal issues to continue raising my complaint with the local authority through each stage of the complaints process.

We were supported every step of the way and our case worker was a rock of support and like a pilot guiding a ship through stormy waters. He demonstrated endless patience answering all my queries. Throughout our journey seeking support he has always provided clear, logical and compassionate advice. Without his and Cerebra's support we could not have secured the fantastic outcome we received at the SENDIST where it was recommended that our son was awarded a significant amount of social care support".

Parents told us:

"Your opinion has really helped give me the confidence to manage the situation in a way that should lead to the best outcome for Daniel".

"I can't thank you enough, the support I will get will mean that I can continue caring without losing my marbles and my daughter gets time to engage with activities away from our home".

"We wanted to express our gratitude for your help and effort to sort out our Travel Assistance application process. Your support means the world to us as parents, thank you".

"Thank you very much for this template email, it reads really well and says what we want it to say".

Our Postal Lending Library helps families to play and learn.

In 2023:

We helped 537 families

We loaned a total of 1,195 items

100% rated our service as excellent

Our Sensory Toy Library helps children to discover a favourite sight, sound or smell with one of our switch toys, fibre optics or sensory kits.

In 2023:

We loaned 278 toys

93% of our library users told us that the toy they'd borrowed had met their child's sensory needs

79% said the toy had improved their child's skills

96% said the toy had helped their child's enjoyment of life

93% said the toy had helped their child to interact with family and friends

76% had decided to purchase their own following the loan

Our most popular toys were:

- I. Sensory in a Suitcase
- 2. Hip Hop Jumping Mats
- 3. Fibre Optics Kits



Our book library has titles on a wide range of topics for both adults and children.

In 2023:

We loaned 528 books

88% told us that their book loan had helped them meet their child's needs.

95% told us that their book loan had helped them to understand their child's condition.

51% told us that their book loan had improved their ability to access services for their child

Borrow Box.

Families can also borrow ebooks and audiobooks using the BorrowBox app and website.

In 2023:

We loaned 389 BorrowBox books

Most popular BorrowBox loans:

- I. The Explosive Child by Ross Greene
- 2. Your Child is Not Broken by Heidi Mavir
- 3. Sensory Processing Diet by Chynna Laird

Top children's book:

I. Matilda by Roald Dahl

Parents told us:

"My niece is 6 years of age, she is autistic and has severe learning needs/disability. She is also mute with severe sensory needs, insomnia, incontinence and behaviour issues. Rebekah doesn't always play with regular toys or engage with her younger sister or her peers. She needs toys to engage with - she likes light related toys so sensory toys are useful.

The toy library is a godsend. We've been able to access toys that we would not otherwise have been able to and the whole family has benefitted. It's a wonderful service — thank you."

"Isabella suffered a brain injury after a prolonged seizure last year. It has left her with right sided weakness and cognitive impairment. Before the injury, she was just a normal 2 year old playing with toys a normal 2 year old would play with. Since the injury, she has increased sensory needs and it was hard to get her to focus and increase her attention span. The injury has affected the family dynamic.

Cerebra's lending library has provided access to some great toys to meet Isabella's sensory needs and increase her attention span. We're taking small steps but using toys from the library has allowed us to enjoy joint activities for longer periods and has helped Isabella improve cognitively".

Our most popular books were:

- I. Your Child is Not Broken: parent your neurodivergent child without losing your marbles bu Heidi Movir with 2 I loans
- 2. A Different Way to Learn: neurodiversity and self-directed education by Naomi Fisher with 14 loans

There are two in joint third:

- 3. Championing Your Autistic Teen at Secondary School: getting the best from mainstream settings by Debby Elley with 10 loans
- 3. Understanding ADHD in Girls and Women

 Joanne Steer with 10 loans

Top children's book:

I. Understand Me: an inspiring journey of a boy with PDA (pathological demand avoidance) by Spencer Scott



Our Innovation Centre (CIC) designs and builds innovative, bespoke products to help disabled children discover and engage with the world around them.

Our ethos is simple – if you can dream big, we can do big. Never accept it's not possible!

In 2023, the Cerebra Innovation Centre has been busier than ever. We received a generous donation from Motability to develop mobility equipment that will increase independence, confidence and comfort for dozens of young people. Over the next three years, we will build 75 bespoke Oxy-Gem Strollers, Scooters and 3D Printed Crutches which will be provided for free to families across the country.

Our hugely popular Sensory Pod Chairs have also been a priority this year. The Innovation Team has continued to build these beautiful, life-changing, furniture items for those who have been on our waiting list. Thank you to everyone for their patience, we are actively seeking funding to be able to make more of these chairs.

