

- **MPs** get behind the NCYPE's Campaign
- **Meet** our new Principal
- **Become** a Super Supporter!
- **Ketogenic** diet clinics come to the NCYPE
- **Norman Pace** discusses his daughter's epilepsy and her time at the NCYPE



**Epilepsy:**  
**the time  
is now**



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Danielle joined St Piers School this year. She has epilepsy, and autism.

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

## Exciting!

### Message from David Ford, Chief Executive



2010 has been one of the most exciting years ever for the NCYPE. Many amazing achievements have been seen across the whole of the organisation. Supporters of our Champions for Childhood Epilepsy Campaign were welcomed at the Houses of Parliament, our Epilepsy Education 4 Schools programme has been launched and received a huge boost from the BIG lottery fund.

Our new Principal, Jon Sharpe, is making fantastic inroads at our school and college and our students have been using some wonderful new equipment thanks to our Total Communication initiative.

When considering these successes against the current climate, they seem even greater achievements. The hard work and commitment from the NCYPE's staff and supporters this year has been second to none. We simply could and would not have achieved so much without you.

However, as a charity focused on 'better futures for young lives with epilepsy' we are constantly thinking about how we can improve our services and circumstances for all young people with epilepsy and their families. One way we are doing this is by becoming the 'digital' Voice of Childhood Epilepsy - using every way we can to get our messages out there. If you haven't received our new e-voice newsletter, you can sign up via the website ([www.ncype.org.uk](http://www.ncype.org.uk)). You can also join the conversation on our facebook page (search for NCYPE), or on our twitter feed, you can find us on @youngepilepsy.

I am looking forward to even greater successes for the NCYPE in 2011. I hope it's not too early to wish you a Merry Christmas and a Healthy New Year,

**David Ford**

# Westminster welcomes epilepsy champions

In July this year the Champions for Childhood Epilepsy Campaign Education Pilot Report was launched with a reception at the House of Commons.

Surrey MP, Sam Gyimah, kindly hosted the reception which was attended by many School Epilepsy Champions, other MPs and the media. He also tabled an Early Day Motion calling for the model to be taken up in schools across the UK.

The education pilot has attracted interest from all over the country. This is a real step towards rolling out the Campaign nationally. Together we really can make a difference and ensure better futures for young people with epilepsy.



Sam Gyimah MP, in class with Elliot at the NCYPE's St Piers School

## Families day - Bristol 2011

The date and venue for the NCYPE Families Day have been announced as Saturday 18 June 2011 at the Bristol Marriot Royal Hotel.

The Families Day is a day for everyone affected by epilepsy, and offers lively talks and workshops given by experts in the field including consultants, epilepsy specialist nurses and psychologists.

At only £15 per adult and £10 per young person, including lunch, refreshments and delegate pack, this is a day not to be missed!

For a booking form visit [www.ncype.org.uk/epilepsy](http://www.ncype.org.uk/epilepsy)

## Surgery could save £280m

As this newsletter was going to press the Champions for Childhood Epilepsy Campaign was hosting an epilepsy surgery summit. **'Epilepsy Surgery: better futures or false economies'**.

It examined clinical and economic arguments for improving provision as well as the obstacles that currently exist. It claimed that the cost savings of a lifetime of medical support vs the cost of surgery could be as much as £280 million, helping 3000 children over 10 years. Presentations were given by Professor Helen Cross, Dr Ailsa McLellan and Mr William Harkness. Visit [www.ncype.org.uk/campaign](http://www.ncype.org.uk/campaign) to download them.



**Conservative MP and Chair of the All Party Group for Epilepsy, Laura Sandys, recently became one of the first two MP's to publicly declare they had epilepsy. We asked for her views on the issues surrounding the condition:**

It was through my role as Chair of the All Party Group for Epilepsy that I came to hear of the great work and campaigns run by the NCYPE. High quality education and support for young people with epilepsy is so important and I hope to learn more through my role with the Parliamentary group.

