

THE NATIONAL CENTRE FOR YOUNG PEOPLE WITH EPILEPSY CHARITABLE TRUST
Report and Financial Statements for the year ended 31 July 2024

**THE NATIONAL CENTRE FOR YOUNG PEOPLE WITH
EPILEPSY CHARITABLE TRUST**

Report and Financial
Statements Year Ended
31 July 2024

Registered charity number: 311877



THE NATIONAL CENTRE FOR YOUNG PEOPLE WITH EPILEPSY CHARITABLE TRUST

Report and Financial Statements for the year ended 31 July 2024

Contents

Message from the Chair	3
Chief Executive's review	5
We are Young Epilepsy	7
Our impact	10
Voice and Support	13
Health and Research	19
Specialist Education	25
Fundraising	33
Administrative Details	40
Structure, Governance and Management	42
Financial review	
– Income and expenditure	43
– Reserves	43
– Funding	44
– Risks	45
– Going concern	46
– Executives' pay increases	46
Statement of Trustees' responsibilities	47
Independent Auditor's Report	48
Financial Statements	
– Statement of Financial Activities	53
– Balance Sheet	54
– Statement of Cash Flows	55
– Notes to the Financial Statements	56

THE NATIONAL CENTRE FOR YOUNG PEOPLE WITH EPILEPSY CHARITABLE TRUST

Report and Financial Statements for the year ended 31 July 2024

Message from Markus H Ruetimann, Chair, Board of Trustees

The year ending July 2024 saw the beginnings of growth and recovery, after four tumultuous years during and after the pandemic. Our financial position has been strengthened with the land sale to Audley Group, the final proceeds from which are to be received in two instalments in the coming financial year, the first of which has been received prior to the approval of these financial statements

The increase in student numbers in St Piers School has been most encouraging. We were also delighted when Ofsted rated St Pier's College 'Outstanding' after its inspection earlier this year, following on from the 'Good' rating for the St Piers School last year. Our fundraising is growing and enabling us to continue to expand Young Epilepsy's national reach, including promoting young people's voice, support and our research partnerships. As we near the end of the current five-year strategic plan, it is refreshing to see how the charity has evolved, grown and adapted, proving its resilience and sustainability. Of course there is still much to do, and in early 2025 we will set out a new strategic plan for 2025–30.

We continue to ensure the voices of children and young people with epilepsy are at the heart of all we do. Through the Youth Voice Network across the UK, we are seeing young people's influence grow, shaping our policies and those of national institutions with whom we work, such as the NHS or the Education sector. Our petition this year #UndertsandMyEpilepsy attracted over 16,000 signatures and amplified the concerns many young people feel about being excluded in school because of their epilepsy.

Partnership working continues to enable us to excel and we have collaborated across the charity, research, health, technology, education and academic sectors, ensuring paediatric epilepsy is top of the agenda so that system change can happen.

It has been heartening to see staff recruitment and retention stabilise, especially in the education and care workforce this year, enabling us to accommodate more students. We strive to make Young Epilepsy the employer of choice by winning awards and gaining important accreditations. Our staff engagement surveys confirm that our culture, teamwork and employment policies have the desired positive effects.

THE NATIONAL CENTRE FOR YOUNG PEOPLE WITH EPILEPSY CHARITABLE TRUST


Report and Financial Statements for the year ended 31 July 2024

I would like to thank our Executive Leadership Team, every employee in this wonderful organisation, and my fellow Trustees for their support throughout the year. This year saw several trustees leaving us and new Trustees taking up the helm. Our sincere thanks go to Vivienne Dews, Keith Cameron, Dr. Julia Coop (who remains as a Governor), Claire Wood-Hill, Nick Bell, Katie Stevens, and Young Trustee Annie Davidson. I am delighted to welcome in our new Trustees Tom Hadley, Ash Tailor, Paola Morris, David Pierpoint, Maria Rodrigues and Tanya Moran. We are all looking forward to benefiting from the experience, insights and expertise over many years to come.

Our special thanks go to our former Chair, Jane Ramsey and to Simon Neville who was acting Chair until my arrival on 8 November 2024.

None of our achievements could have been possible without the support of our partners, funders, supporters, service users, students and their families. This enables our wonderful teams to help children and young people to overcome the challenges of epilepsy so that they can reach their potential.

Our heartfelt thanks go to you all.



Markus H Ruetimann

Chair, Board of Trustees

Chief Executive's review

Mark Devlin

The year showed Young Epilepsy further accelerating progress in our Voice and Support strategy. This has been achieved through growth in the size and influence of our fantastic Youth Voice Network ("YVN"), innovation in our research partnerships, and by increasing the national reach and impact of our support and information services, as well as our campaigning work for children and young people with epilepsy.

We continue to work with the NHS, education and charity partners to make sure that epilepsy does not become a barrier to children and young people having access to the support they need and to being fully included in society. The inclusion of epilepsy in NHS England's Core20PLUS5 children's health inequalities framework, as one of the five key childhood health conditions, is an important breakthrough in recognising epilepsy alongside other serious, chronic childhood conditions. We also collaborated with the Association for Young People's Health on an illuminating report into the experiences of young people with epilepsy from communities that experience marginalisation.

During 2023–24, I continued to co-chair the NHS England Epilepsy Oversight Group (EOG). It was great to see the four key priority areas included in a new NHS bundle of care for childhood epilepsy, which was published by NHS England in November 2023. There are also other reasons to be optimistic. As evidenced in the Epilepsy12 2024 report, published in July, the NHS bundle of care comes in addition to improved access to paediatricians with expertise in epilepsy and epilepsy specialist nurses, as well as improvements in care planning and Individual Healthcare Plans in schools.

However, too many children still wait too long for the right diagnostic tests and expert clinical support or care. In particular, mental health assessments for young people with epilepsy are still far from being available as widely as they should, despite the higher prevalence of mental health issues and strong feedback from young people on this lack of support. Our growing Youth Voice Network continues to work closely with the EOG and has been involved in the co-design of important pilots for mental health assessment in epilepsy services – putting their voices and lived experience right at the heart of the decision-making.

In Spring 2024, we launched a petition called **#UndertsandMyEpilepsy** with the aim of drawing attention to the need for Individual Healthcare Plans for every child with epilepsy. We gathered 16,163 signatures and have delivered the petition to the Secretary of State and Ministers for Education in each of the four UK nations. The

THE NATIONAL CENTRE FOR YOUNG PEOPLE WITH EPILEPSY CHARITABLE TRUST

Report and Financial Statements for the year ended 31 July 2024

Chief Executive's review (continued)

campaign calls on teachers and the Department for Education to make sure all children with epilepsy have an Individual Healthcare Plan in school.

St Piers special education campus in Lingfield, Surrey, has had a hugely successful year. Between the summer of 2023 and early Spring 2024, we had three Ofsted inspections with one Outstanding and two strong Good results across our College and Residential Special School. The Outstanding rating of St Piers Special Further Education College makes it one of only a handful of such highly rated settings for young people with special educational needs in the UK.

This year also saw our first pre-school intake at St Piers. Building work is well underway to develop a purpose-built facility which opened at the end of 2024. This development, coupled with the growing reputation of St Piers, has led to record numbers of admissions for the coming year.

Our long-awaited site development plans move closer to reality, with site works anticipated before the end of 2025. We have exchanged and completed contracts with our development partners, Audley Group.

Our **Research** partnership work continued to grow under the leadership of Professor Helen Cross, Prince of Wales's Chair of Childhood Epilepsy, in partnership with Great Ormond Street Charity and the UCL Great Ormond Street Institute of Child Health. We held the 14th annual Research Retreat in January and a joint research symposium with the newly established Epilepsy Research Institute UK (ERIUK) at the Francis Crick Institute in May. Young Epilepsy is one of four founding partner charities in the creation of ERIUK.

This year we said goodbye to our Chair, Jane Ramsey, who has led the Board of Trustees for the last eight years. We congratulate her for her elevation to the House of Lords as Baroness Ramsey of Wall Heath and thank her for her strong and continued support for children and young people with epilepsy.

We also said goodbye to Rosemarie Pardington, Director of Health and Research/Deputy CEO after seven years in post. Rosemarie has become the CEO of ERIUK. We wish her and the new Institute well and look forward to working with colleagues in Young Epilepsy's capacity as a founding partner of the Institute, which aims to raise the profile of, and investment into, epilepsy research.



Mark Devlin

Chief Executive

We are Young Epilepsy

Epilepsy can be one of the most frightening and isolating conditions a young person can experience; the loss of any sense of safety, living in an unpredictable world and not knowing when their next seizure will happen.

Around 100,000 children and young people aged 25 and under have epilepsy in the UK. For them, life can be very different from that of other young people around them. It can take its toll on their physical and mental health, as well as impacting their education and social life.

Many children with epilepsy are missing out. We can change that and create a society in which all children and young people with epilepsy can thrive and live happy, fulfilled lives.

Our vision

Together, we can create a society where children and young people with epilepsy are heard and can live happy, fulfilled lives.

Our values

Young people at the centre of everything we do

We work together to make a greater difference

We are courageous and ambitious for change

Our programmes

Our programmes aim to create a society where children and young people with epilepsy are heard and can live happy fulfilled lives.

THE NATIONAL CENTRE FOR YOUNG PEOPLE WITH EPILEPSY CHARITABLE TRUST

Report and Financial Statements for the year ended 31 July 2024

We are Young Epilepsy (continued)

Voice and Support

Children with epilepsy have a right to be heard. We stand with them.

With children and young people at the centre of all we do, we are pushing the boundaries to ensure the voices of children and young people with epilepsy are heard, their voices respected and their ambitions realised.

We provide trusted, reliable and accessible information about living with epilepsy. We work holistically with children and young people with epilepsy, their families, health and social care teams, and their school or college, to create a supportive environment for them to thrive and reach their potential.

Health and Research

Children's epilepsies can be complex and the condition is often misunderstood. We deliver cutting-edge health services and coordinate vital research needed to ensure early and accurate diagnosis, better treatments and better support for living with the condition.

Our Health Centre in Surrey offers diagnostic and assessment services for children with epilepsy and other neurological conditions. Set in beautiful grounds and with modern, comfortable and accessible facilities, we support children, young people and their families in a 'home from home' environment.

Childhood epilepsy needs more research. Only by understanding the condition can we help secure the best outcomes for the child. Our work is shaped by the views of children and young people with epilepsy and by working collaboratively with our world-leading clinical research partnership.

Specialist Education

Every young person should have opportunities to develop their skills, gain new knowledge and get the most out of their education in an inclusive and positive environment, no matter what their learning, health or medical needs.

St Piers is our innovative and creative Special Residential School and College for children and young people with special educational needs and disabilities. Our approach is simple: we believe learning is about so much

THE NATIONAL CENTRE FOR YOUNG PEOPLE WITH EPILEPSY CHARITABLE TRUST

Report and Financial Statements for the year ended 31 July 2024

We are Young Epilepsy (continued)

more than classroom study. It is a nurturing journey of discovery in which students grow as individuals, find their independence and explore their capacity to live their lives to the full.

Our people

In July 2024, we had 573 staff across the organisation, with 443 working for St Piers and 130 for Young Epilepsy. Our equity, diversity and inclusion (EDI) focus continued through the year.

The SHINE team has grown to 12 members and we launched the SHINE newsletter, of which five editions have now been published. We moved the SHINE Hub to the Intranet, adding more content and redesigning it to make it more accessible. We created a SHINE 'calendar of events', which includes Mental Health Awareness Week, Time to Talk Day, LGBTQ+ History Month, Stress Awareness Month and Pride.

We launched our LGBTQ+ Employee Network and commenced menopause in the workplace training, with 31 managers now trained. We won the Best Engagement Approach Award at the industry-recognised 2024 Menopause Friendly Employer Awards.

We also opened a contemplation/multi-faith space on the Lingfield campus.

In September 2022, at Young Epilepsy, we introduced Employer Net Promoter Score (eNPS), which is a way of measuring of how happy employees are at work. It asks one simple question: **How would you rate your happiness at work?**

We've asked that question three times per year since and are proud to report that our scores have increased from -40 (155 responses) to +18 (290 responses), giving a clear indication that more staff are responding and are feeling happier at work.

Our impact

Voice and Support

Youth Voice Network

166 members

+69% year on year

16,163

signatures for our petition calling for every child with epilepsy to have an Individual Healthcare Plan for school so they get the support they need.

Young people and families we've directly supported through the year

468 children and young people with epilepsy, and their families, through our support services

93% of young people feel more positive because of the help they have received, including:

- **96** who had 1-2-1 support
- **65** at face-to-face meetups
- **29** at virtual support groups
- **76** at Virtual Youth Clubs
- **145** signposted elsewhere for support

15,000

visits to the Online Guide for Schools

700 people **engaged in our** e-learning

90% of those completed feedback, saying their knowledge and understanding of epilepsy and their confidence in supporting a child with epilepsy had increased

THE NATIONAL CENTRE FOR YOUNG PEOPLE WITH EPILEPSY CHARITABLE TRUST

Report and Financial Statements for the year ended 31 July 2024

Our Impact (continued)

Health and Research

420

diagnostic sessions

93

patient carer feedback score – surpassing exemplary benchmark of 58

45

active research projects

830+

attendees at events and webinars

Specialist Education

85 School students

90.5% attendance

102 College students

94% attendance

Community

Facebook

23,401 followers

+6% increase year on year

Instagram

11,284 followers

+28.7% increase year on year

TikTok

1282

+187% increase year on year

17,937

Supporters with email opt in

+69% increase year-on-year

THE NATIONAL CENTRE FOR YOUNG PEOPLE WITH EPILEPSY CHARITABLE TRUST

Report and Financial Statements for the year ended 31 July 2024

Our Impact (continued)

People

85% of our workforce +12months of service

17% of our workforce is made up of people of the global majority

Brand profile

Since relaunching the Young Epilepsy brand and establishing a PR function, our profile-raising focus has yielded strong results.

We worked with the BBC to produce a short film to be aired on The One Show. Our priority for this exposure was to spotlight on a national stage three young people's experiences as part of the #UnderstandMyEpilepsy campaign.

In year two of our relationship with the Carfest Festival we leveraged the connection to support Purple Day efforts, pulling in coverage and generating social buzz.

Aligning Carfest's Do More Good Week to ensure Young Epilepsy was mentioned on Purple Day saw us get coverage on their social media channels and on the Virgin Radio breakfast show. Plus, we also achieved a collaborative social media post with Chris Evans.

