




Students from the NCYPE's St Piers School enjoying themselves on our campus lake.

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 **First of all I would like to welcome you to the very first edition of the 'Voice', The National Centre for Young People with Epilepsy's (NCYPE) brand new official childhood epilepsy newsletter.**

With the launch of our national Childhood Epilepsy Information Service and the opening of a state-of-the-art student house, the last 12 months have been an exciting time for the NCYPE, as you will see inside.

However more recently our thoughts have been with our Vice President David Cameron and his family following the death of his son Ivan. This sad event has highlighted the profound effect epilepsy can have on the lives of young people and their families.

We are committed to making a lasting difference to all those affected by childhood epilepsy, and I hope you will find the stories inside both informative and inspiring.

I am very proud that Professor Helen Cross has joined us as the new Prince of Wales's Chair of Childhood Epilepsy. Professor Cross is a world authority on childhood epilepsy and you will find an interview with her in this edition of the 'Voice'. We also have exciting news about Roy Williams House opening, which is a new house for Further Education College students, and an update on the new Neville Childhood Epilepsy Centre.

Your support – whether as a parent, professional or funder – plays a vital role in our work.


I look forward to working with you in the future.



... better futures for young lives



Interview with Professor Helen Cross

 **Professor Cross has three organisations to please as the current Prince of Wales's Chair of Childhood Epilepsy: The National Centre for Young People with Epilepsy, University College London's Institute of Child Health and Great Ormond Street Hospital.**

She qualified in medicine at Birmingham University and subsequently trained in paediatrics in Birmingham, then changing to paediatric neurology in London where she obtained her PhD.

Professor Cross has been involved in developing epilepsy services at Great Ormond Street Hospital for Children NHS Trust, particularly the epilepsy surgery programme.

Her research interests include neuroimaging as well as the role of early surgical intervention and new treatments in childhood epilepsy. In addition she is involved in national and international collaboration in the development of epilepsy services, teaching and research.

She is married with three daughters.

We asked Helen a few questions about her new role.

Why did you want to be The Prince of Wales's Chair of Childhood Epilepsy?

This is an exciting new opportunity to further research and services for children with epilepsy.

What is the best element of the job for you?

The diversity, mixing with and having the opportunity to work with many different disciplines.

And the worst?

The likely workload - feeling it's impossible to get everything done, but that is almost part of the challenge.

Why did you want to become a paediatric neurologist?

Children certainly cope with illness in a remarkable way; paediatric neurology continues to give us new challenges and the opportunity to make further discoveries.

What difference do you think the opening of the Neville Childhood Epilepsy Centre at the NCYPE will make?

It will provide a physical location for furthering research and services for children with epilepsy - ultimately with the aim of being the leading centre in Europe.

What are the top three areas of research which will make a difference over the next few years?

Genetics, and the possible discovery of targeted treatment. Advances in higher detail brain imaging and improving outcomes from surgery. Working together internationally to determine effective treatments in specific epilepsies.

Do you think there will ever be a cure for epilepsy?

I think it likely we will make inroads into treatment before a 'cure' - it is not a single condition and therefore a single 'cure' to cover all is unlikely.

What is the main advice you give to families to help them deal with a child's epilepsy?

Each child and family situation is individual. One has to listen, and review the problems at the forefront of the situation at the time. The advice given will of course depend on the type of epilepsy and circumstances of that child. What we think is the advice required may not be what they are looking for - hence the need to listen.

Why is the NCYPE's work so important?

It is important to continually raise the profile of childhood epilepsy - the NCYPE has the advantage of having expertise in all areas of childhood epilepsy and therefore can not only raise the profile but also further the knowledge base of others.

What are your hobbies and interests outside work?

There is little time, but I spend as much time as I can with my family, usually enjoying outside pursuits.

What do your family think of your work?

They think it takes up a lot of time, but also appreciate what I do is important to children with epilepsy and their families, and are very proud.