2023 also saw the development of a new social enterprise project for the team. We've secured funding to launch a new "arm" of the Innovation Centre, which seeks to make a few products that will be available to purchase through our own online store or via a 3rd party. In time, our hope is that this social enterprise will become a new revenue stream for Cerebra, enabling us to return the profits into the Innovation Centre, so that we can continue to bring dreams to life for years to come!





In 2023:
We helped 266 families:
28 with unique designs
221 with repeat designs

The Cerebra Innovation Centre is a collaborative project between Cerebra and the University of Wales Trinity Saint David.



Community effort to build sensory waterfall for SEN pupils

In September we received a grant from the B&Q Foundation to work on a project that would benefit the community. Dr Ross Head, who leads the CIC team, came up with the idea of a tactile sensory sculpture for special educational needs (SEN) pupils to engage and play with.

Choosing Dunvant Primary School in Swansea, Dr Head said he was glad to be able to "give something back" to the school his children attended, knowing it would be welcomed and appreciated but he staff and students there.

The sensory waterfall design consists of three layers. Water trickles from top to bottom through a series of spinning water wheels into lower level basins, with space for about ten small children to play, side by side, around it. It's built out of wood to maintain a natural feel, with drawings and shapes on the outside to make it visually pleasing.

The CIC team were joined by staff from B&Q Swansea and Valspar Paint, who used the opportunity to provide a community day for their staff, and the three teams worked collaboratively to make the whole area of the school grounds nicer.

Ross Head said: "This project has been a fantastic and very successful community collaboration. It has highlighted the importance of civic outreach within our community, and shows that an enthusiastic team can achieve a huge amount in a short time. Seeing the children get more and more inquisitive and excited throughout the day was a real treat, and quite infectious! Everyone involved is keen to help again."





3. We help children to fulfil their greatest potential without barriers to their complete participation in family life and society.

Over 500,000 children in the UK live with a brain condition

This can make normal activities such as learning, playing or simply experiencing the world a huge challenge. We offer solutions and advice to help these children and their families enjoy lives full of hope and discovery.

We'd like you to meet just a few of the families we helped to discover a better life in 2023.



Independence for Arlo

Two year old Arlo likes going on walks, playing with his blocks and reading books. He is a happy little boy and enjoys watching cars in the street. His mum Lauren explained how a clever design from our **Innovation Centre** has given Arlo independence.

"Arlo has a condition called RTD type 3 which affects the nerves in his body causing profound deafness, muscle weakness and breathing problems. Arlo had to rebuild his muscles back and regained the ability to sit and roll. He is nonverbal and knows some signs. Arlo is on life support meaning he requires ventilation via tracheostomy. He is attached to a machine most of the time. This was not easy as Arlo's walking frame didn't have anything to attach the ventilator onto meaning I had to hold the vent while trying to hold everything else.

The Innovation Centre helped get Arlo active by developing a small attachment for his ventilator so that he could carry it on his Kaye Walker. The attachment is small, lightweight and a fun and sporty design to match Arlo's enthusiasm!

Designer David said "it was fun to work with Arlo and Lauren to get Arlo up to speed. His desire to get around inspired me to design this tiny adaption, in the hope it would make a big difference to his mobility and social wellbeing. It is so nice to work with parents who push us to develop more inventive solutions to help their children do what other kids do!"

Lauren told us "Arlo can now walk independently with his vent attached and doesn't have to rely on me to always be by his side around the house. It's made a big difference and helped my boy loads".



Helping Logan through a difficult time

Lisa told us "When we adopted Logan it wasn't disclosed that, as part of his autism, he didn't sleep. This was a massive shock as we weren't prepared for the impact that lack of sleep had on him and on us. After the stress of an extremely difficult, lengthy adoption process, both my partner and I were struggling to manage the lack of sleep. I got in touch with Cerebra's Sleep Advice Service to ask for support.

Our Sleep Practitioner was absolutely fantastic.
The biggest support I received was to be heard. He really
listened, not just to what we were struggling with, but to
the journey of our little one coming to live with us and his
background. I was given a safe space to talk about how I
was feeling — this alone lifted a massive weight to be able
to talk to someone without judgement.

He didn't just listen he acknowledged and showed compassion to our circumstances. He understood everything I said and worked with me to implement changes to the bedtime routine we had in place. I took on-board several different points to work on and tweaked them to meet the needs of our little boy. The information and guidance I received proved to be invaluable. It's helped us to create the perfect bedtime routine from avoiding blue light, having quiet time to the lighting and sounds in our little boys bedroom.