We also saw significant growth as part of our relationship building with ex-premier league footballer, Jay Bothroyd. An interview we arranged for him last year, published in the MailOnline, was picked up by other significant regional titles.

THE NATIONAL CENTRE FOR YOUNG PEOPLE WITH EPILEPSY CHARITABLE TRUST

Report and Financial Statements for the year ended 31 July 2024

Voice and Support

In 2023/2024, we reshaped the Voice and Support team to strengthen our product offer and services in this area. The team now comprises two pillars: 'Voice, policy and influencing' and 'Support and inclusion'.

With input from the YVN, we developed a **Theory of Change** to support our Voice and Support ambition. This is helping us to streamline and focus our work, so that the outcomes for children and young people with epilepsy are improved in three key areas:

- Feeling more informed and confident
- Improved emotional wellbeing
- Feeling more included in learning and play

Support and inclusion

Our Virtual Youth Clubs started in November 2023 and have been a huge success. We have connected 76 young people to others with epilepsy from all over the UK. We run two monthly groups, one for those aged 10–12 and another for those aged 13+. The Virtual Youth Clubs are designed to help build self-esteem and confidence, and create a space where young people can grow, learn and shine. Attendees have said that the Virtual Youth Clubs give them an improved sense of community and help them to feel their epilepsy is understood.

We've improved the way young people can access our support this year. In January 2024, we introduced a digital referral process on our website, making referrals accessible for young people and parents, as well as professionals. We saw a 50% increase in the number of referrals coming through in six months compared to the same period in 2023. In total, our support services have directly supported 468 children and young people with epilepsy, and their families.

We also introduced a new case management system to help us track and manage our services. It enables us to identify areas we should focus on, where additional support may be needed. The system links with our assessment tool, which measures the impact of the support being delivered. Of the young people who used the system, 93% reported feeling more positive because of the help they received.

THE NATIONAL CENTRE FOR YOUNG PEOPLE WITH EPILEPSY CHARITABLE TRUST

Report and Financial Statements for the year ended 31 July 2024

Voice and Support (continued)

We're building on our partnership working to increase the awareness and reach of our services across England. We ran five family meetup events in different regions and attended the Epilepsy Specialist Nurse Association conference.

Our pilot of the digital self-management tool, My Epilepsy, came to an end this year. Taking what we learned from this project, we partnered with Tiny Medical Apps to develop an epilepsy section within their Digital Health Passport App.

Our role in the collaboration was to include young people living with epilepsy and their families in the co-design of the app. We recruited young people for 12 workshops with 88 participants, comprising 49 young people, 34 parents and 5 care workers.

Our online resource, a Guide for Schools, is still supporting teachers across the country. It was accessed more than 15,000 times.

More than 700 people have engaged in our two eLearning courses for education professionals this year. Of those completing the feedback section, 90% said their knowledge and understanding around epilepsy had increased since doing the training. The same number also said they also felt more confident about supporting young people with epilepsy.

Voice, policy and influencing

In October, we launched our #UnderstandMyEpilepsy campaign, standing shoulder to shoulder with young people living with epilepsy across the UK to tackle the issue of inclusion.

We know children and young people are often unnecessarily excluded from events in their life, through a lack of understanding of their condition.

The campaign highlighted the shocking fact that one in three children with epilepsy are not getting the support they need to participate fully at school. Seizures are missed or mistaken for 'not paying attention', school staff don't know what to do when a seizure happens, and children are unnecessarily excluded from learning, sports and trips.

THE NATIONAL CENTRE FOR YOUNG PEOPLE WITH EPILEPSY CHARITABLE TRUST

Report and Financial Statements for the year ended 31 July 2024

Voice and Support (continued)

So, we launched a petition calling for every child with epilepsy to have an Individual Healthcare Plan for school so they get the support they need.

The campaign attracted 16,163 signatures from across the UK.

At Young Epilepsy we are committed to producing high-quality health information. This means providing health information that is based on the latest evidence, involves and meets the needs of children and young people with epilepsy, and is accessible and easy to understand. As part of our commitment, we set the goal to attain the Patient Information Forum (PIF) TICK accreditation and were successfully certified under the scheme in May 2024.

In the context of the approaching general election in 2024, we supported the Children at the Table campaign alongside colleagues in the children's sector, asking the future UK government to:

- Make sure politicians across government work together to improve the lives of babies, children and young people
- Put children's needs and voices at the heart of decision-making
- Invest more of the nation's wealth in babies, children and young people

International Youth Summit, Dublin

In September 2023, six YVN members attended the first Youth Summit at the 35th International Epilepsy Congress in Dublin. They met with 30 young people from more than 10 countries, which led to a report highlighting a range of experiences covering mental health, stigma, employment and self-care.

Bundle of care implementation

In October 2023, NHS England launched the national bundle of care for children and young people with epilepsy, with recommendations influenced by members of the YVN. The bundle highlights their lived experiences through direct quotes.

Throughout the year, we have worked regionally to ensure young people's voices are central to the implementation of these recommendations. Here are some ways the YVN has contributed:

THE NATIONAL CENTRE FOR YOUNG PEOPLE WITH EPILEPSY CHARITABLE TRUST

Report and Financial Statements for the year ended 31 July 2024

Voice and Support (continued)

- **Resource co-production:** YVN members worked to develop informational resources on a range of topics.
- **Service design influencing:** YVN members met with a range of NHS professionals at a regional level to share their experiences and views.
- **Collaboration with the Association of Young People's Health (AYPH):** In October 2023, in partnership with AYPH, the Understanding the experiences of young people with epilepsy from communities that experience marginalisation report was released. It includes YVN members' shared experiences and sets out children and young people's recommendations for improving care, education and support.
- **Acceptance and Commitment Therapy (ACT) co-production:** ACT is a therapeutic intervention for mental health support. We are working with NHSE in the Southwest of England to co-create group resources for young people with epilepsy facing mental health challenges. We are evaluating the impact of the intervention with the hope of testing this new model and seeing it replicated across other NHS regions. As part of the ACT Mental Health Project, YVN members have co-produced systems, resources and therapeutic sessions. They have also produced and starred in a series of short films sharing their experiences, which will be shown during the therapy sessions.
- **Young Epilepsy Loud in London (YELL):** With funding from The City Bridge Foundation, we've launched YELL, a new project aimed at improving confidence, leadership and communication skills in young people with epilepsy living in London. The project also seeks to influence healthcare and education leaders in the city to improve the experiences of young people with epilepsy.
- **FLARE:** We've continued our involvement in the Council for Disabled Children and the Department for Education's FLARE project. By sharing the views and experiences of YVN members with the Department for Education and other organisations, FLARE aims to help them understand how young people want to receive the education and support they need.
- **Hear By Rights Flagship Status:** The National Youth Agency's Hear by Right accreditation scheme the award, which we received last year, recognises best practice and supports organisations to plan, develop and evaluate their participation practices and provision. Inspired by Article 12 from the United Nations Convention on the Rights of the Child, the scheme fosters a culture of development, a continual journey that keeps young people at the heart of decision-making.

THE NATIONAL CENTRE FOR YOUNG PEOPLE WITH EPILEPSY CHARITABLE TRUST

Report and Financial Statements for the year ended 31 July 2024

Voice and Support (continued)

Looking ahead

In 2025, we will be developing a **monitoring and evaluation framework**, based on our **Theory of Change** and in support of our **Outcome Goals**. This will help us to better understand and report on our reach, impact and improved outcomes for the young people we support.

Through the voice of children and young people with epilepsy, we raise awareness of the issues they face and develop support for them and their immediate support network*, helping them to live ambitious and fulfilled lives.

Why we exist:	What we do:	How we do it:	Our desired outcomes:	Our desired impact:
Children and young people with epilepsy don't have access to the right information to understand and manage their life with epilepsy	Campaign and amplify the voices of children and young people with epilepsy	Creating a safe space where children and young people with epilepsy feel heard	Children and young people with epilepsy – and their immediate support network – feel more informed and confident about navigating their life with epilepsy	Children and young people with epilepsy can live ambitious and fulfilled lives
Living with epilepsy has a significant impact on children and young people's emotional wellbeing	Develop and share trusted information for children and young people with epilepsy and their immediate support network	Enabling children and young people with epilepsy – and their immediate support network – to bring about change	Children and young people with epilepsy have improved emotional wellbeing	Awareness and understanding of epilepsy in society is improved and increased
Children and young people with epilepsy are not getting the support they need to participate fully in learning and play	Provide direct support to children and young people with epilepsy who are struggling	Connecting the experiences of children and young people with epilepsy	Children and young people with epilepsy feel more included in learning and play	
	Create strong partnerships to increase our impact			

* immediate support network - parents/carers, education professionals, youth workers etc - with child/young person in mind.



Based on feedback from those attending our Virtual Youth Clubs, we will launch a new **Chat About Your Epilepsy** group later in 2024. The group gives young people the opportunity to ask questions and share their experiences in a safe space, leaving our youth clubs as a place to have fun.

Every child has the right to education and play, so we will be going through a discovery process, with young people and secondary school professionals helping us develop new and improved tools and resources to ensure all young people with epilepsy enjoy that right.

This will then lead to a longer-term **Inclusion Strategy** to be ready for 2025.

We will **expand our YVN**, developing this community of young people with epilepsy across the UK in the coming year. The launch of our YVN Roadshow events will foster community relationships and amplify the voices of children and young people with epilepsy on key issues, such as improving healthcare and education.

THE NATIONAL CENTRE FOR YOUNG PEOPLE WITH EPILEPSY CHARITABLE TRUST

Report and Financial Statements for the year ended 31 July 2024

Voice and Support (continued)

Each event will feature a variety of engaging activities and include guest speakers from healthcare, education and other relevant sectors. Each event will feature a variety of engaging activities and include guest speakers from healthcare, education and other relevant sectors.

We will be supporting young people to **deliver the #UnderstandMyEpilepsy** petition to education ministers across the UK. We'll also be enabling our supporters to message their elected representatives to show why this issue matters to their constituents.

Over the next year we will be growing the information we provide with the PIF TICK mark, with an initial focus on children and young people's seizures and diagnosis. We are also aiming to develop new **resources for younger children** and those at the beginning of their epilepsy journey.

Health and Research

Health services

In 2023–24, we continued to work with a variety of partners to provide direct health services, training and advice to improve outcomes for children and young people with epilepsy.

Diagnostic electroencephalogram (EEG) service

Over the past year, the EEG service has experienced a 5% increase in patient numbers compared to the prior year, a significant growth despite a reduction in workforce capacity.

A total of 420 investigations were conducted. Notably, 10% of these investigations benefited from the newly acquired home video-telemetry systems that were introduced to the service this year.

Three new service level agreement contracts have been secured across the NHS and the private sector.

A Net Promoter Score (NPS) is a metric used to gauge the loyalty and satisfaction in any industry including healthcare. We use this as a measure to see how loyal and satisfied our patients/carers are following the EEG diagnostic test.

During the year, patient and carer feedback has been outstanding, with a Net Promoter Score of 93. This exceptional score reflects high levels of satisfaction and loyalty.

In most industries, a Net Promoter Score above 50 is considered excellent, and above 70 is exceptional. A score of 93 is rare and signifies that we are performing at the highest level compared to peers.

Epilepsy nursing service

Our health service focus is to deliver the best person-centred care available to students at St Piers School and College, as well as to patients attending our clinics. We also offer external training to professionals and clinicians.

We were delighted to be recognised for the quality of service we provide when the St Piers nursing team were nominated in the **Surrey Care Association Awards** for innovation in workforce, recruitment and retention. The team made it as finalists in this prestigious local award.



THE NATIONAL CENTRE FOR YOUNG PEOPLE WITH EPILEPSY CHARITABLE TRUST

Report and Financial Statements for the year ended 31 July 2024

Health and Research (continued)

We supported the Roald Dahl's Marvellous Children's Charity by hosting an **educational day for their epilepsy nurse specialists**. Speakers came together to discuss hot topics such as EEG classifications, sudden unexpected death in epilepsy (SUDEP) and current changes within prescribing anti-seizure medications.

Young Epilepsy's Epilepsy Nurse Consultant attended the National Conference of The Romanian Society Against Epilepsy. She spoke to more than 80 epilepsy nurses on the importance of their role and how to match standards with the UK for education and training opportunities.

We attended the 35th International Epilepsy Congress in Dublin and the British Paediatric Neurology Association's Annual Conference in Bristol, where we had a stand showcasing our charity and the services we offer.

Looking ahead

Starting in November 2024, we'll continue working with the Roald Dahl Marvellous Children's Charity to deliver regular EEG teaching to their national team of epilepsy nurses.

Research

Our research programme exists to ensure the best outcome for every child by optimising diagnosis, treatment and support for all aspects of childhood epilepsy.

Led by the Prince of Wales's Chair of Childhood Epilepsy, Professor Helen Cross, our main research programme is a collaborative partnership with Great Ormond Street Hospital and the UCL Great Ormond Street Institute of Child Health. Over the past 14 years, this programme has grown significantly, with 31 leading researchers supervising 21 PhD students and collaborating with 43 international experts.

Health and Research (continued)

Together, they are working on 45 active projects to:

Goal 01: Gain a better understanding of the medical causes of epilepsy.

Goal 02: Gain a better understanding of how epilepsy affects development and behaviour.

Goal 03: Improve diagnosis and treatment to determine the benefits of early intervention in improving long-term outcomes.

Goal 04: Gain a better understanding of barriers to learning and determining the benefits of educational interventions.

Goal 05: Make life better for children and families and make support systems more effective.

Goal 06: Develop a network of multidisciplinary professionals to strengthen our research and shape the education of future practitioners.

Exciting milestones

Our research has made huge strides in the past year, with several key projects progressing significantly.

The Turning Six Project, which began recruiting in November 2023, is following children who developed epilepsy in their first year of life. We previously assessed these children as babies, tracking their global development, sleep and family wellbeing. Now, as they reach six years old, we're conducting comprehensive psychological assessments to better understand how early-onset epilepsy affects long-term neurodevelopment. This research will provide vital insights for improving prognosis and treatment for children and young people with epilepsy in the future.

The GENE-STEPS project, which is investigating the impact of a rapid genetic diagnosis in babies with early-onset epilepsy, published exciting findings from the first 100 participants. Remarkably, 43% received a diagnosis within weeks and in nearly 90% of these cases this guided treatment decisions and improved outcomes.

The Mental Health Intervention in Childhood Epilepsy (MICE) project has also concluded, demonstrating the success of a psychological intervention that addresses the common mental health challenges faced by young people with epilepsy. This intervention is already showing a meaningful impact on the lives of young people and their families.