See above for Professor Helen Cross's lecture, or go to our website at www.ncype.org.uk/events

Diary Dates

Date	Event
27 April 2009	Study day on Childhood Epilepsy Primary School Staff. Suitable for teachers and support workers
18 May 2009	Study day on Childhood Epilepsy Carers. Suitable for staff working in care homes and care agencies as well as parents
20 May 2009	Professor Helen Cross's Inaugural Lecture at The Royal College of Physicians in London
9 June 2009	Study day on Childhood Epilepsy Educational Psychologists
3 July 2009	Study day on Childhood Epilepsy Secondary School Staff, teachers and support workers
15 Sept 2009	Study day on Childhood Epilepsy Speech and Language Therapists
17 October 2009	Parents and Families Conference

For more information about these events please visit our website at www.ncype.org.uk/events and www.ncype.org.uk/epilepsy

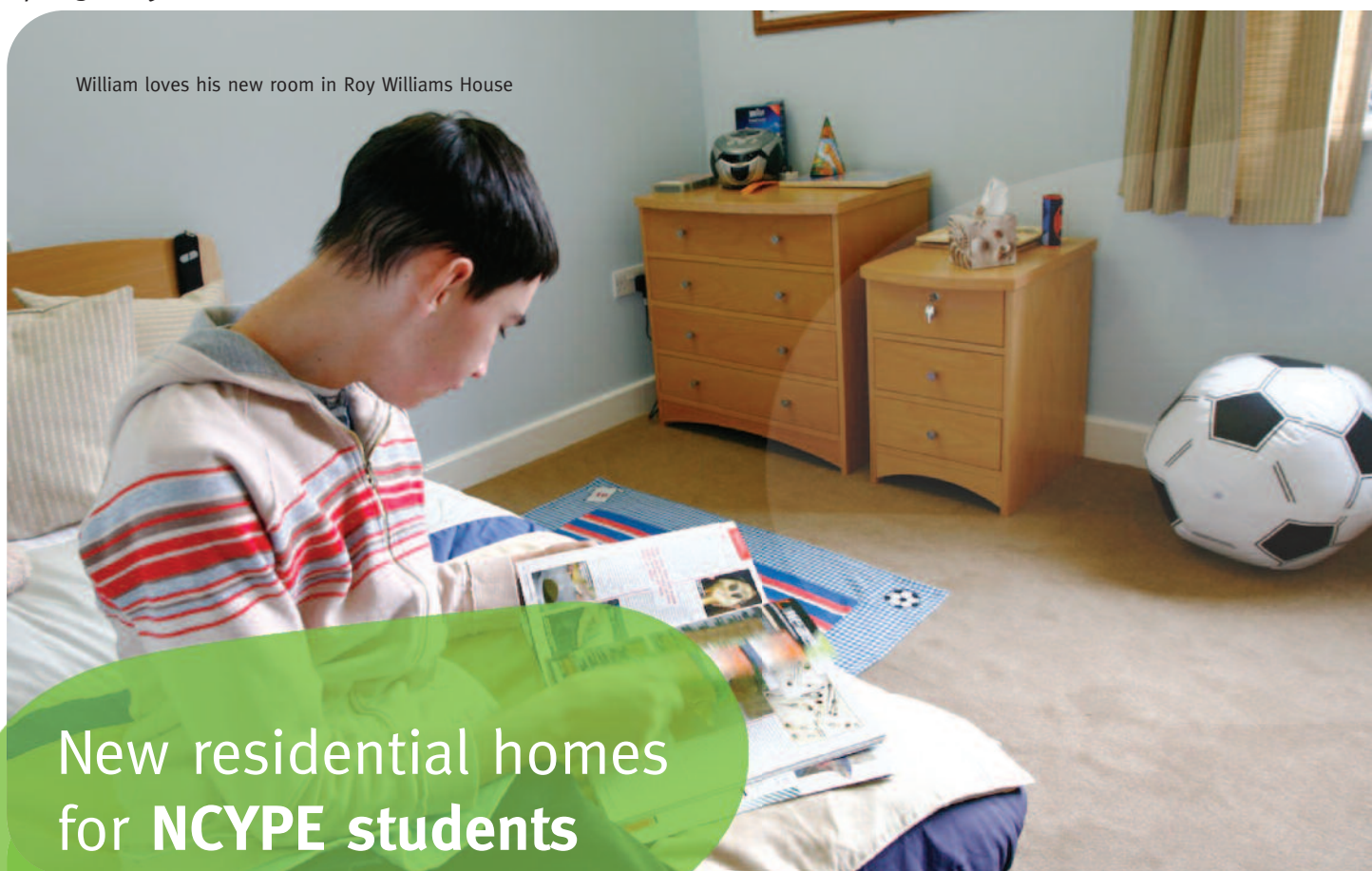
National Epilepsy Week

 National Epilepsy Week is an event that takes place once a year, and aims to raise awareness of epilepsy and its effects on both those who have the condition and their friends and family.


This year National Epilepsy Week will run from 17 - 23 May, including an event for lobbying MPs.

The NCYPE will be showing its support with some exciting developments and new projects....watch this space and keep in touch with news via www.ncype.org.uk

William loves his new room in Roy Williams House




New residential homes for NCYPE students

 The new student accommodation, Roy Williams House, named after the Chairman of the NCYPE, was officially opened by NCYPE President Sir Bryan Nicholson in September.

The house is home to 24 students, with four units each boasting six ensuite student rooms, communal kitchen, dining room and living area, which includes televisions and DVD players. Each floor has breakout areas, staff offices and storage facilities.

Sir Bryan Nicholson said “It may be simply bricks and mortar but it means so much more than that. It is the foundation of our work here – to provide a home from home for children and young people whose lives we want to change for the better.”

 The new Medical Assessment and Research Centre, currently under construction at the NCYPE has been named after Professor Brian Neville, the first incumbent of The Prince of Wales’s Chair of Childhood Epilepsy.

Professor Neville is a leading paediatric neurologist and NCYPE trustee who came up with the concept of the centre and was very involved in the four-year, £6.9m fundraising campaign for the new building. It now has a roof over the main section and insulation, windows and the structure in place for the conference centre.

Professor Brian Neville said: “I have always wanted to see research and expertise in childhood epilepsy gathered in one place and it’s a great honour that the NCYPE has named it the Neville Childhood Epilepsy Centre. I look forward to a successful opening and to the work that it is to follow”.

The Childhood Epilepsy Information Service is holding its second Parents and Families Conference this October.

It is scheduled to take place on Saturday 17 October 2009 in London. If you would like to register your interest for this event please email info@ncype.org.uk or phone **01342 832243** ext 296.

The first conference, held in October 2008, was a highly successful event with over 100 people attending on the day. The event provided many opportunities for parents and families, these included:

- Talks and workshops on topics of interest indicated by parents

- Information stands from a variety of other charities
- A chance to meet people and share experiences

In summer 2009, we are producing a handbook for parents of children newly diagnosed with epilepsy. If you would like to register your interest in receiving a copy, then please email info@ncype.org.uk with your contact details and the word 'HANDBOOK' in the subject line.



Help for Parents and Young People

News from the Neville Childhood Epilepsy Centre



Harriet's Story

Harriet is 13 and suffers from severe epilepsy. She started at St Piers School on the NCYPE campus in September last year. Upon arrival Harriet found new situations very difficult, such as going to school. Her concentration was poor and Harriet found it difficult to learn new skills. Since then she has become a much happier child who now enjoys learning and interacting with others.

Harriet's mother Jan said: "Friends and family have noticed a massive change in Harriet; she's gained independence and become a lot happier and calmer since starting at the NCYPE."



Lingfield Park Racecourse chooses the NCYPE as its charity of the year

The NCYPE is delighted to announce that Lingfield Park Racecourse has selected us as their charity of the year for 2009.

It is hoped that the partnership will raise several thousands of pounds through various events and initiatives throughout the year, which will help the 200 children and young people who live and study at our campus, also in Lingfield, Surrey.

Kevan Hodges, Managing Director of Lingfield Park said: "We know the money raised will make a real difference to the children's lives – and it's great to be able to support a charity so close to home which is doing such inspiring work."