Learning and education are the best solutions to tackling the stigma surrounding epilepsy. I am epileptic and am lucky to have had very few seizures in my life. If more people learnt about epilepsy I really believe that this would help tackle stigma issues.

As soon as one mentions the word 'epilepsy', all sorts of extraordinary ideas come into people's minds, and there can be an assumption that we might need constant attention. For most people this is absolutely not the case! Children with epilepsy have a particularly difficult time in school, because

*MP Laura Sandys supporting the JEC's call for a Fair Deal for Epilepsy*

even if they don't have any seizures they can be wrapped in cotton wool and stopped from participating in outdoor sports.

Stigma needs to be addressed and there's no doubt that one of the best ways of doing this is through discussing epilepsy more openly. At a recent debate in Westminster Hall, my colleague Paul Maynard MP and I came forward as the first MPs to announce we have epilepsy and I hope that in the future others might feel happy enough to come forward.

To read the full interview with Laura, visit [www.ncype.org.uk/campaign](http://www.ncype.org.uk/campaign)



## Schools programme gets a BIG helping hand..

**The Epilepsy Education 4 Schools Programme has received a massive boost from the National Lottery's BIG Lottery Fund. It has received a grant of over £163,000 that will enable the programme to be expanded into the Greater London area.**

This will see an extra 312 schools be offered free epilepsy training, potentially helping thousands of young people in the region.

Training is expected to begin in the New Year. More funding is needed to expand further across the whole of the UK. "The aim is to have eight more regional education teams established over the next two years, so that every single school has the opportunity to improve their knowledge and understanding of epilepsy." says Childhood Epilepsy Information Service Manager, Gill Gallagher.

For more information visit [www.ncype.co.uk/epilepsy](http://www.ncype.co.uk/epilepsy)

## New complex epilepsy handbook launched

Following last year's success of the children's seizure diary and the parents' handbook, this time the NCYPE's Childhood Epilepsy Information Service has developed another handbook for parents and carers of children with complex epilepsy.

'Complex Childhood Epilepsy - A Parent's Handbook', is aimed at parents' whose children have added complications to their condition. It explains some of the more serious epilepsies, often referred to as 'epilepsy plus' or 'difficult to control' epilepsy.



It's all about me!

Living with seizures can be tough for children and teenagers, so the NCYPE's Childhood Epilepsy Information Service has produced two fun-filled seizure diaries aimed at helping young people take control of their epilepsy. Both diaries have jokes, illustrations and space for recording thoughts, feelings, and information about their seizures.

The diary 'Day by Day by Me' contains epilepsy information aimed at the younger age group and the new diary for teenagers 'It's All About Me' gives more detailed epilepsy information for older children.

For free copies of the diary or the handbook contact the NCYPE at [info@ncype.org.uk](mailto:info@ncype.org.uk) or call 01342 832243 ext 508 or go to [www.ncype.org.uk/epilepsy](http://www.ncype.org.uk/epilepsy)

The NCYPE epilepsy confidential helpline is 01342 831342 open Mon-Fri 9am to 1pm

## Watch it!



**The Champions for Childhood Epilepsy Campaign is developing a comprehensive information pack to support the national roll out of our education campaign.**

Generous support from funders has allowed the commissioning of a series of DVD based lectures that can take the NCYPE's expertise and knowledge right into schools and staffrooms across the UK.

The series will cover the basic Epilepsy Champion training modules and provide guidance on following the campaign's 10 point Education Action Plan, supporting schools and teachers to *'go the extra MILE'*.

*Find out more about the 10 point Education Action plan at [www.ncype.org.uk/campaign](http://www.ncype.org.uk/campaign)*

## Join in!

- MARCH 5 - A Night at the Opera
- MARCH 26 - Purple Day
- .....
- APRIL 10 - The Brighton Marathon
- APRIL 17 - The Virgin London Marathon
- .....
- MAY 7 - Southdowns Trekathon
- MAY 15-23 - National Epilepsy Week
- MAY 17 - Tea at the House of Lords
- MAY 20 - