



**Young  
Epilepsy**

**Appointment of Trustees**

**November 2023**



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## Welcome from Jane Ramsey, Chair

Dear Candidate,

I am delighted that you have expressed an interest in applying to be a Trustee of Young Epilepsy. We hope that you find the information in this candidate brief and on our website useful: <https://www.youngepilepsy.org.uk/>

Childhood epilepsy can be frightening, isolating and often a misunderstood condition. There is a huge demand for information and support for parents and professionals and a need to improve access to, and quality of, health and education services. Young Epilepsy is a national charity that is the UK's major provider of services to children and young people with epilepsy and associated learning, emotional and behavioural difficulties. For 125 years, we've led the way in an inclusive, progressive and nurturing approach to the education and support of children and young people with epilepsy so that they can fulfil their potential. It is our job to ensure their voices are heard and their rights protected.

The Board of Trustees currently has 12 members and is responsible for the governance of Young Epilepsy and ensuring that its activities are within its charitable objectives. The Board sets the strategic direction of the charity and is supported by the Education Governing Body (EGB) which oversees St Piers School and College. With some long-standing trustees coming to the end of their terms of office, we are now keen to recruit two trustees. One will bring professional special education experience from wider education settings such as, schools, colleges and ideally residential education or as a school governor. Ideally, this individual will also join the Education Governing Body as Governor and also have experience, or an interest, in safeguarding. In addition, we are looking for a trustee with digital communications experience to ensure we are engaging fully with young people.

If this is an opportunity that appeals to you, and you have the skills set out in the job role and key responsibilities section in this candidate brief, we would very much like to hear from you.

Yours sincerely,

*Jane Ramsey*

Jane Ramsey, Chair









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## 2. About Young Epilepsy

Established in 1897, the National Centre for Young People with Epilepsy is a national charity that is the UK's major provider of services to children and young people with epilepsy and associated learning, emotional and behavioural difficulties. The trading name, Young Epilepsy, launched in Nov 2011, reflects our ambition to reach as many of the 100,000 or 1 in 200 children and young people with epilepsy, as possible.

### What we do

We campaign for children's rights. We deliver health services and research that improve diagnosis and treatments. We support children and young people throughout school, college, and university. We provide information, friendly advice, and practical help for living everyday life. We have developed a new range of services including health information resources, training courses for professionals in health, social care and education and the promotion of good practice in schools.

#### our vision

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.

#### our purpose

To inform, educate, inspire, and engage the nation, through young people with epilepsy living ambitious and fulfilled lives.

#### our values

Young people are at the centre of everything we do

We work together to make a greater difference

We are courageous and ambitious for change

#### our offers

Health & Research

Voice & Support

Specialist education

### Campaigns

Our campaign priorities are led by the views and experiences of children and young people with epilepsy. We work closely with our Young Reps and Young Supporters to inform our campaigning work and support them as advocates for children and young people with epilepsy across the country.

We campaign to improve systems of support for children and young people with epilepsy by influencing policy in government, healthcare and education to ensure the rights of children and young people with epilepsy are upheld. Our latest campaign [#OnTopOfEpilepsy](#) calls on UK healthcare leaders to integrate mental health screening and support into paediatric epilepsy care.

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## Health Services

Young Epilepsy's health and research centre is a diagnostic, rehabilitation and behavioural assessment unit in the UK specialising in in-patient and out-patient services for children and young people with epilepsy. Our interdisciplinary team of health and education specialists offer a holistic approach to healthcare.

## Support

Our Support and Inclusion Team work with children and young people with epilepsy who have a range of abilities and needs and our Youth support coordinators provide one-to-one guidance, whole-family support and social get-togethers for children and young people with epilepsy, and their families. Support includes:

- Giving a young person a safe space to speak.
- Informing young people of their rights.
- Creating a community for young people, to meet others with the condition and share their stories.
- Empowering young people to improve their outlook on living with epilepsy, building their resilience, confidence and independence.
- Helping children and young people manage their wellbeing and mental health, signposting them to the help they need.







## St Piers School and College, Lingfield

Our specialist services include a school, college and residential services providing education, boarding and healthcare in Lingfield, Surrey. Our estate includes St Piers School, a non-maintained residential special school for pupils aged 5 to 19, St Piers College, an independent specialist further education college for young adults aged up to 25 and adult residential provision. The Education Governing Body is tasked with supporting the Board to oversee the education (including residential) services at Young Epilepsy.