Following the announcement of this partnership, the NCYPE is pleased to confirm that we will be holding our first ever charity raceday. We are inviting supporters to join us for this fabulous event which takes place on Friday 2 October 2009.

Tickets are available at £75 per person which includes entry to Lingfield Park Racecourse, an exciting afternoon of racing, along with a superb 3-course lunch in Lingfield Park's exquisite Pavillion Suite.

For further details or to make a booking, please contact Fundraising on **01342 831245** or email **fundraising@ncype.org.uk**. Tickets are limited so don't miss the chance to enjoy a fantastic day at the races whilst helping us to support the children and young people at the NCYPE.

Pantomime Visits



In December last year students from the NCYPE Further Education College were given the opportunity by PriceWaterhouse to go to see their pantomime Dick Whittington.

The general consensus from students was that they had a thoroughly enjoyable time and they were ecstatic that they were able to go on stage and meet the cast. Students said that the pantomime was "good", "great" and "the best".

So when another pantomime opportunity came along, this time *Sleeping Beauty* at the Peacock Theatre in London, students and staff were keen to reserve their seats.

The students were delighted with what they saw. Again "great" was the most popular word used, they liked the characters and booed, chanted and clapped all the way through.

We would like to thank both theatre companies for their support as this kind of activity enhances the 24 hour curriculum, emphasising social interaction, life skills and independence for our students.

Look out for our new FE College prospectus at www.ncype.org.uk

Donation Form

You can make a donation to the NCYPE by filling out the form below; alternatively you can donate online by going to our website www.ncype.org.uk

I would like to donate to the children and young people at the NCYPE.

Amount £

I enclose a:

Cheque ☐ Postal Order ☐ CAF voucher ☐

Or please debit my:

Switch ☐ Mastercard ☐ Visa ☐

Mr/Mrs/Miss/Ms (please circle)

First name: _____

Surname: _____

Address: _____

Postcode: _____

Card no:

Valid from:

Expiry date:

Gift aid:

If you are a UK taxpayer, the NCYPE is able to claim back the tax, currently 28p for every £1 you give, on every donation you make at no additional cost to you.

Gift aid it Yes ☐ No ☐

Signature: _____ Postcode: _____ Date: _____

Once you have completed the form, please send it with your donation to:


The National Centre for Young People with Epilepsy (NCYPE)
Fundraising Department
St Piers Lane
Lingfield
Surrey RH7 6PW


For more information about fundraising, please call us on 01342 831245 or email: fundraising@ncype.org.uk

Your gift.....their future.

You can make a difference. To find out how to leave a legacy to the NCYPE, please call us on **01342 831245**.

Better futures

 The NCYPE is committed to achieving better futures for young people with epilepsy through increasing the influence it has on those who create policy and those who deliver services. For example, we are working with organisations such as the Association of National Specialist Colleges to warn of the impact on education and care services if funding authorities refuse to increase payments in line with inflation. We are also working with the Joint Epilepsy Council to ensure a fairer system for those children who need significant and continuing care as a result of their epilepsy. Over the coming months we will be identifying other ways of influencing organisations such as schools and Primary Care Trusts. We will keep you informed as we develop this aspect of the NCYPE's work.

 Here at the NCYPE we have a dedicated Creative Arts team who give education professionals outside the NCYPE the opportunity to learn more about teaching and communicating with children and young people who have learning difficulties.

We believe creative arts is a powerful communications tool, it is a creative source of pleasure that raises the human condition and enriches children and young people's lives.

The package that the NCYPE offers is intended to enable teachers to run a complete topic, which is based on music, drama and dance.

The topic this year is based on The Victorians. The sessions provide activities in the form of songs and music informing you of everything you need to know about implementing them.

Go to our website at www.ncype.org.uk for course dates. Alternatively if you would like to find out more about the Creative Arts team then please contact Jacci Kellett on **01342 831335** or email **creativearts@ncype.org.uk**



St Piers School



Creative Arts Workshop