



## Appointment of Trustees, 2020



# Welcome from our Board

Thank you for expressing your interest in Young Epilepsy and in our Trustee appointment. This role offers great opportunities for an experienced and ambitious individual to become part of a well-established and influential national charity, at an important time in its development.

Young Epilepsy is the leading charity helping young people with epilepsy and associated conditions in the UK. It delivers services that make a significant, and positive impact, for young people with epilepsy and associated conditions. The organisation has a strong legacy built on philanthropy dating back to the 19<sup>th</sup> century. However, we have not stood still and the charity has a strong tradition of developing ground breaking clinical and educational services for young people with learning disabilities.

We directly educate and care for over 170 children and young people up to the age of 25 severely affected by epilepsy as well as a growing proportion with other associated conditions, including autism, in our school and college. Our reputation extends well beyond our Lingfield campus and we were delighted with the national recognition we recently received from a well known British soap opera which resulted in ITN coverage and an interview with one of our Young Trustees.

We offer on our Lingfield campus a “state of the art” school, which enables us to provide support to our students in impressive sensory, arts and science facilities. Our College provides additional therapy rooms and sensory space, as well as classrooms. To support our service delivery we gain the majority of our funding from local government and health agencies and aim to offer value for money services. We also have a strong fund raising track record, aimed both at investing in facilities on site and supporting the delivery of our research and national services programmes. We have a world class health and diagnostic centre opened some seven years ago on our campus.

Our campus is a very special place, but our ambitions extend significantly beyond our local area. We are immensely proud of our nationally recognised expertise in working with young people. We have much to celebrate both in terms of cutting edge services and our internationally recognised research programme in epilepsy. We are fortunate to have developed partnerships with other leading organisations including Great Ormond Street Hospital, The Institute of Child Health University College London and Kings College Hospital. Coupled with our Prince of Wales Chair in Childhood Epilepsy these partnerships have enabled us to maintain a strong clinical reputation and have given us a voice in policy and research.

Part of our mission is to deliver more to the 112,000 children and young people across the UK who live with epilepsy. We work nationally to deliver support and information to families and share knowledge gained from our research with those with an interest in epilepsy and associated conditions. It is essential part of our strategy to ensure we raise awareness and tackle the lack of knowledge in the wider community about epilepsy.

Our aim is to appoint two new trustees, one with an expertise in education and another in finance to join the existing Trustee and Executive Team to achieve our ambitions: To create a society where children and young people with epilepsy are encouraged to thrive and fulfil their potential. A society in which their voices are respected and their ambitions realised.

If you believe you have the skills, experience and qualities we are seeking, then we want you to come and help us do just that.

# About Young Epilepsy

**We exist to create a society where children and young people with epilepsy are enabled to thrive and fulfil their potential. A society in which their voices are respected and their ambitions realised.**

Epilepsy affects 112,000 young people in the UK and is one of the most common serious long term conditions in childhood. Two thirds of young people will be able to control their seizures over time with antiepileptic drugs or experience spontaneous remission. However, one third will continue to have seizures.

Epilepsy is symptomatic of a complex spectrum of conditions and no two experiences will be exactly the same. The common feature of these conditions is being prone to seizures – which are universally called ‘epilepsy’ or ‘the epilepsies’. The epilepsies, and seizures themselves, are varied in type, severity, frequency and cause.

Through clinical research, real advances are being made in our understanding of the underlying causes of epilepsy, as well as how they affect all aspects of a child’s life. Research presents a real opportunity to improve outcomes. However, health services can still be inconsistent in terms of access to specialist services, speed of diagnosis and adequate face-to-face support.

Beyond the seizures, there are higher rates of cognitive, developmental and behaviour disorders among young people with epilepsy, who are also four times more likely than their friends to experience mental health problems.

Many of these problems remain unrecognised or unsupported and result in academic underachievement or school exclusion. There sadly remains significant social stigma about the condition and many young people feel isolated and anxious.

Even though schools have a legal duty to support students with medical conditions, one in three children with epilepsy still don’t have an individual healthcare plan to ensure they are safe and included in all areas of school life. Young people with epilepsy face further challenges when moving away from home and developing their careers. They are faced with the fact that people with epilepsy are more than twice as likely to be out of work than their friends. So there is a huge need for information to improve public understanding, professional care and access to support for children and young people.

Young Epilepsy is at the forefront of advocating with young people for positive change in attitudes, across society, and towards greater understanding of the condition. We campaign for improved specialist support for children, young people and their families in our national health, education and social care systems.

As an organisation we employ 630 staff across our sites and last year our total income was £25.2m.



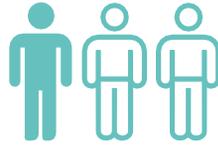
Forestschool, StPiers

# The challenges faced by children and young people

Epilepsy affects almost **6** in every 1000 children and young people.



**Two-thirds** of education professionals have received no training in how to support children with epilepsy in their care.



**1 in 3** children with epilepsy don't have an individual healthcare plan at school.



Young people with epilepsy are **four times** more likely than their friends to have mental health problems.



**Only 52%** of people with epilepsy in the UK are seizure free. With the right treatment around 70% could be seizure free.



In 2018/19, **30%** of 16 to 24 year olds with epilepsy had their Personal Independence Payment (PIP) applications 'disallowed'.



Young people with epilepsy have told us that the lack of available information and support is a key barrier to becoming independent.

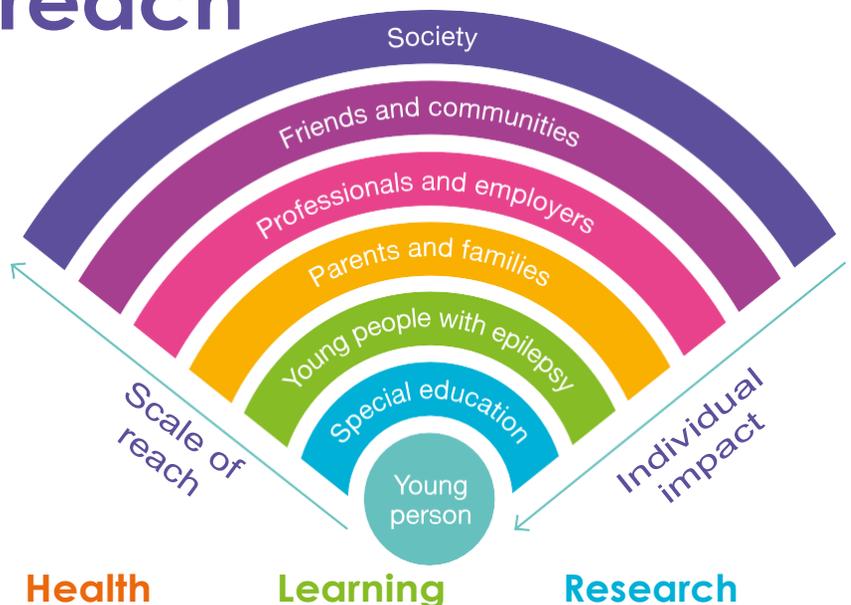


Children and young people with epilepsy say that the most important issues for them are support at school, support for worries and anxieties, and face to face support.

# Young Epilepsy's impact and scale of reach

Young Epilepsy supports young people with epilepsy and their families, as well as the professionals who work with them.

We raise awareness of the issues facing young people with epilepsy to break down barriers and stigma in society.



**Information**

**Health**

**Learning**

**Research**

# St Piers School and College

## Expertise in special educational needs

St Piers School and College support children and young people with epilepsy and associated conditions, as day and residential students.

St Piers School is a caring, supportive, learning environment for children and young people aged 5 to 19.

The students are at the centre of everything we do. Our dedicated, enthusiastic and experienced staff provide first class support. The education, health, care and therapy teams work in partnership and we pride ourselves on having strong relationships in place with parents, carers and funders. This tried and tested approach ensures every St Piers student reaches their optimum level of achievement. The school is an incredible place for children with neurological conditions and behavioural difficulties to thrive, learn new skills, grow in confidence and make new friends.

St Piers College provides a warm, friendly and unique environment for students aged 19 to 25.

Many of the young adults we support have learning and behavioural difficulties as well as specific medical or physical requirements. At St Piers College they are able to thrive, thanks to a calm, structured, safe environment and the support of a team of highly experienced professionals. We don't believe college should only be about academic achievement. Instead, we place a huge emphasis on life skills and independent living, with the aim of making sure each of our students is happy and confident in meeting life's challenges.



## Health

We drive improvements in healthcare and advocate for young people's right to the highest standards of health

- c We will campaign with young people and families for mental health support to be a priority.
- c We will deliver training to support healthcare professionals working with young people with epilepsy.
- c We will deliver innovative clinical services, including home-based telemetry and a magnetoencephalography (MEG) brain scanner.
- c We will campaign with young people and families for more epilepsy specialist nurses.

**Axel is a devoted musician living with epilepsy. At the age of 16 he was diagnosed with juvenile myoclonic epilepsy, Axel has managed to control his epilepsy through medication.**

The music industry demands very late nights and Axel's main trigger is sleep deprivation. He risks his health on a daily basis to do what he loves.

"This is my career choice and I forge forward with it... my family are concerned for my future. My friends are supportive and stand by me but I think they find it difficult to relate to the condition. Unless you suffer with it or are involved with someone who does, it's difficult to understand... I can struggle with feelings of depression."

" I won't stop doing what I love for a living or let epilepsy define me. "





We deliver innovative education services and advocate for young people with epilepsy’s right to an education

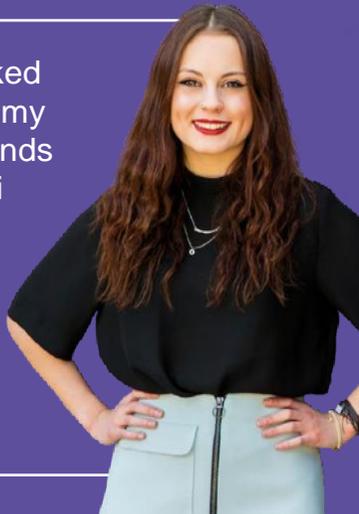
- c We will campaign with young people and families for young people with epilepsy to be safe and included in all education settings.
- c We will expand our Epilepsy Friendly accreditation to more schools, nurseries, colleges and universities.
- c We will provide epilepsy awareness training and resources for education professionals.
- c We will pioneer improvements in the education of young people with epilepsy and special educational needs through our St Piers School and College and beyond.



**Olivia, a 22-year-old university student, first experienced the significant impact of absence seizures from the age of 11.**

“When I was younger my teachers thought I was naughty and not listening to them but I was having absence seizures. It’s not like daydreaming – it’s like having a bad nightmare that leaves you feeling drained and needing to sleep. I have other types of seizures too but absence seizures are the worst for me because they are not obvious, can be embarrassing and many people don’t know how to respond when I black out.”

“Once we worked out the problem, my teachers and friends at school and uni have been so supportive and have helped me catch up when I miss parts of lessons.”



**William is 20 years old and is a college student.**

“My mum researched and found St Piers and showed me the college and asked me what I thought. I came for a visit twice and thought it was amazing as it was tranquil and peaceful.

“I would really like to be a plumber when I leave here and live independently in my own flat. The skills that I am being taught here will help with my aspirations. I am completing my Maths and English at Level 1 which will help me work towards my Level 2 which is the level I will need for plumbing. I am also learning about transition and what this means for me. Currently I am learning about first aid in the home. I go to an off site college to do cooking, which will help me when I move into my own home.”

“Young Epilepsy has given me the opportunity to aspire to my dreams, which would not have been achievable if I had stayed at home.”





## Research

We coordinate and fund research into the causes, treatments and impact of childhood epilepsy

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- c We will use this research to champion earlier, more accurate diagnosis; earlier, better treatment; and holistic, effective epilepsy services.
- c We will raise the profile of our research to increase its impact.
- c We will share our research with clinical experts, young people and the public, both nationally and internationally.
- c We will use research evidence in every area of our work.

Our research programme is a collaborative initiative between Young Epilepsy, Great Ormond Street Hospital and UCL GOS – Institute of Child Health. The programme, currently in its 15th year, is led by Professor Helen Cross OBE, The Prince of Wales’s Chair of Childhood Epilepsy, and coordinated by Young Epilepsy. It exists to establish successively better outcomes by improving early diagnosis and intervention in every aspect of childhood epilepsy.