St Piers has pioneered an approach to education focused on developing empowered, happy young people, who can fulfil their ambitions in a nurturing environment that creates a sense of purpose and self-belief in the individual. We are proud of the history of St Pier's estate, its services for children and young people, and its place in the local community.

To find out more about how we support special educational needs and disabilities at St Piers, visit [St Piers | Homepage](#).

## Information and Online Resources

[The Channel](#) is Young Epilepsy's digital solution to provide children and young people with epilepsy the information they need to make decisions that enable them to achieve their best quality of life. Launched in March 2020, the channel has outstripped expectations, growing from 7,000 unique visitors in July 2020 to almost 20,000 by July 2021.

One of its more significant developments is The Hub which was launched in December 2020 and is a space where children, young people and their parents can share experiences, tips and questions, to support each other to make their lives better.

Our [five-year strategy for 2020 – 2025](#) builds on our strong heritage of national expertise and innovation in the education, health and care of children and young people living with epilepsy. Our strategy is directly shaped by the voices and views of the children and young people with whom we work with and is enhanced by a world-leading clinical research partnership with Great Ormond Street Hospital and UCL GOSH – Institute of Child Health.



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## Our Programmes

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

**Voice and Support** - Campaigning for children's rights, supporting them in school and college, and providing innovative tools, information, and practical help for living day-to-day life. We aim to connect and support children and young people with epilepsy who are in mainstream settings alongside their education on campus.

**Health and 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.

**Specialist Education** – An innovative and creative environment for children and young people with epilepsy, autism, and severe learning difficulties.

Further information can be found in our [Annual Report & Accounts 2021-2022](#) and our [Research and Impact report 2022](#).





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## Our commitment to Equality, Diversity and Inclusion

At Young Epilepsy we are committed to creating a diverse, inclusive and safe environment where we embrace each other's differences and celebrate individuality. We recognise and support our Shine Working Group, made up of staff members from across Young Epilepsy and St Piers, which has a core purpose of making Equality, Diversity, Inclusion and Belonging part of our culture so staff can bring their whole selves to work. We work together to encourage Young Epilepsy and St Piers to be the best workplace it can be for all staff, shape our organisation's EDI&B strategy and objectives, actively reflect on our processes and practices to create real change and amplify the voices of underrepresented groups within our organisation.





## Our People

Young Epilepsy is a team of young people, researchers, product developers, service providers, policy makers, campaigners, and fundraisers, plus an international network of partners.

Our [Executive Team](#) is responsible for providing strategic and operational leadership within the charity and is led by the Chief Executive.

The [Board of Trustees](#) governs the affairs of the charity, ensuring that we are well run and deliver charitable outcomes that benefit children and young people with epilepsy. The Board is supported by six sub-committees:

- Finance, Audit and Risk Committee
- Fundraising and Communications Committee
- Health Services Committee
- Remuneration Committee
- Nominations Committee
- Education Governing Body.

The [Education Governing Body](#) oversees the provision of education (including residential) services at St Piers School and College. Four of the Governors, including the Chair of the EGB, are also Trustees.



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Young people are at the centre of everything we do, and we are striving to ensure that every young person with epilepsy has the opportunity to be heard and their condition better understood.

### **Young Trustees**

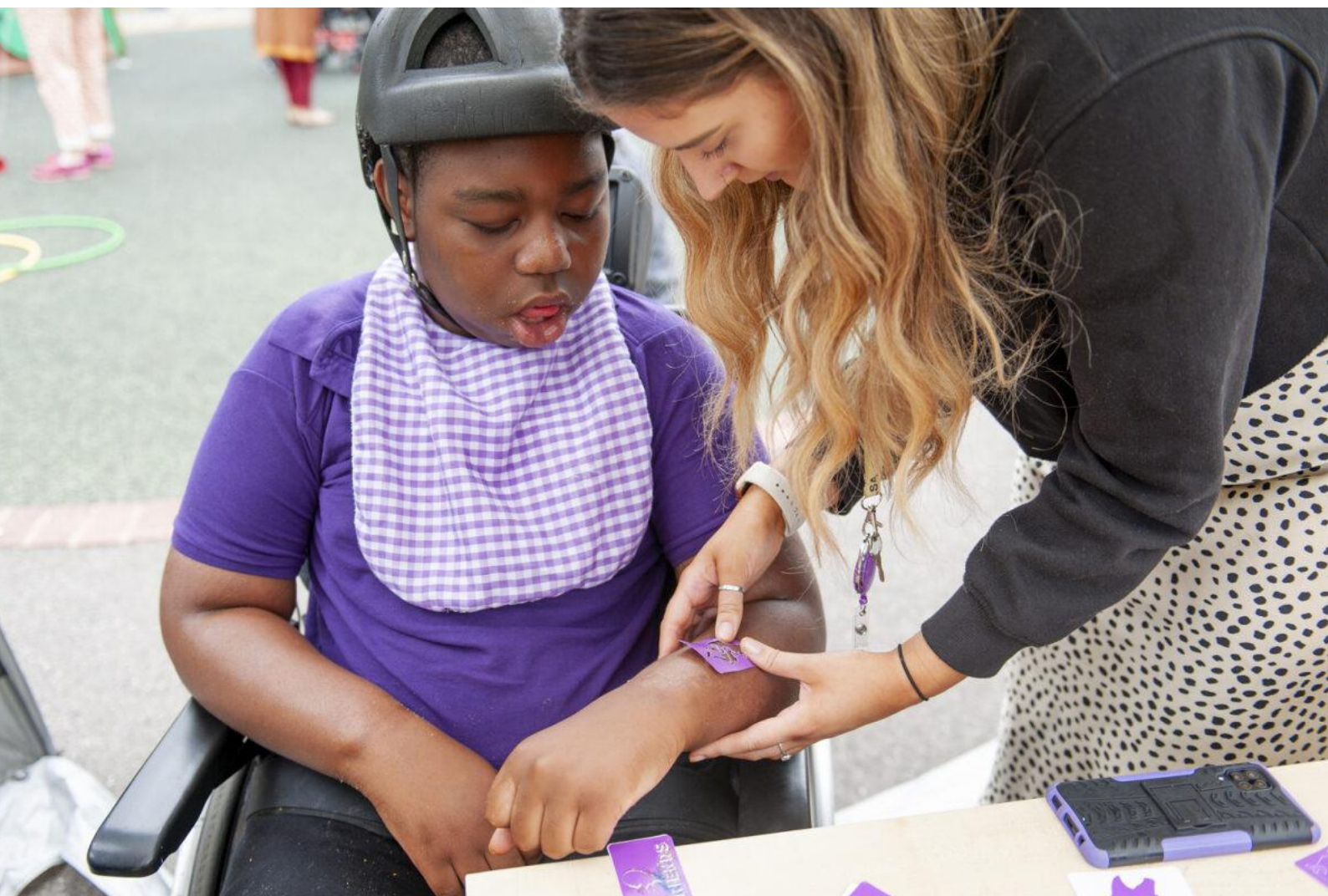
Our Young Trustees are the link between our Young Reps and Young Epilepsy's Board of Trustees (the Board). We have two Young Trustees who are members of the Young Reps group. Young Trustees are not formal voting members of the Board but attend Board meetings in an advisory role to ensure that the needs of Young Epilepsy's beneficiaries are at the forefront of the Board's decision making.

### **Young Reps**

Our Young Reps group is compiled of young people aged 16-25 who represent children and young people living with epilepsy throughout the UK. The group is fundamental in ensuring that young people are at the centre of everything we do; the Young Reps contribute to our strategy and are involved at all levels of the charity to ensure that decisions and overall direction of services provided meet the needs of children and young people with epilepsy.

### **Young Supporters**

The Young Supporters Network is a less formal participation group open to any number of young people with epilepsy aged 13-25. They meet at least every three months and have many opportunities to get involved.



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### 3. The role and responsibilities of the Trustee

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

Trustees are responsible for the performance of the charity, its culture and values and for ensuring that Young Epilepsy complies with all legal and regulatory requirements. They must act as guardians of the charity's assets, both tangible and intangible, taking all due care over their security, deployment and proper application. Trustees provide strategic guidance and leadership to the charity, using their skills and experience to assist the organisation in continuing to make a difference.

The duties of a Trustee are:

- to ensure that the charity complies with its governing documents, relevant legislation and regulatory requirements
- to ensure that the charity pursues its charitable objects (purposes), as defined in its governing documents, including through setting and overseeing a long-term strategy for the charity
- to ensure that the charity defines its goals and evaluates performance against agreed targets
- to ensure the values of the charity are articulated and reflected throughout the charity with its Trustees, staff, volunteers and beneficiaries
- to ensure that the charity applies its resources exclusively in pursuance of its charitable objects and for the benefit of the public
- to protect and manage the resources of the charity and ensure the proper investment of the charity's funds
- to ensure the effective and efficient administration of the organisation, including having appropriate policies, procedures and controls in place
- to safeguard and promote the good name of the charity
- to take reasonable steps to protect from harm people who come into contact with the charity, including promoting a fair, open and positive culture and ensuring all involved feel able to report concerns, confident that they will be heard and responded to
- to exercise effective overall control of the charity's financial affairs and to ensure the financial stability of the charity
- to ensure proper and formal arrangements are followed in the appointment, supervision, support, delegation to, appraisal and remuneration of the chief executive
- to use any skills, knowledge or experience they have to help the Board of Trustees reach sound decisions
- to ensure that the charity has a governance structure that is appropriate to its developing size and complexity.





## 4. Person specification

- A commitment to the ethos, purpose and values of Young Epilepsy
- A willingness and the ability to devote the necessary time and effort to the Trustee role
- The ability to think strategically, coupled with the ability to focus on practical issues
- A willingness to participate in the collective development and training of Trustees
- An understanding and acceptance of the legal duties, responsibilities and liabilities of charity trusteeship
- Skill and sensitivity in dealing with people at all levels, both internally and externally
- The ability to inspire confidence and build positive relationships with Young Epilepsy's principal stakeholders
- A willingness to speak one's mind while at the same time committing to working collaboratively and towards consensus
- A commitment to taking into the account the views of beneficiaries when making decisions
- A commitment to safeguarding the wellbeing of children and young people who are beneficiaries of Young Epilepsy's work
- A commitment to act in the best interest of the charity's beneficiaries and to declare any real or perceived conflicts of loyalty or interest
- A commitment to abide by the Code of Conduct for Trustees.

### Recruitment focus

At this time, we are specifically seeking experience and expertise in the following areas:

- **Professional special education experience; this could include wider education settings such as, schools, colleges or residential education.** You might be a former headteacher of a special school - ideally a boarding school; a school Governor; former CEO of a group of special schools; or experienced, and interested, in SEND from working in mainstream schools. In all cases, we are looking for individuals who can provide senior, strategic input on specialist education.
- **Digital communications and marketing experience, including social media.** We are looking for individuals who bring experience of social media platforms to support, and enhance, our connectivity and communication with young people and escalate our reach into student communities. You might be in a consultancy working on digital campaigns; running digital communications in another charity; or in a social media organisation.

We welcome Trustees with lived experience of epilepsy and parents of children and young people with epilepsy.

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## 5. Terms and Conditions

### Time commitment

The Board of Trustees meets six times a year – twice in London and four times in Lingfield, Surrey. Wherever possible, Trustees are expected to attend Board meetings in person although it is understood that there are occasions where remote attendance only is possible.

Sub-committees meetings are usually run as remote meetings, with the exception of the Education Governing Body which tends to be a mix of in person and online.

All Trustees are expected to join one or more of the sub-committees to the Board of Trustees. In particular, we are seeking Trustees to join:

- The Education Governing Body
- The Nominations Committee
- The Remuneration Committee
- One of the other sub-committees best fitted to the Trustee's experience and expertise.

The Board of Trustees has delegated responsibility for the governance of education and residential provision to the Education Governing Body (EGB), with a number of areas remaining with the Trustee Board. This is an active committee which meets six times a year and has its own sub-committees and the members of this committee will be heavily involved in work of St Piers School and College.

Trustees can serve a maximum of two terms of three years, with a third term in exceptional circumstances.

### Location

St Piers Lane, Lingfield, Surrey, RH7 6PW

### Expenses

Trustees are all volunteers, although reasonable out of pocket expenses are covered.

### Induction/Training

A full induction and training programme is provided.





## 6. How to Apply

Saxton Bampfylde Ltd is acting as an employment agency advisor to Young Epilepsy on these appointments.

Candidates should apply for this role through our website at [www.saxbam.com/appointments](http://www.saxbam.com/appointments) using code **XBKIA**.

Click on the 'apply' button and follow the instructions to upload a CV and cover letter, and complete the online equal opportunities monitoring\* form.

The closing date for applications is **noon on 14th December 2023**.

\* 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.

### **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.



# Saxton Bampfylde

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# Young Epilepsy