THE NATIONAL CENTRE FOR YOUNG PEOPLE WITH EPILEPSY CHARITABLE TRUST

Report and Financial Statements for the year ended 31 July 2024

Health and Research (continued)

We have also seen real progress in the optically pumped magnetoencephalography (OPM-MEG) diagnostic suite, which began recruiting in early 2024. The OPM-MEG enables us to scan tiny magnetic fields in the brain, which helps us to locate where the epileptic seizures may be coming from. By comparing OPM-MEG to traditional techniques, we aim to demonstrate the effectiveness of this technique, revolutionising diagnosis and treatment for children with epilepsy.

Expanding our reach and impact

The diversity of our research portfolio serves to demonstrate our commitment to encouraging work in all areas of epilepsy research. Whilst we continue to conduct research into understanding and treating epilepsy, we recognise the importance of providing outstanding support through educational, psychosocial and service-based approaches.

Our growing list of partnerships enables us to tackle the challenges faced by those affected by epilepsy from every angle. Over the past year, we have formed new collaborations with health technology innovators and worked closely with NHS divisions on groundbreaking mental health pilots.

For example, we have worked in partnership with Surrey Heartlands ICB, on their **PAVES Pilot**, aimed at integrating psychological services directly into children and young people's epilepsy clinics. This integrated approach aims to ensure that the emotional and psychological wellbeing of young people with epilepsy is treated with the same urgency as their physical health.

We have also collaborated with the **South Paediatric Neurosciences Operational Delivery Network** to develop an Acceptance and Commitment Therapy (ACT) **group**. ACT is a therapeutic intervention for mental health support. We are working with NHSE in the Southwest of England to co-create group resources for young people with epilepsy facing mental health challenges before more serious difficulties emerge, equipping them with the tools to manage both their mental health and epilepsy.

Health and Research (continued)

Patient Voice

We are dedicated to making sure that all our research addresses the real needs of young people with epilepsy and their families. To achieve this, we actively involve them in shaping every project from start to finish. Our growing E-CURE Network, now made up of more than 160 parents and caregivers, plays a key role in guiding our research. Alongside the Youth Voice Network, their ongoing input ensures that our work directly benefits the children and families we support.

Sharing our findings

Throughout the year, we have hosted several events to share our latest findings and inspire future breakthroughs.

In January 2024, we held our Annual Research Retreat, where nearly 100 leading experts in epilepsy research and healthcare came together to exchange ideas and inspire the next generation of projects.

In April 2024, we hosted the Ketogenic Diet in Children with Epilepsy (KIWE) Webinar, attracting almost 500 attendees. Professor Helen Cross shared the fascinating history of the ketogenic diet in paediatric epilepsy, while Dr Natasha Schoeler and parent Rai Royal presented project findings and real-life experiences, making this an insightful and impactful event for everyone involved.

In May 2024, we co-hosted a Joint Research Event with the Epilepsy Research Institute at the prestigious Francis Crick Institute. More than 150 attendees heard inspiring talks on topics such as building community within the epilepsy world and supporting mental health in children and young people. As a founding member of the Epilepsy Research Institute, we were also thrilled to hear about attendees' exciting advancements, which promise to rapidly advance research into epilepsy.

This event showcased the importance of ongoing collaboration between charities, beneficiaries and supporters in driving change and making a real difference to the lives of those affected by epilepsy.

THE NATIONAL CENTRE FOR YOUNG PEOPLE WITH EPILEPSY CHARITABLE TRUST

Report and Financial Statements for the year ended 31 July 2024

Health and Research (continued)

Looking ahead

As our research programme continues to grow, we are excited about the milestones ahead in the coming year.

The **Turning Six Project** will reach its conclusion, and we will publish the much-anticipated findings.

Our **OPM-MEG Diagnostic Suite** will continue to expand, with plans to add even more recruitment sites and extend our collaborations with Aston University. This partnership will allow us to compare directly traditional MEG scans with the innovative OPM-MEG technology. The findings from this work will be critical in determining how OPM-MEG can improve upon the current clinical pathway for diagnosing and treating epilepsy.

We are also planning to expand our **Acceptance and Commitment Therapy (ACT) intervention groups** to offer specialised support for parents of children with epilepsy, alongside a series of self-help resources designed to provide ongoing support for families facing mental health challenges related to epilepsy.

Our new **Introductory Member status** with the Association of Medical research Charities will grant us access to invaluable expertise, resources and opportunities for shared learning. Through networking and collaboration with other members, we aim to strengthen our partnerships and expand the reach of our research. By continuing to foster collaborations with academia, healthcare providers and community stakeholders, we remain committed to advancing our mission of ensuring the best outcome for every child by optimising diagnosis, treatment and support for all aspects of childhood epilepsy.

Specialist Education

St Piers School

The 2023–24 academic year marked a pivotal period for St Piers School, driven by a comprehensive leadership redesign that built on previous structural changes. This transformation, alongside changes in leadership across various departments, has significantly enhanced collaboration within the school.

The curriculum has benefited from the specialised contributions of the school’s medical and therapeutic teams, ensuring that every student thrives in a safe, tailored and aspirational learning environment.

This year, the School engaged a new educational consultant with expertise in Special Educational Needs and Disabilities (SEND), complementing our ongoing efforts with external consultants and local authority monitoring.

This continual external oversight allows the school to refine its curriculum, enriching the educational experience with a broader range of learning pathways, accredited courses and community-based learning opportunities. As a result, students are presented with an enhanced academic environment that fosters personal growth and improved outcomes.

Following the 2022–23 Ofsted inspection, St Piers developed an action plan to advance its behaviour management strategies. This included the introduction of a new monitoring system and the appointment of a pastoral manager. Programmes such as the Zones of Regulation and Thrive, and the addition of an Emotional Literacy Support Assistant, have been integrated with PRICE behaviour training, creating a more comprehensive approach to student well-being and emotional support.

The School has also expanded its student body in the 2023–24 academic year, growing from 75 to 101 students in September 2024. This growth is supported by an updated Department for Education registration, which grants a Pupil Admission Number (PAN) of 110 and extends the starting age to four years. The School can now offer education across all key stages.

We’ve also introduced several key initiatives this year to enhance learning. We’ve expanded the use of augmentative and alternative communication alongside the total communication approach, ensuring all students have access to effective communication tools. Additionally, a new assessment system has been implemented, improving the evaluation of student progress.

THE NATIONAL CENTRE FOR YOUNG PEOPLE WITH EPILEPSY CHARITABLE TRUST

Report and Financial Statements for the year ended 31 July 2024

Specialist Education (continued)

St Piers School has also bolstered its sixth-form provision, with the development of the life skills bungalow into a dedicated centre offering unique opportunities such as a student-run sweet shop, small animal care and a podcast radio station. For the first time, a group of students is attending external vocational courses, and two students are preparing to sit GCSE exams in Maths and Physical Education.

St Piers College

The past year at St Piers College has been a remarkable year, one of excellence and innovation, marked by the exceptional achievements of both the students and staff.

The hard work and dedication of the entire College community culminated in an 'Outstanding' rating from Ofsted in March 2024. The College received top marks across all categories: Quality of Education, Learning for High Needs, Behaviour and Attitudes, Personal Development, Leadership and Management, and Overall Effectiveness.

The College is not resting on its laurels. St Piers remains committed to excellence in teaching, learning and professional development. Staff members have undertaken continuous training to enhance their expertise in areas such as ICT, communication, mental health awareness, bereavement, autism, animal therapy, quality assurance and functional skills.

Their commitment to learning also extends beyond the College, as they have shared their knowledge through training at other specialist institutions and engaged with conferences focused on 'SEND, TechAbility and Employability'.

The professional development undertaken by staff is evident in the College's curriculum, which is tailored to meet the diverse needs of students. Ofsted highlighted the fact that students frequently exceed their expected outcomes, praising their positive attitudes and strong motivation to achieve their ambitions. The high levels of support from staff enable students to surpass both academic and personal targets.

St Piers College also promotes student empowerment through its **Student Voice Group**, which plays a significant role in the wider community, supporting causes related to autism and epilepsy. The group was instrumental in hosting the Natspec College National Parliament, where they shared their insights on inclusion

Specialist Education (continued)

and accessibility. Ofsted praised the students' outstanding behaviour, noting the positive impact of staff expectations on their conduct and learning.

The Personal and Social Development (PSD) and enrichment programme at St Piers plays a crucial role in fostering students' physical and mental health while allowing them to explore future interests. The College's personal development and wellbeing curriculum, praised by Ofsted, offers a broad range of community-based activities that foster inclusion and skill development.

The College's enrichment and events programme promotes British values and offers students diverse learning opportunities. Celebrations such as the King's Coronation, the Student Ball and Wear It Pink Day foster a sense of community, while events like Black History Month and PRIDE enhance cultural awareness. These activities help build resilience, confidence and independence, contributing to a greater appreciation of diversity.

Students also have access to activities ranging from animal encounters to ceramics, cake decorating, as well as mainstream college courses in catering and multi-skills.

Vocational studies are a major highlight, with students engaging in subjects such as horticulture, textiles, sport, drama and personal care. Work experience placements, matched to students' abilities and aspirations, have been established with local businesses such as Costa Coffee, East Surrey Hospital and Godstone Farm. The College's Enterprise Project has further strengthened work-related learning, achieving a 100% Gatsby benchmark score and Quality in Careers Standard Accreditation.

Summing up St Piers College, Ofsted stated: "Students feel safe and thrive because the college is a harmonious nurturing, inclusive and exciting place to learn." Looking ahead, St Piers College is determined to build on its success and continue striving towards becoming a National Centre of Excellence.

Specialist Education (continued)

Residential placements at St Piers

Residential placements at St Piers provide an extended-day, 24-hour curriculum designed for children and young people with complex needs, such as learning difficulties, epilepsy and autism. It extends learning beyond traditional school and college hours, providing educational opportunities throughout the day, both in structured and unstructured settings. This approach helps children and young people manage different environments and routines where they can apply their skills contextually.

Key features

Holistic Learning: Integrates learning across home, community, residential, and educational settings, ensuring skills are transferable.

1. **Functional skills:** Focuses on practical, everyday skills such as self-care, communication and vocational abilities.
2. **Person-centred approach:** Tailors learning to individual needs, involving families and caregivers.
3. **Collaborative learning:** Promotes teamwork between residential, education and therapy staff, along with families.
4. **Natural learning:** Uses real-world tasks to promote skills acquisition and generalisation, of tasks that can be applied broadly across different situations.
5. **Continuous assessment:** Regular feedback and assessments allow for adjustments based on progress and changing needs.

Benefits

The curriculum provides several advantages for children and young people with complex needs:

- **Holistic development:** Encourages development across cognitive, social, emotional and physical areas.
- **Real-world application:** Skills are taught in practical, everyday contexts such as shopping, social interactions and decision-making, all of which maintains community inclusion.
- **Increased engagement:** Learning happens in varied environments, such as parks, supermarkets and community centres, keeping students motivated.
- **Individualised learning:** Activities are personalised to each child and young person, fostering a love of learning outside the classroom.

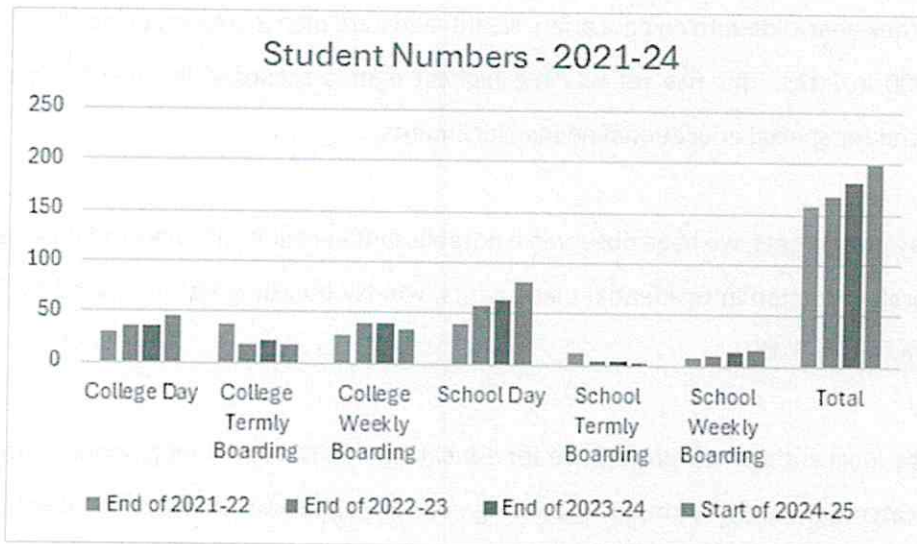
THE NATIONAL CENTRE FOR YOUNG PEOPLE WITH EPILEPSY CHARITABLE TRUST

Report and Financial Statements for the year ended 31 July 2024

Specialist Education (continued)

- **Independence:** Focuses on life skills such as cooking and navigating public transport to build independence and prepare for life after school or college.
- **Collaboration:** Working together to develop programmes that interest students and motivate them to achieve the best possible outcomes.
- **Ongoing adaptability:** Continuous assessment ensures a personalised programme adapts to students' needs.
- **Community integration:** Participation in local activities helps develop social skills and relationships.

Student numbers



Specialist Education (continued)

Meeting increased demand for Reception places and shifts in boarding patterns

The opening of a new infant school has been pivotal in addressing the growing demand for Reception places, contributing significantly to our growth in both the 2023–24 academic year and the upcoming 2024–25 period.

As demand for Reception places continues to rise, the *Times Educational Supplement* highlighted in June 2023 the “urgent need” for funding nursery schools to provide specialist Reception places due to a shortage of suitable special-school or primary school options. This trend reflects a growing strain on educational resources.

Further underscoring this need, in July 2023, the National Association for Special Educational Needs reported that the number of three and four-year-olds with an Education, Health and Care plan increased by nearly a third, from 11,600 in 2020 to 15,400 in 2023. This rise reflects the highest figures recorded in recent years and highlights the increased demand for special educational needs placements.

In addition to the growth in day placements, we have observed a notable shift in residential placement patterns. While there has been an overall reduction in residential placements, weekly boarding has increased by 34%, and termly boarding has decreased by 70%.

This change is largely driven by local authorities’ preference for educating children and young people closer to home, resulting in a smaller catchment area. With students living near enough to return home on weekends, weekly boarding presents a cost-effective solution for local authorities compared to termly boarding.

We fully support the principle of educating young people close to home, allowing them to maintain vital connections with their families and communities. As part of this approach, we have decided to discontinue offering termly boarding for children and young people under 18. This further reduces the number of termly placements in keeping with our commitment to family and community links.

THE NATIONAL CENTRE FOR YOUNG PEOPLE WITH EPILEPSY CHARITABLE TRUST

Report and Financial Statements for the year ended 31 July 2024

Specialist Education (continued)

St Piers Farm Experience update

Enhancing student learning and development

New to St Piers Farm family is the lovely fox-red labrador, Merlot, a therapy dog who joined St Piers in the spring of 2024 thanks to a donation from the National Farmers Union. His gentle nature provides emotional support, particularly benefiting students with special educational needs.

Spud, the farm goat, arrived in September 2023. He is undergoing lead training, allowing students to gain valuable skills and confidence through guided walks around the campus. Our new flock of chickens is now producing eggs. Students participate in collecting, cleaning and packaging the eggs, which are sold on campus. This process helps students practise essential skills such as customer service, handling cash and card payments, and engaging with the community.

Students are actively participating in the creation of sunflower and Bee-Bomb kits, which are sold to generate income that is reinvested into the farm. Also, student groups have taken part in the annual Jim Green Challenge, where projects included a sheep sculpture, scarecrow making and spring bulb planting.

These initiatives provide practical, therapeutic and educational opportunities for our students. The combination of animal interaction, agricultural tasks and business activities fosters personal growth, enhances social skills and strengthens emotional wellbeing, in keeping with the College's commitment to an inclusive learning environment.

As St Piers Farm continues to develop, we've acquired a new equipment shed to support the farm's operations, with plans to establish a dedicated area for growing and harvesting seasonal root vegetables in the 2024–25 academic year. This initiative will offer students hands-on experience in cultivating root vegetables, deepening their understanding of sustainable farming practices.

Looking ahead

A major focus for the 2024–25 academic year is the creation of an infant school building, designed to cater to Reception and Year 1 students. Plans are in place to refurbish an existing building to house 12 students, with state-of-the-art amenities, including soft play areas, a sensory room, therapy spaces, classrooms, a multi-

THE NATIONAL CENTRE FOR YOUNG PEOPLE WITH EPILEPSY CHARITABLE TRUST

Report and Financial Statements for the year ended 31 July 2024

Specialist Education (continued)

activity learning area and a large playground. This project is a significant milestone for St Piers, further expanding its capacity to offer high-quality, inclusive education across all age groups.

With these exciting developments and strategic growth initiatives, St Piers continues to evolve as a leading institution in special education, fostering an environment where all students can achieve their fullest potential.

THE NATIONAL CENTRE FOR YOUNG PEOPLE WITH EPILEPSY CHARITABLE TRUST

Report and Financial Statements for the year ended 31 July 2024

Fundraising

We raise funds through appeals, events, relationship management with supporters, individual donors, volunteer fundraisers, corporate partners and high-value funders, trading activity and through grant applications.

Our fundraising activity is managed internally without the involvement of commercial participators or professional fundraising agencies.

Accountability for our fundraising activity

We are registered with the Fundraising Regulator and follow their Code of Practice and publish our Fundraising Promise, complaints policy and procedure on our websites.

We comply with the guidance set out by the Fundraising Regulator, including publishing our charity and contact details on its website.

How we monitor activities of volunteer fundraisers who support Young Epilepsy

We provide support to volunteer fundraisers who choose to raise funds for Young Epilepsy through relationship management and a Service Level Agreement. We monitor their activity through designated online giving platforms and social media channels and engage in regular dialogue with fundraisers.

Number of complaints received associated with our fundraising activity or presence

In the year to 31 July 2024 no fundraising complaints in relation to our fundraising activity were received (2023: Nil).

What we do to protect people in vulnerable circumstances

All employees who work for Young Epilepsy sign up to a clear behaviour code of conduct and receive safeguarding training as part of their induction, with refresher training delivered at appropriate intervals. This applies to team members directly engaged in fundraising activity.

Young Epilepsy adopts a rigorous and robust approach to safeguarding, given the particularly vulnerable group of children and young people with epilepsy we work with. Our fundraising team is required to follow procedures that implement our approved Child and Adult Protection and Safeguarding Policy, reviewed annually.

THE NATIONAL CENTRE FOR YOUNG PEOPLE WITH EPILEPSY CHARITABLE TRUST

Report and Financial Statements for the year ended 31 July 2024

Fundraising (continued)

We have a Fundraising with People in Vulnerable Circumstances Policy, and also follow guidance laid out by the Chartered Institute of Fundraising, the Charity Commission and the Fundraising Regulator. The policy is published on our website and is supported by staff training.

Anyone under the age of 16 is recorded as such on our Customer Relationship Management system and is not contacted for marketing purposes.

Our fundraising performance

Fundraised income for the year was £1.7m (2023: £1.4m).

We spent £0.7m towards fundraising, yielding a 2.47 return on investment. The increase in income was a result of growth in unrestricted funds, which this year reached over £1m for the first time.

There was continued significant growth in Sport and Challenge Event income, which raised £293K. This demonstrates the benefits of investing in the team and in digital marketing to support regular official runs and virtual fundraising opportunities, including partnering with 'Run for Charity' and 'Action Challenge'.

Our virtual events programme earned over £54K, including the very successful '26 miles in 26 Days for Purple Day Challenge', which raised nearly £38K. The London Marathon raised nearly £50K from 15 runners. Our huge congratulations to all those who laced up for us, with special thanks to top Marathon fundraiser, Gemma Sherlock, who raised over £8K.

Our supporters continue to impress us with their tireless, creative and enthusiastic activities.

Our special thanks go to all those who raised funds through their own challenges and events in the year.

Purple Day, 26 March 2024, was our best yet, with over £56k raised, nearly double the previous year. As well as a virtual challenge event and a successful marketing campaign, more than 50 schools, 22 community groups and 10+ businesses joined forces with us, an unprecedented level of engagement.

THE NATIONAL CENTRE FOR YOUNG PEOPLE WITH EPILEPSY CHARITABLE TRUST

Report and Financial Statements for the year ended 31 July 2024

Fundraising (continued)

Legacy income was £42K from three legators, Mary Parkin Will Trust, Frances Ann Roxburgh and Anthony David Ryall .

We invested significantly in supporter acquisition this year, using a digital marketing agency to increase our reach through social media and online advertising. We welcomed 7,309 new contactable supporters, bringing our total to 17,937.

Young Epilepsy had its most successful Christmas fundraising campaign to date, with over £62K raised. Nearly half of this came via our first Big Give campaign. Every pound donated via the Big Give website between 28 November and 5 December was worth double.

Our initial fundraising goal was to raise £15K made up of online donations and the matched funding pot generously provided by Nevilles PLC and the Big Give champion funding. After three days, we reached our target, so we increased it to £25K and by the end of the campaign our final fundraising achievement was more than £29K.

Our Grant fundraising income was £394K, of which £338K was restricted income to support our Health and Research and Voice and Support services, as well as projects at St Piers School and College.

During the year, we secured a two-year grant of £96K from the City Bridge Foundation for our Voice and Leadership project, working with the Youth Voice Network in Greater London. This project will run to September 2025.

We also secured the support of the Foyle Foundation with a £50K one-year grant towards our Inclusion Programme to support education professionals who work with children with epilepsy in school, running to April 2025.

We also greatly valued the support of eight repeat grant-funders who help ensure the continuity of our projects and services.



THE NATIONAL CENTRE FOR YOUNG PEOPLE WITH EPILEPSY CHARITABLE TRUST

Report and Financial Statements for the year ended 31 July 2024

Fundraising (continued)

Community fundraising had a year of growth, raising £182K. Highlights included our Charity of the year partnership with Tandridge Golf club, which to date has raised approximately £65K through their annual golf day, 100-hole golf challenge and their participation in Ride London. We also held our annual Star Run, which raised just under £10K and was again kindly supported by Wingate Solutions.

We were chosen as a participating charity for Carfest 2023, resulting in a donation of £52K. We were delighted to be chosen to take part again in Carfest 2024.

Corporate fundraising had another successful year, raising £303K. Highlights include our participation in the Rontec Pennies Scheme, which was a huge success, raising £54K. We were also delighted to be the recipients of education grants from Angelini Pharma for our Transitions project and from Jazz Pharma for our Inclusion project.

Special thanks go to key individuals and families whose support has helped fund our vital services this year. We are grateful for the ongoing support for the Bernard Lewis Family Charitable Trust, whose regular gifts help fund our Youth Support work, and to the Wyfold Charitable Trust for their ongoing contribution to our services. We are also thankful to the George E Neville Foundation for their ongoing support and funds towards our research programme.

Thank you to the Cunnane family

We want to pass on a very special thank you to Andy and Laura Cunnane, along with their wider family and friends.

In 2023–24, the Cunnane family demonstrated the power of personal passion and community engagement, raising more than £90,000 plus Gift Aid for Young Epilepsy. Their fundraising efforts were inspired by their journey with their son Jude, who passed away 21 October 2021, and have continued with support from their network and a variety of events.

THE NATIONAL CENTRE FOR YOUNG PEOPLE WITH EPILEPSY CHARITABLE TRUST

Report and Financial Statements for the year ended 31 July 2024

Fundraising (continued)

This was a record-breaking fundraising year as Laura led a team of 51 cyclists in the Ride London event and raised more than £46K. Andy's love for running saw him raise £21K for Young Epilepsy through Team Jude at the London Marathon and his participation in the Jurassic Ultra Marathon generated £4K.

The family's dedication to the cause also motivated new supporter Andrew Crowe to contribute a £10K gift. Through their involvement with the Cunnane family, O'Hara funeral directors chose Young Epilepsy as their Charity of the Year and raised around £10K through their Golf Day. Also, for the third consecutive year, the Hey Jude Rocks Charity Ball continued to honour the Cunnane's son Jude, while raising vital funds for Young Epilepsy's research programme.

We pass on our heartfelt thanks to all our donors, grant funders and voluntary fundraisers, both first-time supporters and regular donors, for their generous support.

Looking ahead

The year ahead will see us continue to grow unrestricted income. Our priority aims are to develop a fundraising income for St Piers School and College as well as developing new regular giving products, launching a Young Epilepsy Lottery in September 2024.

We will invest in data insight and digital marketing and increase our engagement with schools. The year ahead will also see us developing our legacy marketing proposition and continuing to invest in the growth of our Sport and Challenge event income.

Special thanks to the following Individuals who have supported us this year.

Gordon Fraser

Simon Arnold

Alexander and Tilly Hunter

Jennifer Fowke

Martin Spillane

David Holdcroft

Gemma Sherlock

Emma O'Brien

Philip Gray



THE NATIONAL CENTRE FOR YOUNG PEOPLE WITH EPILEPSY CHARITABLE TRUST

Report and Financial Statements for the year ended 31 July 2024

Fundraising (continued)

Tom Glanfield

Zachary Knight

Sterling GroL

Andrew and Laura Cunnane

Clare Sheckter

Andrew Crowe

Special thanks to the following companies, grant and trust funders and other organisations that have supported us this year:

The National Lottery Community Fund

City Bridge Foundation

Bernard Lewis Family Charitable Trust

The Wyfold Charitable Trust

Nutricia Advanced Medical Nutrition

The Alison Hillman Charitable Trust

Anne and John Walters Trust

Michael O'Sullivan Charitable Trust

Community Foundation for Surrey

The Percy Bilton Charity

Nineveh Charitable Trust

Veriton Pharma (Serb)

UCB Pharma

Neville UK PLC

Desitin Pharma Ltd

George E Neville Foundation

The Foyle Foundation

Innovate UK

Rontec

Neuraxpharm

Jazz Pharmaceuticals

Angelini Pharma

Car Fest Ltd

THE NATIONAL CENTRE FOR YOUNG PEOPLE WITH EPILEPSY CHARITABLE TRUST

Report and Financial Statements for the year ended 31 July 2024

Fundraising (continued)

TBSL Ltd

O'Hara Funeral Directors

Tandridge Golf Club



THE NATIONAL CENTRE FOR YOUNG PEOPLE WITH EPILEPSY CHARITABLE TRUST

Report and Financial Statements for the year ended 31 July 2024

Administrative details

Young Epilepsy is the operating name of The National Centre for Young People with Epilepsy Charitable Trust, which is a charity registered with the Charity Commission (registered number 311877). The registered address of Young Epilepsy is Young Epilepsy, St Piers Lane, Lingfield, Surrey, RH7 6PW.

During the year, and in the months following the year-end to publication, the Trustees were as follows:

Jane Ramsey (resigned 18 July 2024)
Simon Neville
Prof Helen Cross OBE
Keith Cameron (resigned 11 February 2024)
Vivienne Dews (resigned 11 February 2024)
Dr Julia Coop (resigned 11 February 2024)
Lesley Steeds
Claire Wood-Hill (resigned 13 December 2023)
Nicholas Bell (resigned 21 March 2024)
Tamsin Jones
Dr Amit Bali
Katie Stevens (resigned 18 July 2024)
David Pierpoint (appointed 2 October 2023)
Tom Hadley (appointed 2 October 2023)
Paola Morris (appointed 13 November 2023)
Ash Tailor (appointed 21 March 2024)
Tanya Moran (appointed 10 May 2024)
Maria Rodrigues (appointed 10 May 2024)
Markus Ruetimann (appointed 8 November 2024)

The Board of Trustees is responsible for the governance of Young Epilepsy and ensuring that its activities are within its charitable objectives. It sets the strategic direction, the responsibility for the execution of which is delegated to the executive management of the organisation through the Chief Executive Officer, Mark Devlin.

The executive management team is made up of:

Mark Devlin	Chief Executive
Nazar Al-Khalili	Director of Finance, IT and Facilities
Sally Brighton	Director of Fundraising and Development
Simone Hopkins	Executive Principal, St Piers School and College
Rosemarie Pardington	Director of Integrated Care (resigned 26 January 2024)
Sarah Stookes	Deputy CEO, Director of HR, Health and Safety, Health Service

THE NATIONAL CENTRE FOR YOUNG PEOPLE WITH EPILEPSY CHARITABLE TRUST

Report and Financial Statements for the year ended 31 July 2024

During the year, Young Epilepsy's bankers and professional advisers were:

Bankers

Lloyds Bank plc
Mid Corporates – Education, Charities and Government
3rd Floor
25 Gresham Street
London EC2V 7HN

Solicitors

Anthony Collins Solicitors
134 Edmund Street
Birmingham B3 2ES

Property Lawyers

Pinsent Masons
30 Crown Place
Earl Street
London EC2A 4ES

External Auditors

BDO LLP
2 City Place
Beehive Ring Road
Gatwick
West Sussex RH6 0PA

Internal Auditors

MacIntyre Hudson
6th Floor
2 London Wall Place
London EC2Y 5AU

THE NATIONAL CENTRE FOR YOUNG PEOPLE WITH EPILEPSY CHARITABLE TRUST

Report and Financial Statements for the year ended 31 July 2024

Structure, Governance and Management

Young Epilepsy is regulated by a scheme of the Charity Commission dated 31 October 2002, as amended by deeds of amendment dated 22 January 2004 and 21 October 2004.

Young Epilepsy has one Corporate Trustee, The National Centre for Young People with Epilepsy, a company limited by guarantee registered in England (number 00756798). The sole purpose of the Corporate Trustee is to act as the Trustee of the Charity. The Board members of the Corporate Trustee are referred to as "Trustees" in this report.

Young Epilepsy had one wholly owned subsidiary trading company, St Piers (Services) Limited (Company registration number 04131530). Its principal activity was the development of property for the use of disabled children. Notice was given to dissolve St Piers Services Limited on the 12 December 2023.

The Board of Trustees is responsible for the governance of Young Epilepsy and ensuring that its activities are within the charitable objectives. It sets the strategic direction, the responsibility for the execution of which is delegated to the executive management through the Chief Executive Officer. Trustees can serve a maximum of two terms of three years, with a third term only in exceptional circumstances.

New Trustees are recruited through an open process and are appointed by the Board of the Corporate Trustee. Young Epilepsy regularly seeks to refresh the Trust Board with Trustees who have the experience and expertise required to enable the Charity to perform to a high level.

New Trustees receive an induction programme including mandatory safeguarding training. They are provided supporting materials including formal governance documents. Other training courses are available for Trustees as required.

The Board of Trustees meets on a regular basis. During the year they were supported by the Education Governing Body, which oversees St Piers School and College, and six sub-committees:

- Finance, Audit and Risk Committee
- Fundraising and Engagement Advisory Committee
- Health Services Committee
- Remuneration Committee
- Nominations Committee
- Education Governing Body

THE NATIONAL CENTRE FOR YOUNG PEOPLE WITH EPILEPSY CHARITABLE TRUST

Report and Financial Statements for the year ended 31 July 2024

Financial review

Income and expenditure

Total income for the year was £25.1m (2023: £22.2m). Of this, fees from local government and health authorities were £22.0m (2023: £20.4m). This is mainly due to a greater number of students in both the school and college and small uplifts in fees agreed with the local authorities. Fundraising and legacy income at £1.9m (2023: £1.4m) also showed an increase on the previous year. Other income includes a non-refundable deposit from Audley Group for £600K in respect of the land sale.

Total expenditure for the year amounted to £25.4m (2023: £24.0m). The higher costs reflect the additional students in the year. Overall, we had a net deficit after depreciation of £0.3m (2023: £1.8m deficit).

Reserves

The level of free reserves should be sufficient to cover operational expenditure commitments in the short term (excluding expenditure on acquisitions and other funded projects) with consideration of operational risks and external factors. This definition is intended to provide the Charity with a way of identifying those reserves that are readily available in relatively liquid form if required by the Charity and which are necessary for operational matters. These will also include funds available through external bank borrowings and overdraft facilities.

The annual benchmark for free reserves is established during the Board's approval of the budget. It is derived from stress testing the budget to ascertain a worst-case scenario, forming the foundation for determining the free reserves target set at £1.1m. The following reserves are held:

Restricted funds

These funds are tied to a specific activity by the funder or by the nature of the appeal and cannot be used to fund other activities by Young Epilepsy. More details of our restricted funds totaling £0.7m at the end of 2024 (2023: £0.7m) can be found in note 12 of the financial statements.

Funds representing functional fixed assets

These funds are equivalent to the net book value of the land and buildings used to support Young Epilepsy's charitable and commercial operations. The Trustees have designated these funds totalling £21.6m at the end of 2024 (2023: £21.2m) as representing the element of our reserves that are tied to our charitable assets, including land and buildings. Consequently, these reserves are not available to be spent on ongoing activities.

Pension reserve

These funds are held to meet the future liabilities of our Final Salary Pension Scheme. The current pension scheme deficit of £4.7m (2023: £4.6m), calculated in accordance with the requirements of Section 28 of FRS 102, is shown as a liability against unrestricted funds.

THE NATIONAL CENTRE FOR YOUNG PEOPLE WITH EPILEPSY CHARITABLE TRUST

Report and Financial Statements for the year ended 31 July 2024

Financial Review (continued)

An annual payment of £0.7m was made to the fund in the year to further reduce the deficit. The payment for 2024–25 will rise to £0.8m per annum with stepped increases over the next six years. This is in line with the agreement signed between the Charity and the Trustees of the pension fund for the April 2022 triennial valuation.

Free reserves

Free reserves represent unencumbered funds not allocated for specific purposes or designated as fixed assets. As at the year end, these reserves amounted to £0.1m (2023: £1.2m), which is lower than the Board-approved annual target of £1.1m. Following the sale of land referenced in Note 17 to the Financial Statements and the receipt of a total of £2.8m in August 2024 and December 2024, the Charity is now in a position where this target level has been reached.

The Trustees recognise that the pension scheme deficit will not crystallise in the near future and that all reserves levels will continue to be monitored closely.

Funding

In total, 88% (£22.0m) of our income for 2023–24 was made up of fees from local authorities and other supporting bodies. This funding is used to provide education and residential care for the students at St Piers School and College and healthcare from our facility in Lingfield. The remaining funding (£3.1m) includes donations, legacies, accommodation rented to staff and a non-refundable deposit of £600K from the land sale and was used to provide national services and support functions, and to ensure the free reserves are within the target level.

THE NATIONAL CENTRE FOR YOUNG PEOPLE WITH EPILEPSY CHARITABLE TRUST

Report and Financial Statements for the year ended 31 July 2024

Financial Review (continued)

Risks

The Trustees have identified the principal risks and uncertainties to which Young Epilepsy is exposed and developed relevant managing actions. These are:

- *Failure to generate sufficient income or efficiencies to maintain scale, financial sustainability and quality of core offers.* On the income side we have increased the number of placements at school and college. The former has been extended by including a new infants' school, which opened in May 2024. This has resulted in higher income compared with previous years. In addition, we continue to review our pricing for both new placements and existing ones and have been negotiating these with the local authorities. Higher costs and difficulties in recruiting have impacted most organisations in the UK, not just those in our sector. We have managed these by ensuring value for money in all our expenditure and by managing our staffing well (detailed below). We continue to invest in our fundraising activities to generate further funds for research and services for young people. We are also finalising our estates development programme from the proceeds of the sale of part of our land which we are reinvesting in our estate. This will help manage costs and generate income in the future.
- *Inability to attract and retain diverse, talented staff with the right skills and capability to deliver positive impact for students.* This is managed by ensuring we are paying competitive rates to all our staff, managing our agency spend through neutral vendor, having in place a government licence for recruiting overseas workers, and providing quality training for all our employees.
- *Harm caused to children and young people.* This is managed by focusing on safeguarding specifically by having regular refresher training for staff, reducing staff turnover in key areas; continually reviewing our safeguarding reporting thresholds and ensuring these are aligned to relevant guidance and external reporting requirements; regular monitoring and reporting of safeguarding incidents, and the analysis of any emerging trends with relevant action plans. We also implement reflective practice and the promotion of a learning environment to promote continuous improvement.
- *Failure to maintain or improve Residential, Health and Education regulatory ratings.* This is managed by the continuation of a range of audits, unannounced visits and compliance tools across all areas; continuing to recruit high-calibre staff to relevant positions and focusing on learner progress to ensure expectations of performance and standards remain high. In November 2023, we had an Ofsted inspection of our college and received an "outstanding" rating.
- *Data security is not properly managed.* The risk is that there are insufficient controls that could allow data losses or breaches. This is managed by having mandatory training for all staff, especially around the NHS toolkit. We are also now Cyber Essentials Plus compliant. Risks and mitigations are managed through the Information Governance Steering Group which is chaired by Senior Information Risk Owner (SIRO).

THE NATIONAL CENTRE FOR YOUNG PEOPLE WITH EPILEPSY CHARITABLE TRUST

Report and Financial Statements for the year ended 31 July 2024

Financial Review (continued)

Going concern

The financial statements are drawn up on the going concern basis, which assumes Young Epilepsy will continue in operational existence for the foreseeable future. As at the year-end Young Epilepsy had free reserves of £0.1m (2023: £1.2m). However, following the sale of land, referenced in Note 17 to the Financial Statements, and the receipt of a total £2.8m in August 2024 and December 2024, the Trustees believe that Young Epilepsy is now well placed to manage operational and financial risks successfully.

The Trustees arrived at this decision following a review of the financial position and financial forecasts, taking into account the levels of cash, overdraft facility, working capital, net current assets and the systems of financial control and risk management.

Young Epilepsy substantially relies on funding from local authority contracts for its current and future commitments and we seek to manage the risks around this income stream. The Trustees believe the contracts we have in place with local authorities will be fulfilled and the planned income for the coming years will be received.

The going concern basis used in the preparation of these financial statements is based upon the expectation that Young Epilepsy's net income or net expenditure are at a level to ensure reserves and cash flow requirements are met.

Based on this work, the Board considers Young Epilepsy's current and forecast cash resources to be sufficient to cover the working capital requirements of the Charity for at least 12 months from the date of signing the accounts and has determined that it remains appropriate to continue to adopt the going concern basis in preparing the accounts. The Trustees have not identified any material uncertainties relating to going concern.

Executive pay increases

The Remuneration Committee reviews executive performance and remuneration annually. We aim to pay salaries at the median level for similar organisations within the not-for-profit sector, and to ensure that increases are consistent with those awarded in the overall organisational review of remuneration.

The Charity Governance Code

The Board of Trustees takes its governance responsibilities seriously and, as a large charity, aims to have a governance framework that is fit for purpose, compliant and efficient. The Board has established a solid foundation in governance in which all of its Trustees are clear about their roles and legal responsibilities, are committed to supporting the charity to deliver its objectives most effectively for its beneficiaries' benefit, and contribute to the charity's further development.

We monitor our governance framework against the Charity Governance Code principles to ensure we are following best practice and the highest standards of governance.

THE NATIONAL CENTRE FOR YOUNG PEOPLE WITH EPILEPSY CHARITABLE TRUST

Report and Financial Statements for the year ended 31 July 2024

Statement of Trustees' responsibilities

The Trustees are responsible for preparing the Annual Report and the financial statements in accordance with applicable law and regulations.

Charity law requires the Trustees to prepare financial statements for each financial year in accordance with United Kingdom Generally Accepted Accounting Practice (United Kingdom Accounting Standards and applicable law). Under charity law, the Trustees must not approve the financial statements unless they are satisfied that they give a true and fair view of the state of affairs of the group and the Charity and of the incoming resources and application of resources, including the income and expenditure, of the group and the Charity for that period.

In preparing these financial statements, the Trustees are required to:

- select suitable accounting policies and then apply them consistently;
- make judgements and accounting estimates that are reasonable and prudent;
- state whether applicable UK Accounting Standards have been followed, subject to any material departures disclosed and explained in the financial statements; and
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the Charity will continue in business.

The Trustees are responsible for keeping adequate accounting records that are sufficient to show and explain the Charity's transactions and disclose with reasonable accuracy at any time the financial position of the Charity and enable them to ensure that the financial statements comply with the Charities Act 2011. They are also responsible for safeguarding the assets of the Charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.



Markus Ruetimann

Date: 6th March 2025

THE NATIONAL CENTRE FOR YOUNG PEOPLE WITH EPILEPSY CHARITABLE TRUST

Report and Financial Statements for the year ended 31 July 2024

Independent Auditor's Report to Trustees of The National Centre for Young People with Epilepsy Charitable Trust

Opinion on the financial statements

In our opinion, the financial statements:

- give a true and fair view of the state of the Charity's affairs as at 31 July 2024 and of the Charity's incoming resources and application of resources for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Charities Act 2011.

We have audited the financial statements of The National Centre for Young People with Epilepsy Charitable Trust ("the Charity") for the year ended 31 July 2024, which comprises of the statement of financial activities, the Charity balance sheet, the statement of cash flows and notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 102 The Financial Reporting Standard applicable in the UK and Republic of Ireland (United Kingdom Generally Accepted Accounting Practice).

Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the Auditor's responsibilities for the audit of the financial statements section of our report. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Independence

We remain independent of the Charity in accordance with the ethical requirements relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements.

Conclusions related to going concern

In auditing the financial statements, we have concluded that the Trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the Charity's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the Trustees with respect to going concern are described in the relevant sections of this report.

THE NATIONAL CENTRE FOR YOUNG PEOPLE WITH EPILEPSY CHARITABLE TRUST

Report and Financial Statements for the year ended 31 July 2024

Independent Auditor's Report (continued)

Other information

The Trustees are responsible for the other information. The other information comprises the information included in the Annual Report, other than the financial statements and our auditor's report thereon. Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon. Our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements, or our knowledge obtained in the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether there is a material misstatement in the financial statements themselves. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact.

We have nothing to report in this regard.

Matters on which we are required to report by exception

We have nothing to report in respect of the following matters in relation to which the Charities (Accounts and Reports) Regulations 2008 requires us to report to you if, in our opinion:

- the information given in the Trustees' Report for the financial year for which the financial statements are prepared is inconsistent in any material respect with the financial statements; or
- adequate accounting records have not been kept by the Charity; or
- the Charity's financial statements are not in agreement with the accounting records and returns; or
- we have not received all the information and explanations we require for our audit.

Responsibilities of Trustees

As explained more fully in the Trustees' responsibilities statement, the Trustees are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the Trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the Trustees are responsible for assessing the Charity's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the Trustees either intend to liquidate the Charity or to cease operations, or have no realistic alternative but to do so.

Auditor's responsibilities for the audit of the financial statements

We have been appointed as auditor under section 144 of the Charities Act 2011 and report in accordance with the Act and relevant regulations made or having effect thereunder.

THE NATIONAL CENTRE FOR YOUNG PEOPLE WITH EPILEPSY CHARITABLE TRUST

Report and Financial Statements for the year ended 31 July 2024

Independent Auditor's Report (continued)

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

Extent to which the audit was capable of detecting irregularities, including fraud

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud. The extent to which our procedures are capable of detecting irregularities, including fraud is detailed below:

Non-compliance with laws and regulations

Based on:

- Our understanding of the Charity and the sector in which it operates;
- Discussion with management and those charged with governance; and
- Obtaining and understanding of the Charity's policies and procedures regarding compliance with laws and regulations.

We considered the significant laws and regulations to be the Charities Act 2011 and United Kingdom Accounting Standards, including Financial Reporting Standard 102 The Financial Reporting Standard applicable in the UK and Republic of Ireland (United Kingdom Generally Accepted Accounting Practice).

The Charity is also subject to laws and regulations where the consequence of non-compliance could have a material effect on the amount or disclosures in the financial statements, for example through the imposition of fines or litigations. We identified such laws and regulations to be the Charities Act 2011, Employment Law, Health & Safety Legislation, Data Protection and relevant tax legislation.

Our procedures in respect of the above included:

- Enquiry with management and those charged with governance regarding any known or suspected non-compliance with laws and regulations;
- Review of minutes of meeting of those charged with governance for any instances of non-compliance with laws and regulations;
- Review of financial statement disclosures and agreeing to supporting documentation; and
- Review of legal expenditure accounts to understand the nature of expenditure incurred.

THE NATIONAL CENTRE FOR YOUNG PEOPLE WITH EPILEPSY CHARITABLE TRUST

Report and Financial Statements for the year ended 31 July 2024

Independent Auditor's Report (continued)

Fraud

We assessed the susceptibility of the financial statements to material misstatement, including fraud. Our risk assessment procedures included:

- Enquiry with management and those charged with governance regarding any known or suspected instances of fraud;
- Obtaining an understanding of the Charity's policies and procedures relating to:
 - Detecting and responding to the risks of fraud; and
 - Internal controls established to mitigate risks related to fraud.
- Review of minutes of meeting of those charged with governance for any known or suspected instances of fraud;
- Discussion amongst the engagement team as to how and where fraud might occur in the financial statements; and
- Performing analytical procedures to identify any unusual or unexpected relationships that may indicate risks of material misstatement due to fraud.

Based on our risk assessment, we considered the areas most susceptible to fraud to be management override of controls and income recognition.

Our procedures in respect of the above included:

- Testing a sample of journal entries throughout the year, which met a defined risk criteria, by agreeing to supporting documentation;
- Assessing significant estimates made by management for bias; including allocation of costs, useful economic lives and impairment considerations, pension scheme assumptions, going concern assumptions;
- Assessing the design and implementation of the control environment to identify areas of material weakness to focus the design of our audit testing;
- In addressing the risk of fraud through management override of controls, testing the appropriateness of journal entries and other adjustments, in particular any journals posted by senior management;
- In addressing the risk of fraud in income recognition we considered management's incentives and opportunities for fraudulent manipulation of the financial statements and designed specific audit tests to respond to this risk, in particular, tests to address the completeness of income risk; and
- Tested a sample of income assessing income recognition to confirm that this has been recognised in accordance with the Charities SORP.

We also communicated relevant identified laws and regulations and potential fraud risks to all engagement team members and remained alert to any indications of fraud or non-compliance with laws and regulations throughout the audit.

Our audit procedures were designed to respond to risks of material misstatement in the financial statements, recognising that the risk of not detecting a material misstatement due to fraud is higher than the risk of not detecting one resulting from error, as fraud may involve deliberate concealment by, for example, forgery, misrepresentations or through collusion. There are inherent limitations in the audit procedures performed and the further removed non-compliance with laws and regulations is from the events and transactions reflected in the financial statements, the less likely we are to become aware of it.

THE NATIONAL CENTRE FOR YOUNG PEOPLE WITH EPILEPSY CHARITABLE TRUST

Report and Financial Statements for the year ended 31 July 2024

Independent Auditor's Report (continued)

A further description of our responsibilities for the audit of the financial statements is located at the Financial Reporting Council's ("FRC's") website at: <https://www.frc.org.uk/auditorsresponsibilities>. This description forms part of our auditor's report.

Use of our report

This report is made solely to the Charity's trustees, as a body, in accordance with Part 4 of the Charities (Accounts and Reports) Regulations 2008. Our audit work has been undertaken so that we might state to the Charity's trustees those matters we are required to state to them in an auditor's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the Charity and the Charity's trustees as a body, for our audit work, for this report, or for the opinions we have formed.

DocuSigned by:

Fiona Condron

BC8C15A11E97446...

BDO LLP, statutory auditor

Gatwick, UK

Date 07 March 2025

BDO LLP is eligible for appointment as auditor of the Charity by virtue of its eligibility for appointment as auditor of a company under section 1212 of the Companies Act 2006.

BDO LLP is a limited liability partnership registered in England and Wales (with registered number OC305127

THE NATIONAL CENTRE FOR YOUNG PEOPLE WITH EPILEPSY CHARITABLE TRUST
Statement of Financial Activities of the Charity for the year ended
31 July 2024

	Note	2024 Unrestricted funds £'000	2024 Restricted funds £'000	2024 Total Funds £'000	2023 Unrestricted funds £'000	2023 Restricted funds £'000	2023 Total Funds £'000
Income from:							
Donations and legacies	3	960	926	1,886	641	713	1,354
Charitable activities							
Fees – local authorities and other supporting bodies		22,020	-	22,020	20,355	-	20,355
Investment income							
Other trading activities							
Income from rents and meals		379	-	379	343	-	343
Other Income		816	-	816	140	-	140
Total	5	<u>24,175</u>	<u>926</u>	<u>25,101</u>	<u>21,479</u>	<u>713</u>	<u>22,192</u>
Expenditure on:							
Raising funds							
Cost of raising funds		697	-	697	546	-	546
Charitable activities							
Educational, medical and residential care		697	-	697	546	-	546
		23,900	819	24,719	22,848	614	23,463
Total		<u>24,597</u>	<u>819</u>	<u>25,416</u>	<u>23,395</u>	<u>614</u>	<u>24,009</u>
Net income/(expenditure)		(422)	107	(315)	(1,908)	99	(1,810)
Transfers between funds	13	72	(72)	-	43	(43)	-
Other recognised gains and losses:							
Actuarial (loss) / gain on defined benefit pension scheme	11	(482)	-	(482)	1,615	-	1,615
Net movement in funds		(832)	35	(797)	(251)	56	(195)
Total funds brought forward		17,790	652	18,442	18,041	596	18,637
Total funds carried forward		<u>16,958</u>	<u>687</u>	<u>17,645</u>	<u>17,790</u>	<u>652</u>	<u>18,442</u>

THE NATIONAL CENTRE FOR YOUNG PEOPLE WITH EPILEPSY CHARITABLE TRUST
Report and Financial Statements for the year ended 31 July 2024

Balance Sheet	2024 Notes	£000s	£000s	2023 £000s	£000s
Fixed assets					
Tangible assets	8		21,556		21,239
			<u>21,556</u>		<u>21,239</u>
Current assets					
Debtors	9	3,678		4,775	
Cash at bank and in hand		-		872	
		3,678		5,647	
Creditors due within 1 year		(2,884)		(3,811)	
		<u>(2,884)</u>		<u>(3,811)</u>	
			794		1,836
Net current assets					
Total assets less current liabilities and net assets excluding pension scheme liability			22,350		23,075
Defined benefit pension scheme liability	11		(4,705)		(4,633)
			<u>17,645</u>		<u>18,442</u>
Net assets including pension scheme liability					
Funds					
Restricted funds:					
Income funds	12	687		652	
			687		652
Unrestricted funds:					
Funds representing functional fixed assets	13	21,556		21,239	
Free reserves	13	107		1,184	
Pension reserve	13	(4,705)		(4,633)	
			<u>16,958</u>		<u>17,790</u>
Total funds	14		<u>17,645</u>		<u>18,442</u>

The financial statements were approved by the Board and authorised for issue on the 06/03/2025



Markus Ruetimann
 Chair of Trustees

The notes on pages 56 to 76 form part of these financial statements

THE NATIONAL CENTRE FOR YOUNG PEOPLE WITH EPILEPSY CHARITABLE TRUST
Report and Financial Statements for the year ended 31 July 2024

Cashflow Statement	2024 £'000	2023 £'000
Cash flows from operating activities:		
<i>Net cash generated by/(used in) by operating activities</i>	427	(1,530)
Cash flows from investment activities:		
Interest received	1	-
Purchase of tangible fixed assets	(1,387)	(185)
Sale of tangible fixed assets		
Net cash used in investment activities	<u>(1,386)</u>	<u>(185)</u>
Cash flows from financing activities:		
Interest paid	(3)	-
Net cash (used in)/generated from financing activities	<u>(3)</u>	<u>-</u>
Change in cash and cash equivalents in the reporting period	(962)	(1,715)
Cash and cash equivalents brought forward	872	2,587
Cash and cash equivalents carried forward	<u>(90)</u>	<u>872</u>

No reconciliation of net debt has been prepared as the Charity only holds cash and cash equivalents. The notes on pages 54 to 73 form part of these financial statements.

THE NATIONAL CENTRE FOR YOUNG PEOPLE WITH EPILEPSY CHARITABLE TRUST

Report and Financial Statements for the year ended 31 July 2024

Notes to the Financial Statements year ended 31 July 2024

1. Charity status

The Charity's sole trustee is The National Centre for Young People ("the corporate Trustee"), a company which is limited by guarantee, the liability of each member in the event of the company winding up is limited to £1. The registered office of the corporate Trustee is St Piers Lane, Lingfield, Surrey RH7 6PW. The Charity is registered with the Charity Commission and constitutes a public benefit entity as defined by FRS102.

2. Accounting policies

a) Basis of accounting

The financial statements have been prepared under the historical cost convention, and are in accordance with the Statement of Recommended Practice: Accounting and reporting by Charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS102) (the 'SORP'), FRS 102: The Financial Reporting Standard applicable in the UK and Ireland ('FRS 102') (2nd Edition), the Charities Act 2011 and UK Generally Accepted Practice as it applies from 1 January 2019.

The preparation of the financial statements in accordance with FRS102 requires the Trustees to make judgements, estimates and assumptions that affect the application of policies and reported amounts in the financial statements. The areas where assumptions or estimates were significant to the financial statements are disclosed in note 2 below.

b) Going concern

The financial statements are drawn up on the going concern basis, which assumes Young Epilepsy will continue in operational existence for the foreseeable future. As at the year-end Young Epilepsy had free reserves of £0.1m (2023: £1.2m). However, following the sale of land, referenced in Note 17 to the Financial Statements, and the receipt of a total of £2.8m in August 2024 and December 2024, the Trustees believe that Young Epilepsy is now well placed to manage operational and financial risks successfully.

The Trustees arrived at this decision following a review of the financial position and financial forecasts, taking into account the levels of cash, overdraft facility, working capital, net current assets and the systems of financial control and risk management.

Young Epilepsy substantially relies on funding from local authority contracts for its current and future commitments and we seek to manage the risks around this income stream. The Trustees believe the contracts we have in place with local authorities will be fulfilled and the planned income for the coming years will be received.

THE NATIONAL CENTRE FOR YOUNG PEOPLE WITH EPILEPSY CHARITABLE TRUST

Report and Financial Statements for the year ended 31 July 2024

Accounting policies (continued)

The going concern basis used in the preparation of these financial statements is based upon the expectation that Young Epilepsy's net income or net expenditure are at a level to ensure reserves and cash flow requirements are met.

Based on this work, the Board considers Young Epilepsy's current and forecast cash resources to be sufficient to cover the working capital requirements of the Charity for at least 12 months from the date of signing the accounts and has determined that it remains appropriate to continue to adopt the going concern basis in preparing the accounts. The Trustees have not identified any material uncertainties relating to going concern.

Based on a detailed review and analysis of the forecasts and projections, the Board considers Young Epilepsy's current and forecast cash resources to be sufficient to cover the working capital requirements of the Charity for at least 12 months from the date of signing the accounts and has determined that it remains appropriate to continue to adopt the going concern basis in preparing the accounts. The Trustees have not identified any material uncertainties relating to going concern.

c) **Income**

Income, including amounts receivable under the land sale agreement, is accounted for on an accruals basis, except cash donations, which are accounted for when received. Income received with gift aid is accounted for gross. Fee income from contracts is accounted for with regard to any in-year admissions and leavers along with any contractual reviews of service levels. Legacy income is recognised when there is entitlement to the funds, probability of receipt and the amount due is able to be measured reliably. Grants receivable based on performance are accounted for as the Charity earns the right to consideration by its performance. Where income is received in advance of performance, its recognition is deferred and included in creditors. Where entitlement occurs before income is received, the income is accrued.

The value of gifts in kind, donated services and donated facilities are recognised as income when the Charity has control over the item or received the service, any conditions associated with the donation has been met, the receipt of economic benefit from the use by the Charity is probable and that economic benefit can be measured reliably. This is in accordance with the Charities SORP (FRS102).

d) **Expenditure**

Expenditure is accounted for on an accruals basis. Costs are attributed directly to activities where possible on either actual or estimated time basis. Indirect costs are shown as support costs, where these relate to the infrastructure in which charitable services are provided, including gaining support for the furtherance of the Charity's objectives. Governance costs comprise those costs incurred in the governance of the Charity and its assets and are primarily associated with constitutional and statutory requirements.

THE NATIONAL CENTRE FOR YOUNG PEOPLE WITH EPILEPSY CHARITABLE TRUST

Report and Financial Statements for the year ended 31 July 2024

Accounting policies (continued)

e) **Fixed assets and depreciation**

Capital assets costing below £1,000 have been written off in the year in which the expenditure is incurred. Assets above £1,000 are capitalised. All building work and capital improvements that are not completed at the year-end are included under "Assets Under Construction". These are moved to "Freehold Land and Buildings" on completion. Depreciation has been provided on tangible and intangible fixed assets at the following rates, which are anticipated to reduce their cost to residual value by the end of their expected useful lives. Land has not been depreciated.

Assets are derecognised when the risks and rewards of ownership have passed. In the case of the sale of land, the disposal will be recognised in the year ended 31 July 2025.