Professor Helen Cross  
OBE, The Prince of  
Wales’s Chair of  
Childhood Epilepsy



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“ We cannot hope to make lasting, meaningful change without services governed by defensible evidence in all disciplines of our work. Our world-leading research provides this evidence. It is central to all that we do. ”

Amy Muggerridge, Research Manager  
at Young Epilepsy

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# Trustee roles

Young Epilepsy's Board of Trustees (the Board) is legally responsible for ensuring that the organisation achieves its mission. The role of trustees on the Board is to hold the charity "in trust" for current and future beneficiaries by ensuring the organisation has a clear vision, values, and strategic direction, and is focused on achieving these.

Trustees are responsible for the performance of the charity and its culture and for ensuring that Young Epilepsy complies with all legal and regulatory requirements.

Young Epilepsy trustees as part of the Board act as guardians of the charity's assets, both tangible and intangible taking all due care over their security, deployment and proper application, and ensure that the organisation's governance is of the highest possible standard.

Trustees provide strategic guidance for the organisation, using their skills, backgrounds and contacts to assist the organisation in continuing to make a real difference.

## Specific Duties

The specific duties of a trustee are:

- To ensure that the fundamental values and guiding principles of the charity are articulated and reflected throughout the charity with its trustees, staff, volunteers and beneficiaries, and to safeguard and promote the good name, and reputation, of Young Epilepsy.
- To determine the overall strategic direction and development of the charity, by agreeing organisational policies, budgets and objectives, and to ensure targets are set and performance is measured against such targets.
- Ensure the charity complies with its governing documents, relevant legislation and regulatory requirements.
- Collectively to own and hold the Board to account for its decisions and activities, ensuring the avoidance of any personal conflict of interest.
- To contribute any specific skills, knowledge or experience which he/she may have to help the Board reach sound decisions.
- To ensure the effective and efficient administration of the charity and its financial stability.
- Collectively agree the levels of delegated authority and to ensure that that these are recorded by means of minutes, terms of reference for committees and sub committees, with role descriptions for trustees, honorary officers, and key staff and to ensure that there are clear reporting procedures which are also recorded in writing and complied with.
- To collectively ensure that the responsibilities delegated to the Chief Executive are clearly expressed and understood and directions given to him/her come from the Board as a whole.
- To collectively ensure that the Chief Executive develops a learning organisation and that all staff paid and unpaid review their performance and regularly receive feedback.
- To collectively exercise effective overall control of the charity's financial affairs and to ensure that the way in which the charity is administered is not open to abuse, unscrupulous associates, employees or volunteers and that the systems of control are rigorous and constantly maintained through regular evaluation and improvement in light of experience.

## Governance and Performance

- To ensure that the charity has a governance structure that is appropriate to its developing size and complexity, and meets its charitable objectives.
- To collectively ensure that there are mechanisms in place for beneficiaries, volunteers, other individual groups or organisations to bring to the attention of the trustees any activity that threatens the probity of the charity.
- Engage with volunteers and other beneficiaries to keep informed about the organisation's activities and wider issues that affect the charity's work.
- To reflect annually on the Board's performance and your own performance as a trustee.

- To ensure that there are systematic, open and fair procedures for the recruitment or co-option of trustees.
- To elect a Chair and other officers.
- To collectively ensure that there are succession plans for the Chair and Chief Executive.
- To participate in the collective development and training of trustees.
- To abide by the code of conduct for trustees.
- To ensure that major decisions and Board policies are made by trustees acting collectively.

#### Other

- As requested by the Chair, to represent the Board at functions and events, and lead or be a member of committees/panels/groups.

### Specific attributes of a trustee with a finance background

The ideal candidate will bring to the Board strong skills and experience in finance and treasury management. They will also have a good understanding of the principles of strategic planning, good governance and risk management.

