



Spring into action!

- **Join** our Better Futures Campaign
- **Support us** like TV's Nathaniel Parker
- **Come** to our Families Conference
- **Focus** on Total Communication



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Rosie is seven and has refractory epilepsy, autism and speech and language difficulties. She joined St Piers School in 2008 and loves watering the gardens!

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We want to hear from you!
Email voice@ncype.org.uk with your ideas, comments or if you want to unsubscribe from our mailing list.

Campaign for change

Message from David Ford, Chief Executive



Welcome to the new look, bigger and brighter Voice. I am pleased to see how much input we have from across the NCYPE in this issue. You only have to look at our new picture board on the centre pages to see just how much fun life on the

NCYPE campus can be. It's also a very busy time for the organisation with more external training courses than ever being offered by our Childhood Epilepsy Information Service and some lively and high profile events being held by our Fundraising team.

I am also pleased to be leading the Better Futures Campaign with Alan Cruickshank. It is essential that education and health services for the 60,000 children and young people with epilepsy across the UK are improved. Our pilot work with local schools in Surrey to raise epilepsy awareness has had great feedback and we hope to roll it out further afield in the next few months. I am convinced that the campaign is beginning to have a real impact, so please get behind it as much as you can and support the Better Futures cause.

I am looking forward to taking part in Purple Day for epilepsy awareness on 26 March. I hope you are planning plenty of purple activities – contact fundraising@ncype.org.uk for more information or visit our website at www.ncype.org.uk

Better Futures Campaign

Did you know...

- 1 Around 60,000 young people under 18 have epilepsy in the UK, on average this is one child in every primary school and five in every secondary school.
- 2 Up to half of these children and young people are estimated to be not reaching their potential in school.
- 3 Over half of deaths in children and young people with epilepsy are avoidable.
- 4 Only a quarter of children who could benefit from surgery which might cure their epilepsy or reduce their seizures actually get it.
- 5 Misdiagnosis is common; children with epilepsy are not diagnosed and children without epilepsy are diagnosed as having it.
- 6 Epilepsy in childhood is as common as insulin dependant diabetes.

For these reasons, the NCYPE has launched the Better Futures Campaign, designed to improve the lives of children and young people with epilepsy across the UK. Alan Cruickshank, the campaign's leader at the NCYPE, explains more...



“The Better Futures Campaign is working to provide training, guidance and support to a range of organisations and directly with service providers - lobbying those in charge to ensure the right policies are in place. We are determined to find practical solutions, tackle gaps in services, and ultimately make a real difference for thousands of children.

At school, children are too often sent home after a seizure when this may not be necessary. ‘Absence’ seizures (a more common type in children) often go unnoticed or are perceived as ‘daydreams’. This can have a devastating impact

on learning. Anti-epileptic drugs themselves have negative side-effects. Without better understanding and support, schools often struggle to understand the needs of a child with epilepsy.

Change is also vital in health services. A recent survey found only 18% of Primary Care Trusts could estimate how many under 18s in their area had epilepsy, making it difficult to plan services. Formal guidelines from the National Institute for Health and Clinical Excellence (NICE) exist but are not implemented in many areas. It is essential that standards of care are improved.

The social and economic impacts of poorly diagnosed or managed epilepsy are huge. It is time for change. To help this, the NCYPE has created two Better Futures action plans to make a real difference on the ground – one for schools and one for health services.

Discover more about the campaign on the NCYPE website – www.ncype.org.uk – see the action plans, find out about the education pilot scheme and tell us about your experiences.



All about St Piers School

Headteacher of the NCYPE's St Piers School, Nick Byford gives an overview of how the school works and what it achieves:

"The simple fact is that St Piers achieves results where other special needs schools do not. The school has 79 students aged between 5 and 19, with developmental abilities ranging from 6 months to about 14 years. A mixture of residential and day students, the majority have very complex medical and educational issues.

St Piers has an ethos of making the previously inaccessible accessible. It achieves this by ensuring every child is included in everything. St Piers students do not miss out on anything. Whatever the activity, whether canoeing on our lake, practising horticulture and animal care up at the campus farm, or simply working on literacy, St Piers children can do it in a way that is appropriate to their ability.