We feel that we are now able to manage and know we can always come back to Cerebra gives us peace of mind – we know that support is there when it is needed.



Amelie is going places

Six-year-old Amelie is a bubbly and happy little girl. She loves playing outside and worships her little brother, Arthur. They really are inseparable at times.

From birth, Amelie was diagnosed with quadriplegia cerebral palsy and faces challenges each day. Her condition has affected all her limbs and her core. She is also weaker on the right hand-side of her body. This doesn't stop her from being as active as possible though, and this is where our Innovation Centre has stepped in to help.

Dad, Rob explains: "We first got in touch with the Cerebra Innovation Centre around four years ago when Amelie's physiotherapist was helping us find something to assist her with her leg exercises. We were just amazed by the range of things they had created for children to help them with all kinds of activities.

The team kept in touch and we were able to keep them updated with Amelie's progress. Then, earlier this year, we were looking at other ways to help build her strength through a fun activity and this led to the design and build of her very own skateboard!'

The skateboard helps Amelie to develop her upper body, both in terms of strength and dexterity. She lies on her front with a belt support fastened across her lower back and uses her arms to pull herself along It's just like a paddleboard, but on land.

The design is adaptable and can be extended or shortened depending on the needs of Amelie as she grows. Rob explained "it's been great for building strength in her arms and improving her mobility. Not only that, but it puts a huge smile on her face. She absolutely loves it!"



Helping Lu and her parents with those sleepless nights

It was a very difficult start to life for three year old Luwhen she was diagnosed with Wolff Parkinson White syndrome.

Growing up, Lu started to develop learning difficulties, but this doesn't stop her from doing the things she loves, like being outside – particularly by the sea or running around in the woods. Lu does, however, have problems sleeping at night and this also has an impact on her parents. Lu wouldn't get off to sleep at night and this was happening all the time. As mum Katherine told us, "night was just a different type of day".

During one of Lu's appointments with her paediatrician, it was recommended that Katherine get in touch with Cerebra and our **Sleep team**. After receiving support from one of our Sleep Practitioners Lu soon started to feel a lot calmer and a lot more focused on going to sleep.

Katherine told us: "We've definitely already seen some improvements. Lu is much happier and we're all coping so much better. My partner and I used to dread bedtime, but Lu can actually sense that we're now much happier and confident about it.

"I never thought there was someone out there who would be able to help with sleep and it's been great to receive professional, trusted help. Sleep is like currency... it's that precious! Lu is getting more sleep and waking up less. Step-by-step, we're getting there!"



Helping Theodore to sleep through the night

Mum Gabby told us how her three year old son Theodore was not only struggling to fall asleep on his own but was also waking during the night. She explains how our **Sleep Advice Service** helped.

"Our son Theo loves horses, cars, the farm and rockets — he's not too keen on having his hair washed loud noises and being told no! He's also non-verbal which has a huge impact on communication for all of us in the family. We've worked out a means of communication by pointing, him taking our hands, singing nursery rhymes and offering choices.

We were at a stage where Theodore wouldn't go to sleep alone and was taking on average 1.5 to 2 hours to fall asleep every night. This went on for months on end. When he did fall asleep he'd then treat bedtime as a nap and would wake 4 hours later for a period of 3-5 hours during the night.

This was a very testing time for us as when his sleep was at an all-time low we were expecting our second child and I was unwell during my pregnancy.

The advice we received has made a huge difference to us. Our Sleep Practitioner advised us on how to make changes in our approach to nap and bedtime. We put in a lot of work over the course of a few months and it helped massively. Once things started to improve, they continued to and Theo has been sleeping well ever since".



A camera for Archer

"Our son Archer is a happy boy, he loves playing with cars, building sandcastles, collecting rocks at the beach and Maui from the movie Moana! Archer has a right hemiplegia, caused by his severe epilepsy and made worse by his recent neuro surgery where he had a left hemispherotomy to completely disconnect the left side of his brain in an effort to control seizures. He has no function (yet) in his right hand and wrist which can make it difficult for him to use some toys.

Archer has shown a real interest in photography – I'm a photographer myself and he's constantly interested in my cameras. For his 3rd birthday we bought him and his twin siste VTech Kiddi Zoom cameras but the shutter button was on the right hand side which meant he was unable to use it as he has no function (yet!) in his right hand and wrist.

We got in touch with the **Innovation Centre** to see if they could suggest any adaptations that would help. They asked us to send Archer's camera in asap so that they could look at it and hopefully find a solution quickly in time for Archers birthday. And they did! As there was another button at the left hand side to turn the camera around for selfies, the team switched the buttons over so that Archer could use it left-handed. The team turned the job around really quickly so that Archer received the camera in time for his birthday.

He loved his camera and snopped away on it all day at the safari park. Without your help adapting Archer's camera he simply wouldn't have been able to use it and that would have been such a shame. We truly appreciate it".



Finding calm at bedtime

Four-year-old B has sensory issues as well as developmental issues, particularly around communication. It was taking B a long time to fall asleep and he was often waking during the night, taking a long time to settle.

B's mum told us "Our Paediatrician advised us to contact Cerebra for support with B's sleep. He had already been prescribed medication to help but there were side effects to this. We weren't sure how much more could be advised. We also have an older autistic child who struggled with sleep and so we had already done so much research and tried lots of things – but we were keen to say yes to any support we were offered.

Within a few months, things were much better – B was settling earlier and his parents had learnt how to keep him calm when needed. B's mum told us "the support we received from the **Sleep Service** has been incredible. The factual information and personalised suggestions have been so helpful and has really helped to improve our son's sleep. He now rarely needs medication and the whole family is more rested, with improved mental health and better relationships.

As a couple, we have not had a night away from home together in over 6 years because we never felt able to leave our sons with other people because of their poor sleep patterns. However now we have been able to plan to leave our sons with grandparents for a whole night so that we can go and get married! That would not have been possible without the changes that Cerebra has helped us to make. We are so grateful for this service."



Excitement and wonder for Charlie and Daisy

Mum Victoria introduces us to her family and explains how our **Toy and Book Library** has brought a sense of wonder to her children.

"Our twins Charlie and Daisy are three years old. Daisy is very sensory and loves music. Her favourite thing to do is sing and dance and make lots of noise. She is an adorable little girl who is full of fun and often very silly. Daisy likes to be as independent as she can and doesn't like people touching her or interfering in her games.

Charlie is a very sweet little boy who loves books. He likes to be quiet and calm a lot of the time but he also loves to spin arounc and bounce. Charlie's favourite thing to do is go on a swing in the park. Charlie doesn't like load noises or new places.

Neither of the twins are able to communicate their needs or wants, which can lead to frustration and meltdowns. Neither can walk outside. Both get upset in new environments so it is difficult to go anywhere. Neither understand instructions or how to behave so meeting people and making friends is hard. Their behaviour can be inappropriate and they can get very upset. They can both be very anxious. Daisy has cerebral palsy and gets very tired out. Charlie has ASD and struggles daily. Neither can feed, wash, dress themselves or use the potty/toilet.

We are unable to cover the cost for many new items so the library was a great find. We received a lovely friendly service and we are able to borrow some really great stuff. It has made a big difference to be able to experience things like the fibre optic machine and mood egg with our children. I get excited when I know a package is being delivered. It's so nice to see my children in awe and mesmerised by the equipment".



Helping Sam to play with his siblings

Mum Emma explains how our **Toy and Book Library** has helped Sam to explore new toys and allowed him to spend special time playing with his brothers and sister.

"Our son Sam has Angelman Syndrome and needs assistance with all aspects of life.

Sensory toys are so expensive to buy and replace all the time as Sam can be quite rough with his toys. Getting free access to sensory toys is important for every disabled child and having the opportunity to borrow the toys has been invaluable for Sam and our whole family.

He loves to explore new toys and getting access to a variety of toys from the library helps us learn which are Sam's favourite ones to play with. He has shown great excitement and awareness when a Cerebra sensory toy box arrives. I would take the toys out in an organised fashion so Sam can enjoy the intensive interaction and anticipation involved with the individual toys.

I really love the opportunity to spend some quality 1:1 time with Sam. He is usually unable to sit still so trying to catch his attention is challenging. I've discovered with the help of a toy box loan he can relax and show a calm demeanor to enjoy sensory based lights, music and tactile activities.

Family life is busy and the toy box can give a central focus for the rest of the family to engage in play within Sam's world, as we explore the toys together. Sam loves having special time with his three siblings and we all look forward to seeing what we can borrow next.

Sam was very chilled out with the sensory in a suitcase! He got into his hanging tent and I was able to hand him UV tubes and spiky light up balls as he watched and smiled at the flashing lights and slow moving images in the background from the projector".



Rhys makes a splash

Teenager Rhys has a rare, progressive genetic condition which affects his extremities and his physical strength. His mum, Adele, contacted our Innovation Centre to see if they could come up with a plan to help Rhys enjoy the ocean.