The role will include being a member of the Finance, Audit and Risk Committee. The overall purpose of this committee is to assist the Board in its duty to supervise the broad direction of Young Epilepsy's financial affairs including:

- Acting as a sounding board and source of advice to the executive team on major areas of change, innovation and development.
- Monitoring and reviewing all aspects of the Young Epilepsy's financial performance including financial reporting, management accounts, financial forecasts, capital plans, restricted funds, cash flows and banking covenants.
- Considering the financial implications of proposals for areas of major new strategic development.
- Assisting in identifying Young Epilepsy's major risks and developing appropriate approaches to risk management.
- Reviewing Young Epilepsy's arrangements in relation to reserves, including its reserves policy.
- Monitoring and reviewing Young Epilepsy's arrangements in relation to investments, including its investment policy.
- Considering the adequacy and appropriateness of the external and internal audit arrangements.
- Considering the risks and costs associated with Young Epilepsy's defined benefit pension scheme.

### Specific attributes of a trustee with an education background

The ideal candidate will bring to the Board strong senior level experience within successful schools or colleges (special school experience would be particularly welcome) and /or within the education regulation sector.

The role will include being a member and in time the Chair of the Education Governing Body (the EGB) of St Piers School (a non-maintained special school for pupils aged five to 19) and St Piers College (an independent specialist further education college for young adults aged up to 25).

The EGB reports to the Board and its responsibilities include:

- Monitoring the effective management and performance of St Piers School and St Piers College.
- Advising the Board on achievements and areas for improvement.
- Making recommendations to the Board on the following matters:
  - Strategic direction
  - Quality assurance
  - Safeguarding
  - Education budgets
  - Curriculum
  - Staffing
  - Compliance with statutory requirements

The EGB has six scheduled meetings at regular intervals throughout the school and college year.

# Person specification

- Commitment to the ethos, purpose and role of Young Epilepsy with the capacity to relate to people with disabilities.
- Skill and sensitivity in dealing with people at all levels, both internally and externally.
- Intellectual capacity to grasp issues outside personal experience and to take a strategic view.
- Ability to inspire confidence and build positive relationships with Young Epilepsy's principal stakeholders.
- A commitment to working collaboratively and to work towards consensus in making decisions to support the effective operation of the charity and its performance.
- A strong commitment to taking into the account the views of beneficiaries of the charity when making decisions about the services provided by Young Epilepsy.
- A strong commitment to safeguarding the wellbeing of children and young people who are beneficiaries of Young Epilepsy's work.
- The capacity to utilise a personal network of contacts and to make new links for the charity.
- An ability to work effectively as a member of a team.
- Strategic vision coupled with the ability to focus on practical issues.
- A willingness to speak one's mind.

## Diversity

The charity seeks to ensure that the composition of the Board reflects equality and diversity.

## Terms of appointment

There are six Board meetings per year and each trustee is expected to sit on a sub-committee or take a special lead interest in an area of activity. The Education Trustee will also be a member of the EGB and therefore also be expected to attend six scheduled meetings throughout the year.

Board meetings for 2020 will take place on the following dates:

26 March  
7 May (Away Day)  
9 July  
1 October  
3 December

These roles are unremunerated.



# How to Apply

Saxton Bampfylde Ltd is acting as an employment agency advisor to Young Epilepsy on this appointment. Candidates should apply for this role through our website at [www.saxbam.com/appointments](http://www.saxbam.com/appointments) using code **UAIAS**.

Click on the 'apply' button and follow the instructions to upload a CV and cover letter outlining why you would like to be a Trustee for Young Epilepsy. The closing date for applications will be at **noon on Thursday 27<sup>th</sup> February**.

Informal one to ones with the Chair will take place with the Selection Committee at Young Epilepsy in mid-March and it is anticipated that a formal interview will take place on **Wednesday 1<sup>st</sup> April**.

#### GDPR personal data notice

According to GDPR guidelines, we are only able to process your Sensitive Personal Data (racial or ethnic origin, political opinions, religious or philosophical beliefs, trade union membership, genetic data, biometric data, health, sex life, or sexual orientation) with your express consent. You will be asked to complete a consent form when you apply and please **do not** include any Sensitive Personal Data within your CV (although this can be included in your covering letter if you wish to do so), remembering also not to include contact details for referees without their prior agreement.

\* The equal opportunities monitoring online form will not be shared with anyone involved in assessing your application. Please complete as part of the application process.