The school has its own 'Creative Arts' department which is decorated to reflect a different theme every term. Through drama, dance and music, every student takes part and it has been very successful in helping to develop their imaginations.

Much of what St Piers does is achieved through multi-disciplinary team working. Unlike other special needs schools, St Piers has a full set of teaching and care staff, therapy team and medical expertise on campus. Over 100

staff all work together constantly to achieve the right balance of medical and educational support. This means there is a better than 1:1 staff to student ratio.

Staff receive a huge amount of training and support with us. We have trained our own Special Educational Needs (SEN) teachers for the past 8 years, with staff from the care teams studying for Certificates in Education and PGCEs - so far with 100% success rate!

Children who have previously 'failed' at other special needs schools come out of their shell here. Frustrations - that can often bring up behavioural issues - are lifted and real personalities come to the fore. Seizures are treated as part of everyday life. All staff are trained to deal with seizures and if one occurs, in class or during a school activity, there is no panic and no one minds. Students foster this commonality and it manifests itself in them bonding and looking out for each other.

If a child needs medical attention or a psychological observation, someone can attend within 10 minutes. This type of acute observation ensures that medication and therapies can be managed in a much more precise way.

Find out more about St Piers via the school pages on our website: www.ncype.org.uk/school



School gets enterprising

Some of the classes at St Piers have been working on mini enterprise schemes. The picture shows David putting a design on cotton bags and making pictures to put onto calendars. The money raised was given to Christian Aid as the class is also studying Christianity. Part of this included local vicar, Graham Paddock, visiting the school to show the students his clerical clothing.

Voice interview...

Introducing NCYPE's first celebrity ambassador, Nathaniel Parker!



Nathaniel Parker and NCYPE Director of Health and Social Care, Karen Deacon

We asked him a few questions...

How does it feel to become NCYPE's first celebrity ambassador?

It's a huge privilege and I was surprised and honoured to be honest. I can't claim to be any sort of expert on epilepsy, but what I've learnt from my work so far with the NCYPE has taught me a great deal and been extraordinarily emotive. I was shocked to learn that over 60,000 children have epilepsy in the UK and that it can affect anyone at anytime. It seems to be something that is 'swept under the carpet' in wider society and I am delighted to be helping bring it to the fore.

How was your recent visit to NCYPE?

I wasn't sure what to expect, but was amazed by the students and the extremely high level of care they receive at the NCYPE. I was also blown away by the new Neville Centre, the technology available is astounding.

What was your knowledge of epilepsy before and has your awareness of epilepsy been raised by your visit?

I thought I knew what epilepsy was, but since visiting the NCYPE I realised that I knew nothing! So yes - my awareness has been very much raised, which is great.

What do you think of the Better Futures Campaign message?

It's plain that the Better Futures Campaign is crucial to raising awareness of epilepsy issues nationwide. The good it could do in terms of improving health and education services would be fantastic.

Can more be done in schools to combat the stigma attached to children with epilepsy?

Absolutely, working with schools is essential in helping children to get the most they can from their education. Inclusion and training are a must in raising understanding, both in staff and pupils.

Othello famously suffers from the 'Falling Sickness' but epilepsy is usually only seen in medical dramas on television. Do you think more TV soap characters should be featured coping with conditions such as epilepsy?

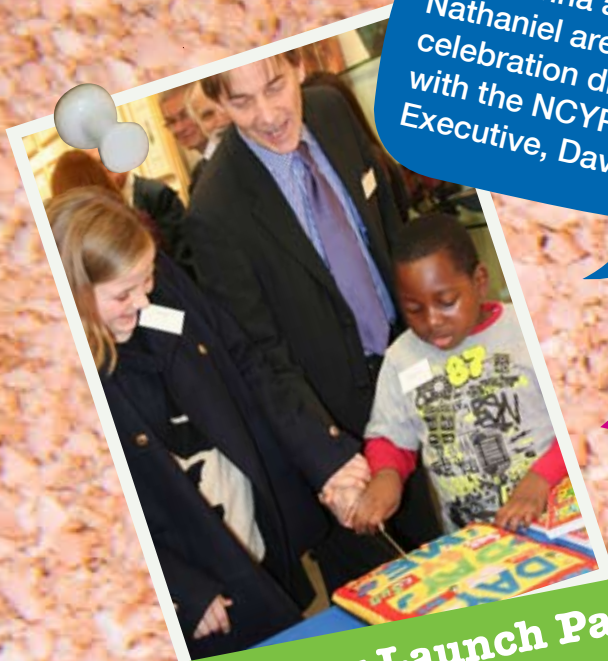
Good question! Actually, I played Cassio in the film version of Othello which starred Laurence Fishburne as Othello and Kenneth Branagh as Lago. Although it's taken out of some productions, we kept the falling sickness scene in and it worked very well. It's interesting to think that epilepsy was relevant to society then, otherwise Shakespeare would not have included it in the play. I think inclusion is a big issue in modern media and is being considered more and more.

What's coming up for you this summer?

I'm really enjoying being on the panel of the TV Book Club on Channel 4 at the moment. It's talking to the authors and discovering other people's views on the books. I've also got two films coming out this year, one called 'Malice In Wonderland' in which I play both the King and Queen of Hearts as a gay gangster and another called 'The Domino Effect' in which I play a tramp - two extremely varied roles!

Out and about v

Here, Anna and Nathaniel are cutting the celebration diary cake with the NCYPE Chief Executive, David Ford.



Music Hall Magic



Seizure Diary Launch Party

The official launch of the NCYPE's fantastic new Seizure Diary for children was recently held at Chris Beetles' Gallery in central London. Many of the illustrators attended, along with former Children's Laureate, Anne Fine, and members of the wider epilepsy community. This included Lynn Savill of the Gravesend Epilepsy Network who received an MBE for her charity work in the New Years Honours List. Well done Lynn!

This is Lynn Savill!



Instead of the traditional carol concert, the students at the NCYPE's Further Education College held a concert inspired by learning about Edwardian music hall. Organised by drama tutor, Murray Smith, each tutor group did their own sketch with a unique take on Christmas. Murray's group are pictured performing their 'Hawaiian Christmas'.

the
voice
of childhood epilepsy

with NCYPE



Sweet Success for Save a Cow



The NCYPE Student Support Worker at FE, Léanie Kaleido, is also a singer-songwriter and was keen to use her passion for music to benefit the students in FE. She started a Band Club to encourage students to play instruments as a band and to write their own lyrics and music. The club would not have got off the ground though without support from the local Freemasons who provided instruments and microphones for the club to use.

Band Club



Students from the NCYPE's Basden house held a sweet sale in aid of the 'Save a Cow' fund which provides 3rd world families with livestock to help keep communities and families going. The students made truffles, rocky road and coconut ice and raised over £100 for the cause.

Clowning Around



The Clown Doctors recently paid a visit to St Piers School, ensuring everyone got their required laughter therapy! The clowns, from Theodora Children's Trust, worked with some of the less verbal pupils, using total communication techniques - as shown in the picture - and also had fun with some of the sixth formers as well as taking part in an assembly.

Diary Dates

MARCH 26

Purple Day

.....
MAY 19

NCYPE Open Day

.....
JUNE 13 – 19

National Epilepsy Week

.....
JULY 3

Parents and Families
conference

.....
JULY 14

NCYPE Open Day

.....

On course to save lives



The Childhood Epilepsy Information Service (CEIS) has launched a new course covering all aspects of the administration of emergency medication for epilepsy.

These one day courses are run throughout the year and are aimed at parents, carers, nurses, teachers, or anyone who may have to administer emergency (rescue) medication.

The one day course covers general epilepsy awareness topics and also has a practical session. A half day course is also available for anyone who has previously attended a study day and would like to learn more about emergency medication.

“This course is vital for anyone who is in regular contact with a child with epilepsy,” says CEIS manager, Gill Gallagher (pictured). “The information learnt really could save a life.”