The CIC team designed a wedge seat that mounts on top of a standard paddle board and allows Rhys to sit comfortably and unaided. Floats attached to either side of the board give an extra level of safety, ensuring that the paddle board is less likely to capsize.

Adele commented: "What I liked about the paddle board is that there is low risk of Rhys falling off it. As he can wear his hearing aids and glasses he's able to see the wildlife and have a better experience in the water. Getting out and about is so good for his health and wellbeing. Being able to go out on the board helps Rhys keep fit; it keeps his strength and maintains his physical and mental wellbeing.

I have always pushed Rhys a little bit as part of his condition means that he is likely to be deafblind when he's older and as his condition progresses he will be more nervous as things change. Being able to go out onto the sea and feel comfortable with it now, while his sight and hearing is fairly good, will mean that in the future it'll be a familiar space for him and he'll have the opportunity to stay active."

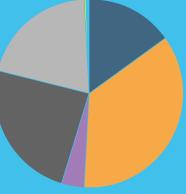
Here's what Rhys told us: "I really enjoyed paddle boarding. We saw jellyfish! We saw crabs! I enjoyed the paddling, it keeps me fit. I feel safe and comfortable on the board. I'd like to go paddle boarding again and I'd like to take my friends."



4. Together we are helping families who have a child with a brain condition to discover a better life. Thank you for joining us on our journey in 2023.

Number of individuals who supported our income streams in 2023:

Raffle	7,921
Lottery	18,748
Regular Gi	ving 2,007
Donation (Card 12,581
Gift Aid	10,641
Trusts & Fo	undations 26
Corporate	34
Legacies	67
Other	163
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If you would like a financial breakdown, please do contact us directly. You can also view our published accounts on the Charity Commission website.

How it helped:

Research Projects	38%
CIC	19%
Sleep	18%
☐ Support Services	11%
■ LEaP	7%
☐ Health & Wellbeing	7%



Support from a number of Trusts and Foundations and Corporate Grants has meant even more children are able to discover a better life with their families.

Thanks to:

Alpkit, Glasgow Credit Union, Nationwide, Hargreaves Foundation, Joseph Strong Frazer Trust, A M Pilkington Charitable Trust, Stuart Cormack Memorial Trust, Anthony Hart Charity Trust, Gillian Stevenson Charitable Trust, Souter Charitable Trust, Astor Foundation, Swansea Welsh Church Act Trust Fund, DWF Foundation, Patrick Trust, 1961 Charitable Trust, Broome Family Trust, JAZZ Apples, Gordon Fraser, WCVA, Hargreaves Foundation, Valero, Motability, Hospital Saturday Fund.

We are grateful for:

The financial support given by the following solicitors, who specialise in accident or clinical negligence cases relating to brain conditions or Court of Protection Deputyships and Personal Injury Trusts.

Over the past 12 months, these solicitors have provided support to a number of families Cerebra work with. They have also provided detailed and insightful articles and interviews across a wide range of topics, which are available to view on the News section of our website.

E Fletchers, Irvings Law, Bolt Burdon Kemp, CL Medilaw, Irwin Mitchell











Thanks to everyone who signed up to Team Cerebra this year.

You are all superheroes!

Team Cerebra took on the London Landmarks Half Marathon Our thanks go to: Aseel Hamoud, Darcie Jago, Victoria Fenech Buontempo, Caroline Baker, Charlotte Wailes, Kimberly Mendonca, Kate Hitchcock and Isaac Rayworth.

Caroline Baker told us: "I'm running for Cerebra as they have really helped my son and us as a family for years now. From loaning us a sensory suitcase, to adapting a fish tank, assisting with sleep via the sleep service and providing such useful resource booklets in general too.

So I wanted to give something back".

The Morello Marvels team raised £2,188 by taking part in a series of para-triathlons.

Our 10k Steps a Day in May fundraising challenge raised £640 and our Big Give Appeal raised £14,090. Thanks to everyone who took part.



- Join our 'Count Me In' lottery.
 It costs just £1,20 a week and gives you the chance to win £1,500 in our weekly draw.
- Buy some winning tickets for our summer and winter roffle draws.
- Leave a very special legacy by making a gift in your Will to Cerebro

We look forward to where the journey takes us next.
Why not join us?

Be a **fundraising superhero** and help families discover a better life together.

Just give us a call on 01267 240850 or visit www.cerebra.org.uk





Thank you for working wonders for children with brain conditions

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