Better futures for young lives with epilepsy

This is the NCYPE
Better futures for young lives with epilepsy

www.ncype.org.uk
Here at The National Centre for Young People with Epilepsy (NCYPE) we want to create better futures for young lives. As a national charity and a centre of expertise for all young people with epilepsy, we have over 100 years’ experience to share.

About us

On our Surrey campus, students with complex epilepsy and other conditions make great progress at our residential special School and Further Education College.

Professionals and families get expert training and support through our Childhood Epilepsy Information Service.

The NCYPE works in partnership with Great Ormond Street Hospital and the Institute of Child Health at University College, London.

Our new, world class Neville Childhood Epilepsy Centre brings together medical, therapy and research expertise to help diagnose and treat young people with epilepsy across the UK and beyond.

Whether you are a young person or parent, teacher or clinician, supporter or future member of staff – find out more in this brochure or at our website www.ncype.org.uk about how we can work together to create better futures for young lives with epilepsy.

David Ford, Chief Executive
Epilepsy means someone is having recurrent seizures (sometimes called ‘fits’) where excess electrical activity in the brain sends confused messages to the rest of the body. This can lead to twitching of the limbs, stiffness, loss of consciousness or brief ‘absences’ where the brain switches off but the person appears normal.

Around 60,000 children and young people under 18 in the UK have epilepsy. In most cases the condition can be controlled by anti-epileptic drugs (AEDs) and the young person can attend mainstream school. For some young people, seizures can cause learning problems and the AEDs can lead to unwanted side effects.

Added to that is the stigma which leaves many young people battling low self esteem, bullying and a lack of understanding from both peers and adults.

Through our ‘Better Futures Campaign’ the NCYPE is pressing policymakers, health trusts, local authorities and schools to provide improved services and support so that these 60,000 young people can have a better future.

Join our campaign at www.ncype.org.uk.
Changing lives

St Piers School

All students at St Piers School are supported by an expert team of dedicated teachers, support staff and therapists.

Young people attend our school and sixth form on a day or residential basis. Many have a range of learning disabilities caused by their epilepsy. As well as an adapted National Curriculum, interactive technology and innovative use of music, art and drama all ensure that students learn and gain new skills.

Campus sports activities such as canoeing are combined with trips to the theatre and shopping as well as short holiday breaks for residential students.

Sixth formers also have the opportunity to undertake work experience with local employers and learn other life skills as they make the transition to further education or supported living.

Student houses are designed to give home-from-home support. Each student has their own bedroom with shared dining and living rooms, and where appropriate some houses have sensory areas.

All students benefit from the on-site consultant-led medical unit, part of the new, purpose-built Neville Childhood Epilepsy Centre on the NCYPE campus.

School Fact:
We run the Sure Start Children’s Centre for all local families – see www.surestartrfield.org.uk to find out more.
The NCYPE Further Education College aims to inspire each student to reach their full potential. We offer high quality, tailored education on a day or residential basis for young people aged 16 to 25 with different levels of learning disabilities.

A ‘waking day’ curriculum, where students learn life skills - such as cooking, cleaning and how to manage their own money – at evenings and weekends, complements the structured learning that takes place during the timetabled week at the college.

Many students attend local mainstream colleges for additional learning opportunities. Fridays are set aside as an enrichment day where students choose from options such as swimming, film-making, drama, floristry and ICT.

There are numerous after-college activities, the most popular being football, disco and karaoke. Staff work with students to organise social balls, barbeques, sports events and outings.

As with St Piers School, all students benefit from expert teaching, support and therapy as well as the specialist medical facilities at the Neville Childhood Epilepsy Centre on our campus.

College Fact:
Three quarters of college students gain work experience with local employers or in other departments on campus.
“I had more help from the NCYPE in four hours than from my local services in four years.”

“I was amazed by the students and blown away by the Neville Centre.”

“The staff at NCYPE provided excellent pastoral care for my daughter.”