For more details of this course, or any of the other health and education courses run by CEIS, or to book a place call 01342 832243 ext 296 or email info@ncype.org.uk

Parents and Families conference – 3 July Manchester



After the roaring success of last year, places are filling up fast for our next Parents and Families Conference. It is being held on Saturday 3 July from 9.30am – 17.30pm at the Ramada Manchester Piccadilly Hotel in the heart of Manchester. We will again be running some fantastic workshops and have key speakers and other specialists available on the day to give plenty of good advice and help to attendees. At only £15 per adult and £10 per 12-18 year old, this really is a day not to be missed!

For more information contact the Childhood Epilepsy Information Service on 01342 832243 ext 296, email info@ncype.org.uk or visit the epilepsy pages on our website, www.ncype.org.uk

It's a celebration!

The FE College has formed an Equality and Diversity team, consisting of two elected students; Rohan Jayaratne and Matthew Lee and a range of staff representatives.



The team is working together to ensure that all areas of the college provision meets Equality and Diversity legislation, that the NCYPE policies are upheld and that Equality and Diversity is promoted and celebrated by all learners and staff.



Some of NCYPE's Equality and Diversity team

Many fun and exciting events have been held so far this academic year, from charity table top to bacon butty sales! Burns night and Chinese New Year were also recently celebrated. Many more events are also planned including Fair Trade day, Purple Day (international epilepsy awareness day) and International Day.

On yer bike

Two specially adapted bikes funded by the Hedley Foundation have been donated to the NCYPE following a visit by Chair of trustees John Rodwell. The bikes will benefit the students in many ways – helping with mobility, communication, sensory experiences, freedom, environmental awareness, relaxation and fun!

A special bike shed has been built and partly funded by students to keep the bikes safe. The NCYPE's sensory team are now hoping to establish a sensory bike trail, with fundraising help, in the Basden House garden area.



Moving on

We are sad to announce that the NCYPE's FE College Principal, Amanda Quincey is to leave us at Easter. She is to take on the role of Principal at Treloar Trust, Hampshire.

"While I will be sad to leave the NCYPE, after four and a half years as Principal, my new position is a challenging and natural career progression for me, in a role encompassing responsibility for education, care and medical services," said Amanda, "I have very much enjoyed being Principal of the FE College and being a Director of the NCYPE. It is a privilege to work with such outstanding staff teams and I wish you every success for the future."



We would like to thank Amanda for all her hard work at the NCYPE and wish her very well at Treloar.

NCYPE students get a taste of honey!



Well known TV actor, Joe McGann, was delighted to be upstaged by the Honey Monster while presenting a new Variety Club Sunshine Coach to NCYPE students last month. The Honey Monster could not hold the scissors though, so Joe did the honours! "Everyone I have spoken to about the NCYPE

has said what amazing work is done here," said Joe. "The opportunities and confidence that kids get from being at the NCYPE are fantastic. I am delighted to be here."

The Coach was generously funded by sponsors, Mr and Mrs Cripps of TC Contractors and Councillor Mrs Joan Spiers.



Looking to the future • Setting new standards

ACH provides high quality residential care homes for people with learning disabilities. Our vision is of homely environments in which the care and support provided is professional, empowering and person centred.
web www.achuk.com
email info@achuk.com
tel **020 8502 4466**

We would like to thank ACH for their generous sponsorship of this issue of the Voice newsletter.

www.ncype.org.uk

Tee off for Charity!

Keen golfers are invited to enter teams in our 2010 Golf Classic, being held on 29 April at the Wildernesse Golf Club in Sevenoaks.

Entering a team of four is just £440 for the whole day which runs from 7.45am to mid afternoon. This includes; breakfast on arrival, an 18 hole Stableford Competition with team, individual and putting prizes, followed by a buffet lunch, prizegiving and an auction.

Find out more about how to take part in NCYPE's exciting fundraising events by calling the team on 01342 831245 or email fundraising@ncype.org.uk



Case Study

Tom's assessment goes swimmingly

When six year old Tom Batchelor came to the Neville Childhood Epilepsy Centre for a three day assessment of his epilepsy he thought all his Christmases had come at once!