Plant and Machinery	20% on cost
Computer Software	20% on cost
Computer Equipment	20% on cost
Motor Vehicles	25% on cost
Buildings	1%–7% on cost

Within Buildings, individual components are depreciated over the useful economic life as follows:

Construction	100 years
Roof	55 years
Lift	50 years
Bathroom	30 years
Windows & Doors	30 years
Heating	30 years
Kitchen	20 years
Air Conditioning	15 years
Boiler	15 years

THE NATIONAL CENTRE FOR YOUNG PEOPLE WITH EPILEPSY CHARITABLE TRUST

Report and Financial Statements for the year ended 31 July 2024

Accounting policies (continued)

Donated fixed assets are capitalised at their open market values at time of donation and depreciated in line with the above rates.

f) **Pensions**

The Charity has three principal pension schemes for staff: the St Piers Lingfield Retirement Benefits Scheme, the Teachers' Pension Scheme (TPS) and The Pensions Trust. The first two schemes are defined benefit schemes, which are externally funded and contracted out of the State Second Pension.

St Piers Lingfield Retirement Benefits Scheme

During the year, the Charity operated a defined benefit scheme, which had been closed to new members on 7 April 2000, hence any liabilities will be restricted to current members only, and this number will decline over time. On 30 November 2022, this scheme was closed to new accrual, so the remaining active members will no longer accrue benefits.

The difference between the fair value of the assets held in the St Piers Lingfield Retirement Benefits Scheme and the scheme's liabilities measured on an actuarial basis using the projected unit method is recognised in the Charity's balance sheet as a pension scheme asset or liability as appropriate. The pension scheme balance is recognised net of any deferred tax balance.

Teachers' Pension Scheme

Pension costs in respect of the TPS charged to the SOFA are equal to the contributions paid to this arrangement. The contribution rate is calculated in such a way that it is a substantially level percentage of current and future pensionable payroll. Not less than every four years, with a supporting interim valuation in between, the Government Actuary conducts a formal actuarial review of the TPS in order to specify the level of future contributions.

Changes in the defined benefit pension scheme asset or liability arising from factors other than cash contributions by the Charity are charged to the SOFA in accordance with FRS 102 section 28. Under the definitions set out in Financial Reporting Standard 102 section 28, the Teachers' Pension Scheme is a multi-employer pension scheme. The Charity is unable to identify its share of the underlying assets and liabilities of the scheme. Accordingly, the Charity has taken advantage of the exemption in FRS 102 section 28 and has accounted for its contributions to the scheme as if it were a defined contribution scheme.

The Pensions Trust

A money purchase pension scheme with The Pensions Trust is available to all members of staff.

THE NATIONAL CENTRE FOR YOUNG PEOPLE WITH EPILEPSY CHARITABLE TRUST

Report and Financial Statements for the year ended 31 July 2024

Accounting policies (continued)

h) Fund accounting

Where funds are received for specific purposes set out by the donor or implied by the terms of appeal, these are shown as restricted income in the Statement of Financial Activities. Expenditure for the purposes specified is applied against the income and any amounts unexpended at the balance sheet date are shown within restricted funds. Amounts used to purchase tangible fixed assets are transferred to funds representing functional fixed assets at the time the assets are acquired.

Accounting estimates and key management judgements

Accounting estimates and judgements

In preparing the financial statements within the accounting frameworks set out in note 2, the Trustees are required to adopt those accounting policies most appropriate to the Charity's circumstances with a view to presenting fairly the Charity's financial position. In determining and applying accounting policies Trustees make estimates and judgements and the matters set out below are considered to be the most important in understanding the judgements that have been involved in preparing the financial statements and the uncertainties that could impact the amounts reported.

Sale of land

The Charity sold part of its land during the year to Audley Group. Although the agreement was signed before the year end, the risks and rewards of ownership had not passed at the balance sheet date and therefore the proceeds of the sale have not been recognised nor has the disposal of the land.

Estimation of assets useful lives

The charge in respect of periodic depreciation is derived from determining an estimate of an asset's expected useful life and the expected residual value at the end of its life. The estimates of the lives by asset category are set out in note 2(f). The useful lives and residual values are determined by management at the time the asset is acquired and reviewed annually for appropriateness.

Provision for doubtful debts

Provisions have been made against specific invoiced debts where the collectability of these debts is uncertain taking into account their age, activity on the account and any correspondence.

THE NATIONAL CENTRE FOR YOUNG PEOPLE WITH EPILEPSY CHARITABLE TRUST

Report and Financial Statements for the year ended 31 July 2024

Accounting policies (continued)

Actuarial assumptions in respect of defined benefit pension scheme

The application of actuarial assumptions relating to the Defined Pension Scheme is incorporated in the financial statements in accordance with FRS102. In applying FRS102, advice has been taken from an independent qualified actuary. In this context, significant judgement is exercised in a number of areas, including future change.

The Teachers' Pension Scheme is a defined benefit scheme in the UK. In the opinion of the Trustees', it is not possible for the charity to obtain sufficient information to enable it to account for the scheme as a defined benefit scheme. Therefore, it accounts for the scheme as a defined contribution scheme.

3. Donations and Legacies

	2024	2023
Projects and residential house funds	74	81
Youth Development Funds	144	31
ACT Mental Health	-	114
Policy & Advocacy	107	-
Lottery Funding	127	123
ACT Mental health, Youth and Digital projects	-	91
Unrestricted donation	918	608
Research Funds	197	50
Education Funding Agency (EFA)	277	223
	<u>1,844</u>	<u>1,321</u>
Legacies	42	33
Total Donations and Legacies	<u>1,886</u>	<u>1,354</u>

The legacies are final payments in respect of legacies which were substantially recognised in previous years.

£926K (2023: £713K) of donations overall relate to restricted income.

THE NATIONAL CENTRE FOR YOUNG PEOPLE WITH EPILEPSY CHARITABLE TRUST
Report and Financial Statements for the year ended 31 July 2024

4. Employees

	2024	2023
	£'000	£'000
Staff costs consist of:		
Wages & Salaries	15,781	15,231
Social security	1,435	1,365
Pension Costs	<u>1,194</u>	<u>1,210</u>
	<u>18,410</u>	<u>17,806</u>

Included within wages and salaries are agency costs of £991,400 (2023 – £1,127,459) and termination payments of £113,333 (2023 - £68,469) incurred during the year.

Employer's pension cost comprise the following:

	2024	2023
	£'000	£'000
Teachers' pension scheme	300	227
Defined contribution scheme	540	492
Deficit repayment for defined benefit scheme	539	501
	<u>1,379</u>	<u>1,220</u>

The average number of employees during the period was:

	2024	2023
	No.	No.
Teaching and Education Support Staff	242	202
Residential Care	186	189
Medical and Clinical Staff	37	63
Other staff	<u>93</u>	<u>100</u>
	<u>558</u>	<u>554</u>
Full-time equivalent	<u>366</u>	<u>372</u>

THE NATIONAL CENTRE FOR YOUNG PEOPLE WITH EPILEPSY CHARITABLE TRUST
Report and Financial Statements for the year ended 31 July 2024

Employees (continued)

Number of staff with total remuneration (including settlements and benefits but excluding pensions) greater than £60,000 in bands of £10,000:

	2024	2023
	No.	No.
£60,001–£70,000	10	9
£70,001–£80,000	2	3
£80,001–£90,000	-	2
£90,001–£100,000	2	-
£100,001–£110,000	2	1
£110,001–£120,000	1	1
£120,001–£130,000	-	1
	<hr/> 17 <hr/>	<hr/> 17 <hr/>

Contributions made in the year for the provision of the defined contribution scheme on behalf of 13 (2023 – 14) higher paid employees was £64,730 (2023 – £40,883).

There are 2 (2023 – 1) higher paid staff to whom retirement benefits are accruing under the defined benefit schemes.

The total remuneration paid to the Executive team amounted to £704,886 (2023 – £766,332).

THE NATIONAL CENTRE FOR YOUNG PEOPLE WITH EPILEPSY CHARITABLE TRUST
Report and Financial Statements for the year ended 31 July 2024

5. Total Expenditure

	Education, Medical and Residential Care £000	Fundraising £000	2024 £000	2023 £000
Staff costs	14,207	486	14,693	14,265
Other direct expenditure	1,008	211	1,219	951
Support staff costs	3,693	-	3,693	3,543
Support costs	4,646	-	4,646	4,162
Auditor's remuneration	96	-	96	75
Depreciation	1,071	-	1,071	1,003
2024 Total	24,721	697	25,418	23,999
2023 Total	23,452	547	23,999	

Auditor's remuneration relates solely to audit related services and is inclusive of Value Added Tax where not recovered. Included in expenditure are governance costs amounting to £194,852 (2023 – £138,594), which relate to audit fees, recruitment, legal advice for trustees and costs associated with constitutional and statutory requirements. Direct costs, where relevant, are allocated to the fundraising team, but all other support costs are allocated to Education, Medical and Educational Care, which generate the majority of our income

6. Trustees' transactions

The Trustees do not receive any remuneration in respect of their services. Seven Trustees (2023 – 6) received expenses reimbursed in line with the Trustees Expenses Policy amounting to £674 (2023 – £790). Further costs incurred on behalf of Trustees relate to Trustees' indemnity insurance costs of £1,640 (2023 – £1,476).

THE NATIONAL CENTRE FOR YOUNG PEOPLE WITH EPILEPSY CHARITABLE TRUST
Report and Financial Statements for the year ended 31 July 2024

7. Taxation

The organisation is a charity within the meaning of Para 1 Schedule 6 Finance Act 2010. Accordingly, the Charity is potentially exempt from taxation in respect of income or capital gains within categories covered by Chapter 3 of Para 11 of the Corporate Tax Act or Section 256 of the Taxation of Chargeable Gains Act 1992, to the extent that such income or gains are applied exclusively to charitable purposes. The subsidiary trading company makes qualifying donations of taxable profit to the Charity to the full extent allowable. Unless material any corporation tax liability arising in the subsidiary is included within the expenditure by the Group.

8. Tangible and intangible assets

	Freehold Land and Buildings	Plant & Machinery	Computer Software	Computer Equipment	Assets under construction	Vehicles	Total
Cost	£'000	£'000	£'000	£'000	£'000	£'000	£'000
At 1 August 2023	39,975	785	699	598	-	403	42,460
Additions	146	584	11	111	533	3	1,388
At 31 July 2024	40,121	1,369	710	709	533	406	43,848
Depreciation							
At 1 August 2023	19,578	604	397	284	-	357	21,220
Charge	766	38	101	131	-	36	1,072
At 31 July 2024	20,344	642	498	415	-	393	22,292
NBV current year	19,777	727	212	294	533	12	21,556
NBV prior year	20,397	181	302	314	-	46	21,239

Freehold land and buildings have been included in the balance sheet at historic cost less the depreciation charged on the buildings. All assets are held for direct charitable use.



THE NATIONAL CENTRE FOR YOUNG PEOPLE WITH EPILEPSY CHARITABLE TRUST

Report and Financial Statements for the year ended 31 July 2024

9. Debtors

	2024	2023
	£'000	£'000
Trade debtors	2,519	1,761
Other debtors	81	881
Accrued income & prepayments	1,078	2,133
	<u>3,678</u>	<u>4,775</u>

All amounts shown under trade debtors fall due for payment within one year.

10. Creditors

	2024	2023
	£'000	£'000
Trade creditors	1,270	2,344
Bank overdraft	90	-
Accruals and Deferred income	1,524	1,467
	<u>2,884</u>	<u>3,811</u>

11. Pension Schemes

St Piers Lingfield Retirement Benefits Scheme

The Charity operates the St Piers Lingfield Retirement Benefits Scheme ("the Scheme"), a UK registered trust-based pension scheme that provides defined benefits. Pension benefits are linked to the members' final pensionable salaries and service at their retirement (or date of leaving if earlier). This scheme was closed to new members on 7 April 2000, hence any liabilities will be restricted to current members only, and this number will decline over time. On 30 November 2022, this scheme was closed to new accrual so the remaining active members will no longer accrue benefits.

The Pension Scheme Trustee is responsible for running the Scheme in accordance with the Scheme's Trust Deed and Rules, which sets out their powers. The Pension Scheme Trustee is required to act in the best interests of the beneficiaries of the Scheme. There are three categories of pension scheme members:

- active members: currently employed by the Employer;
- deferred members: former active members of the Scheme who are not yet in receipt of a pension;
- and
- pensioner members: in receipt of pension.

THE NATIONAL CENTRE FOR YOUNG PEOPLE WITH EPILEPSY CHARITABLE TRUST

Report and Financial Statements for the year ended 31 July 2024

Pension schemes (continued)

The Pension Scheme Trustee is required to carry out an actuarial valuation every 3 years. The last actuarial valuation of the Scheme was performed by the Scheme Actuary for the Pension Scheme Trustee as at 5 April 2022. This valuation revealed a funding shortfall of £6,008,000. The Employer has agreed to pay regular contributions of £14,000 per month to cover Scheme expenses. In respect of the deficit in the Scheme as at 5 April 2022, the Employer has agreed to pay the following contributions:

Year beginning 1 August	Contributions £'000
2023	630
2024	842
2025	969
2026	943
2027	652
2028	672
2029	692

The Charity has also agreed to pay additional contributions equal to 20% of audited Net Income in excess of £0.5m each year. The additional contribution in any year will be limited in value to the remaining payments outstanding on the July 2023 Recovery Plan, or such subsequent Recovery Plan as is put in place, less any additional contributions already made under the 2023 agreement.

The Charity therefore expects to pay a minimum of £992,333 to the Scheme during the accounting year beginning 1 August 2024 to the St Piers Lingfield Retirement Benefit Scheme.

The results of the most recent formal actuarial valuation as at 5 April 2022 have been updated to 31 July 2024 by a qualified independent actuary. The assumptions used were as follows:

THE NATIONAL CENTRE FOR YOUNG PEOPLE WITH EPILEPSY CHARITABLE TRUST
Report and Financial Statements for the year ended 31 July 2024

Pension schemes (continued)

	2024	2023
<i>Significant actuarial assumptions:</i>		
Discount rate	5.0%	5.1%
Inflation (RPI)	3.4%	3.3%
Inflation (CPI)	2.75%	2.6%
<i>Other actuarial assumptions:</i>		
Rate of increase in salaries	2.75%	2.60%

Rate of increase in pensions:

Non-Pensioners – Pre-05 benefits	3.20%	3.20%
Non-Pensioners – Post-05 benefits	2.50%	2.50%
Pensioners – Pre-05 benefits	3.20%	3.20%
Pensioners – Post-05 benefits	2.50%	2.50%
Revaluation of deferred pensioners in excess of GMP	2.75%	2.60%

The demographic mortality assumptions adopted at 31 July 2024 imply the following life expectancies at age 65:

	2024	2023
<i>Mortality assumptions:</i>		
Mortality	S3PMA/S3PF A CMI 2019 1.25%	S3PMA/S3PFA CMI 2019 1.25%
<i>Life expectancies:</i>		
Male currently age 45 at 65	22.1 years	22.1 years
Female currently age 45 at 65	24.8 years	24.8 years
Male currently age 65	20.8 years	20.8 years
Female currently age 65	23.3 years	23.3 years

Under FRS102 the expected return on the schemes assets is now assessed using the discount rate underlying the valuation of the schemes liabilities, which is based on AA rated corporate bond yields.