“Often charities just talk – when the NCYPE campaigns, it takes action!”

“I feel much more independent here – it has helped me cope with my epilepsy.”

“Since being at St Piers School my son does a hop, skip and a jump into school every day.”
The Neville Childhood Epilepsy Centre is the first purpose-built centre for paediatric epilepsy in the UK.

The state-of-the-art building, funded by major donors, hosts a wide range of diagnostic, assessment and rehabilitation services for young people aged three to 19 with epilepsy and other neurological conditions.

We have the latest electroencephalogram (EEG) equipment in specially designed suites and a team of on-site paediatric neurologists, therapists, nurses and psychologists. The care we offer both to NCYPE students and young people coming for assessment is second to none.

Our experts can design a personalised epilepsy management package that can be implemented once a young person coming for assessment or rehabilitation returns home.

The Neville Childhood Epilepsy Centre is also the base for a coordinated programme of international paediatric epilepsy research across the NCYPE and other institutions, including the Institute of Child Health at University College London and Great Ormond Street Hospital for Sick Children.
Epilepsy
A Parent's Handbook
At the NCYPE our message to parents, professionals and young people coping with epilepsy is: ‘We are here to help!’

We provide a professional and comprehensive information service based on the NCYPE campus – and we travel across the country delivering training courses to doctors, nurses and to teaching, therapy and social work professionals, to name but a few.

Our telephone helpline and enquiry service offers people the chance to speak confidentially with trained staff who have knowledge and understanding of childhood epilepsy.

Part of our role is to educate others about epilepsy and issues associated with the condition, including the impact on learning, the different types of seizures affecting young people, and how to help a child or teenager with epilepsy lead as normal life as possible.

Study days, tailor made training courses, conferences for families and an education programme for schools – whatever your needs, our Childhood Epilepsy information Service can help.
Fundraising at the NCYPE

Whether it's running a marathon, climbing Mount Kilimanjaro, nominating NCYPE as Charity of the Year in your workplace, holding a coffee morning or making a regular donation - there are hundreds of ways to help students at the NCYPE by raising funds for everything from toys, books and playground equipment to specialist tricycles, sensory rooms and minibuses.

Our fundraising team provides help and support for everyone who wants to raise funds for us and we would love to hear from you!

The work of the NCYPE is special and we want everyone to know about it. We invite all of our fundraisers to visit us and see first hand how the money will make a difference to the lives of young people in our care.

Trust and corporate donations also play a vital role in our fundraising efforts, with major donors funding the NCYPE’s state-of-the-art Neville Childhood Epilepsy Centre (see page 12).

See how you can help us at: www.ncype.org.uk/fundraising
The NCYPE was established in 1897 by a religious charity as a ‘colony’ for teaching agricultural skills to men with learning or physical disabilities.

Staff also used the farm, gardens and wildlife to teach children with epilepsy after a school was built here in 1904.

Soldiers with epilepsy caused by brain injury received rehabilitation on-site after World War One. By 1939 the colony was leading the way in national epilepsy research.

In 1957 the Lingfield Epileptic Colony became simply the Lingfield Hospital School for Epileptic Children, and the adults moved to what is now the National Society for Epilepsy in Buckinghamshire.

Children and young people with neurological conditions other than epilepsy were finally admitted to the school in 1972 and in 1989 our name changed to St Piers. By 2001 our Further Education College was open and we were known as The National Centre for Young People with Epilepsy.
The National Centre for Young People with Epilepsy

Chair: Anna Walker CB
Chief Executive: David Ford
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St Piers Lane, Lingfield, Surrey RH7 6PW
Tel: 01342 832243  Fax: 01342 834639  Email: info@ncype.org.uk  www.ncype.org.uk

Childhood Epilepsy Helpline 01342 831342 Monday-Friday 9:00am – 1:00pm
Email: enquiries@ncype.org.uk

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