Why? Well, the care was fantastic and the room was lovely, the technology was state of the art and the people were kind and attentive, but all of this was nothing compared to the fish tank in reception! When the epilepsy specialist nursing staff saw that Tom had fallen in love with the fish they made sure his EEG could be disconnected at regular intervals for up to 30 minutes at a time and they even fitted his EEG equipment out at the fish tank!

Tom has a non progressive condition called hemi-hyperplasia / lipomatosis which means that one side of his face and brain is larger than it should be. Tom's Dad Karl said, "The Neville Childhood Epilepsy Centre is one of the best places we've been to with Tom. He has always loved fish and water so having a



"Everyone here has taken extra time to deal with us. Overall it has been a very positive experience."

Karl Batchelor

large fish tank here has been a real hit with him, he would stay here all day if we let him!"

Tom's EEG results will be looked at by the consultant neurologists based at the Neville Centre and a full report will be sent to his doctors at Great Ormond Street Hospital.

We've adopted 'hello'!

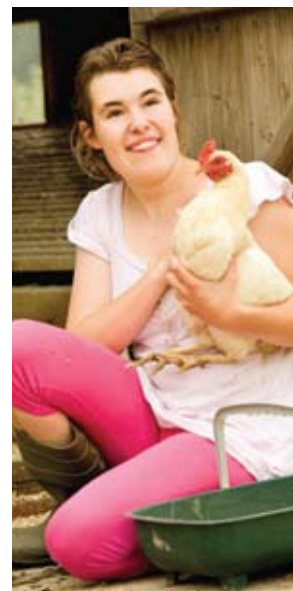
When national charity I CAN asked people all over the UK to take part in its 'Adopt a Word' scheme to support children with communication difficulties, the speech and language team at the NCYPE could hardly refuse. But which word to choose?

'Hello' was the choice as it's used to start a conversation with all students at the NCYPE no matter how they communicate. Next time you say hello to someone think about how many ways you could actually say it. You might be surprised!

Come to an Open Day

Come and find out more about our special school, Further Education college and world-class medical facilities – all on our stunning 60 acre rural campus. Open Days are all held on Wednesdays from 10am - 2pm, 19 May, 14 July and 13 October.

Prospective students or parents should contact Mandy Richmond on 01342 831348. Other enquirers please contact Jackie McFall on 01342 832243. Email: openday@ncype.org.uk



Totally focussed!



Head of Speech and Language Therapy at the NCYPE, Linda Edwards, talks about the exciting developments happening with Total Communication that should have far-reaching benefits within and beyond the NCYPE.

We all like to make choices and interact socially, but some people find it more difficult than others. Total Communication is an approach where all forms of verbal and non verbal communication are recognised, valued and actively promoted within an individual's environment.

Students at the NCYPE can have extremely varied communication abilities. With Total Communication, students can access information in a form that they can understand or simply prefer. This can be through sign language, objects, pictures or a combination of all three. 'Seeing' the options or the day's routine allows them to know what is coming next and actively participate in decisions instead of having life just happen to them.

For the Speech and Language team at the NCYPE, communication support covers assessment, training and delivery. Every student is assessed so that we can

communicate with them in the best way possible. Staff are offered training in five Total Communication modules so they can feel confident in supporting students' communication.

It's exciting to have secured some extra funding to trial new communication devices. These include touch screen communicators with special software installed that helps certain students communicate their wishes and decisions. Each one will be tailored to an individual student and will almost certainly help them have a fuller life.

The funding also means we can update our current communication software. It will help make information accessible by translating 'normal' text documents into picture-led, simpler text. With an expanded training programme, more staff will be able to learn how to make the most of the equipment.

We are really keen to commission our own Signalong manual. Signalong is a sign-supported communication system that we've been using very successfully at the NCYPE for over 10 years. We currently have a manual of 100 words and we're hoping to expand this to over 300 words with new, easier-to-see, icons. This would really help the spread of this fantastic way of communicating.

For more information about Total Communication, Signalong or other speech and language therapies at the NCYPE email: speechandlanguage@ncype.org.uk

Don't forget
Purple Day
26th March 2010

Download your
FREE pack now!
www.ncype.org.uk