At 31 July 2024, the discount rate used to calculate the schemes liabilities and hence the assumed rate of return on the Schemes assets was 5.0% p.a. (2023 – 5.1%).

THE NATIONAL CENTRE FOR YOUNG PEOPLE WITH EPILEPSY CHARITABLE TRUST
Report and Financial Statements for the year ended 31 July 2024

Pension schemes (continued)

	Value at 2024 Assets £'000	% of total Scheme	Value at 2023 assets £'000	% of total Scheme
The fair value of the assets in the scheme were:				
Bonds	0	0%	1,228	12%
Gilts	3,130	31%	2,976	29%
Cash	206	2%	104	1%
Annuities	802	8%	820	8%
Other	6,044	59%	5,069	50%
Total market value of assets	<u>10,182</u>		<u>10,197</u>	
Present value of scheme liabilities	<u>(14,887)</u>		<u>(14,830)</u>	
Net pension liability	<u>(4,705)</u>		<u>(4,633)</u>	
	2024 £'000		2023 £'000	
The actual return on assets over the period was				
	509		(2,025)	
Interest income	507		421	
Return on assets less interest income	<u>2</u>		<u>(2,446)</u>	
Total return of assets	<u>509</u>		<u>(2,025)</u>	

	2024 £'000	2023 £'000
<i>Analysis of changes in the value of the scheme liabilities over the year:</i>		
Opening present value of the defined benefit obligation	(14,830)	(19,060)
Service cost	-	(14)
Interest cost	(727)	(635)
Member contributions	-	(7)
Benefits paid	1,154	825
Actuarial (loss)/gain	(484)	4,061
Closing present value of the defined benefit obligation	<u>(14,887)</u>	<u>(14,830)</u>

THE NATIONAL CENTRE FOR YOUNG PEOPLE WITH EPILEPSY CHARITABLE TRUST
Report and Financial Statements for the year ended 31 July 2024

Pension schemes (continued)

	2024 £'000	2023 £'000
<i>Analysis of changes in the value of the scheme assets over the year:</i>		
Opening market value of Scheme assets	10,197	12,551
Expected return on Scheme assets (excluding interest income)	2	(2,446)
Interest income	507	421
Employer contributions	794	762
Member contributions	-	7
Benefits paid	(1,154)	(825)
Administration expenses	(164)	(273)
	<u>10,182</u>	<u>10,197</u>
Closing market value of Scheme assets	10,182	10,197

	2024		2023	
	£'000	£'000	£'000	£'000
<i>Analysis of the amounts charged to Statement of Financial Activities:</i>				
Current service cost	-		(14)	
Administration expenses	(164)		(273)	
		<u>(164)</u>		<u>(287)</u>
Total service cost		(164)		(287)
Net finance charge		(220)		(214)
		<u>(384)</u>		<u>(501)</u>
Total pension cost charged to Statement of Financial Activities		(384)		(501)

	2024 £'000	2023 £'000
<i>Analysis of actuarial (loss)/gain recognised in the Statement of Financial Activities:</i>		
Actual gain/(loss) on assets less interest	2	(2,446)
Actuarial (loss)/gain on defined benefit obligation	(484)	4,061
	<u>(482)</u>	<u>1,615</u>
Total (loss)/gain recognised in the Statement of Financial Activities	(482)	1,615

THE NATIONAL CENTRE FOR YOUNG PEOPLE WITH EPILEPSY CHARITABLE TRUST
Report and Financial Statements for the year ended 31 July 2024

<u>Pension schemes (continued)</u>	2024	2023
	£'000	£'000
<i>Movement in deficit during the year:</i>		
Deficit in scheme at the beginning of the year	(4,633)	(6,509)
Movement in year:		
Current service cost	-	(14)
Administration expenses	(164)	(273)
Net finance charge	(220)	(214)
Contributions	794	762
Return on assets excluding interest income	2	(2,446)
Actuarial (loss)/gain	(484)	4,061
	<hr/>	<hr/>
(Deficit) in scheme at end of year	(4,705)	(4,633)
	<hr/>	<hr/>

Teachers' Pension Scheme

Under the definitions set out in Financial Reporting Standard 102 section 28, the Teachers' pension scheme (TPS) is a multi-employer pension scheme. As the TPS is underwritten by central government and the Charity has no future obligation to make contributions to the scheme, this is effectively a defined contribution scheme in so far as it affects the Charity. As a result, contributions to this scheme are accounted for as if the scheme was a defined contribution scheme.

The Charity has set out below the information available on the Scheme and the implications for the Charity in terms of the anticipated contribution rates.

The Teachers' Pension Scheme is a statutory, contributory, unfunded, defined benefit scheme. The regulations under which the TPS operates are the Teachers' Pensions Regulations 1997, as amended. Contributions are credited to the Exchequer on a "pay as you go" basis under arrangements governed by the Superannuation Act 1972. A notional asset value is ascribed to the Scheme for the purposes of determining contribution rates.

The Government Actuary's report of March 2019 revealed that the total liabilities of the Scheme (pensions currently in payment and the estimated cost of future benefits) amounted to £218.1 billion. The value of the assets (estimated future contributions together with the proceeds from the notional investments held at the valuation date) was £196.1 billion. The assumed real rate of return is 2.4% in excess of prices. The rate of real earnings growth is assumed to be 2.2%. The gross rate of return is 4.45%

TPT Retirement Solutions

The charity participates in the scheme, a multi-employer scheme which provides benefits to some 638 non-associated participating employers. The scheme is a defined benefit scheme in the UK. It is not possible for the charity to obtain sufficient information to enable it to account for the scheme as a defined benefit scheme. Therefore, it accounts for the scheme as a defined contribution scheme.

The scheme is subject to the funding legislation outlined in the Pensions Act 2004, which came into force on 30 December 2005. This, together with documents issued by the Pensions Regulator and Technical Actuarial Standards issued by the Financial Reporting Council, set out the framework for funding defined benefit occupational pension schemes in the UK.

THE NATIONAL CENTRE FOR YOUNG PEOPLE WITH EPILEPSY CHARITABLE TRUST

Report and Financial Statements for the year ended 31 July 2024

Pension schemes (continued)

The scheme is classified as a “last man standing arrangement”. Therefore, the charity is potentially liable for other participating employers’ obligations if those employers are unable to meet their share of the scheme deficit following withdrawal from the scheme. Participating employers are legally required to meet their share of the scheme deficit on an annuity purchase basis on withdrawal from the scheme.

A full actuarial valuation for the scheme was carried out at 30 September 2020. This valuation showed assets of £800.3m, liabilities of £831.9m and a deficit of £31.6m. To eliminate this funding shortfall, the Trustees have asked the participating employers to pay additional contributions to the scheme as follows:

Deficit contributions

From 1 April 2022 to 31 January 2025: £3,312,000 per annum (payable monthly), unless a concession has been agreed with the Trustees the term to 31 January 2025 applies. The scheme’s previous valuation was carried out with an effective date of 30 September 2017. This valuation showed assets of £794.9m, liabilities of £926.4m and a deficit of £131.5m. To eliminate this funding shortfall, the Trustees asked the participating employers to pay additional contributions to the scheme as follows:

From 1 April 2019 to 30 September 2025: £11,243,000 per annum (payable monthly and increasing by 3% on 1 April).

The recovery plan contributions are allocated to each participating employer in line with their estimated share of the Series 1 and Series 2 scheme liabilities.

Where the scheme is in deficit and where the company has agreed to a deficit funding arrangement the company recognises a liability for this obligation. The amount recognised is the net present value of the deficit reduction contributions payable under the agreement that relates to the deficit. The present value is calculated using the discount rate detailed in these disclosures. The unwinding of the discount rate is recognised as a finance cost.

	2024 £'000	2023 £'000
Present value of provision		
Present value of provision	2	5
Reconciliation of opening and closing provisions		
Provision at start of period	5	8
Deficit contribution paid	(3)	(3)
Provision at end of period	<u>2</u>	<u>5</u>

THE NATIONAL CENTRE FOR YOUNG PEOPLE WITH EPILEPSY CHARITABLE TRUST
Report and Financial Statements for the year ended 31 July 2024

12. Restricted Funds

	As at 31 July 2023 £'000	Income £'000	Expenditure £'000	Transfer £'000	As at 31 July 2024 £'000
Research Funds	22	197	(175)	-	44
Lottery Funding	40	127	(117)	9	59
ACT Mental Health	114	58	(63)	0	109
Mental health, Youth and Digital projects	1	144	(134)	(9)	2
True Colours Trust - Epilepsy Infancy	110	-	-	-	110
Voice & Leadership	17	49	(27)	-	39
Other Funds	-	73	(70)	(24)	(21)
EFA grants	276	277	(232)	(48)	273
	72	-	-	-	72
Restricted Funds	652	925	(818)	(72)	687

	As at 31 July 2022 £'000	Income £'000	Expenditure £'000	Transfer £'000	As at 31 July 2023 £'000
Research Funds	82	50	(110)	-	22
Mental health, Youth and Digital projects	-	91	(90)	-	1
Lottery Funding	-	123	(83)	-	40
ACT Mental Health	-	114	-	-	114
Youth Development programs	239	31	(160)	-	110
True Colours Trust - Epilepsy Infancy	17	-	-	-	17
Other Funds	247	81	(44)	(8)	276
EFA grants	11	224	(128)	(35)	72
Restricted Funds	596	714	(615)	(43)	652

Fund accounting

Where funds are received for specific purposes set out by the donor or implied by the terms of appeal, these are shown as restricted income in the Statement of Financial Activities. Expenditure for the purposes specified is applied against the income and any amounts unexpended at the balance sheet date are shown within restricted funds. Amounts used to purchase tangible fixed assets are transferred to funds representing functional fixed assets at the time the assets are acquired



THE NATIONAL CENTRE FOR YOUNG PEOPLE WITH EPILEPSY CHARITABLE TRUST
Report and Financial Statements for the year ended 31 July 2024

13. Unrestricted Funds

	As at 31 July					As at 31 July
	2023	Income	Other	Expenditure	Transfers	2024
	£'000	£'000	Gains/(Losses) £'000	£'000	£'000	£'000
Charity						
Unrestricted funds						
Designated funds						
Fixed Assets	21,239	-	-	-	317	21,556
Pension reserve	(4,633)	-	(72)	-	-	(4,705)
	<u>16,606</u>	<u>-</u>	<u>(72)</u>	<u>-</u>	<u>317</u>	<u>16,851</u>
General unrestricted funds						
	<u>1,184</u>	<u>23,765</u>	<u>-</u>	<u>(24,597)</u>	<u>(245)</u>	<u>107</u>
Total unrestricted funds	<u>17,790</u>	<u>23,765</u>	<u>(72)</u>	<u>(24,597)</u>	<u>72</u>	<u>16,958</u>

	As at 31 July					As at 31 July
	2022	Income	Other	Expenditure	Transfers	2023
	£'000	£'000	Gains/(Losses) £'000	£'000	£'000	£'000
Charity						
Unrestricted funds						
Designated funds						
Fixed Assets	22,063	-	-	-	(824)	21,239
Pension reserve	(6,509)	-	1,876	-	-	-4,633
	<u>15,554</u>	<u>-</u>	<u>1,876</u>	<u>-</u>	<u>(824)</u>	<u>16,606</u>
General unrestricted funds						
	<u>2,485</u>	<u>21,227</u>	<u>-</u>	<u>(23,385)</u>	<u>857</u>	<u>1,184</u>
Total unrestricted funds	<u>18,039</u>	<u>21,227</u>	<u>1,876</u>	<u>(23,385)</u>	<u>33</u>	<u>17,790</u>

THE NATIONAL CENTRE FOR YOUNG PEOPLE WITH EPILEPSY CHARITABLE TRUST
Report and Financial Statements for the year ended 31 July 2024

14. Analysis of net assets between funds

Charity	2024		
	Unrestricted Funds £'000	Restricted Funds £'000	Total £'000
Tangible Fixed Assets	21,556	-	21,556
Net Current Assets	107	687	794
Total Assets Less Current Liabilities	21,663	687	22,350
Defined Benefit Pension Scheme Liability	(4,705)	-	(4,705)
Net Assets	16,958	687	17,645

Charity	2023		
	Unrestricted Funds £'000	Restricted Funds £'000	Total £'000
Tangible Fixed Assets	21,235	-	21,235
Net Current Assets	1,186	652	1,838
Total Assets Less Current Liabilities	22,421	652	23,073
Defined Benefit Pension Scheme Liability	(4,633)	-	(4,633)
Net Assets	17,788	652	18,440

THE NATIONAL CENTRE FOR YOUNG PEOPLE WITH EPILEPSY CHARITABLE TRUST
Report and Financial Statements for the year ended 31 July 2024

15. Reconciliation of expenditure to net cash flow generated by (used in) operating activities

	2024 £'000	2023 £'000
<i>Net expenditure for the reporting period</i>	(315)	(1,813)
Adjustments for:		
Depreciation	1,071	1,003
Adjustment for pension funding	(410)	(259)
Interest from cash deposits	(1)	-
Interest paid	3	-
Decrease/(Increase) in debtors	1,096	(2,428)
(Decrease)/Increase in creditors	(1,017)	1,957
<i>Net cash generated by/(used in) operating activities</i>	<u>427</u>	<u>(1,540)</u>

16. Operating Leases

The total of future minimum rentals receivable under non-cancellable rental agreements are as follows:

	2024 £'000	2023 £'000
Total minimum lease payments		
Within one year	61	60
Within two to five years	97	51
	<u>158</u>	<u>111</u>

17. Post Balance Sheet Events

On 18 December 2024 the sale of 151,025 square feet of land owned by the Charity was legally completed. The sale proceeds of £6.7M are to be received in two instalments with the first amount of £2.8M having been received on 20 December 2024 and the second instalment being due in June 2025. Until such time as all proceeds from the sale are received, the charity has retained a legal charge over the land subject to the sale. The buyer will retain £0.5M of the sales proceeds until certain planning obligations have been fulfilled by Young Epilepsy.

Plans are underway for the proceeds to be re-invested into the Charity's estate to benefit current and future students at the School and College.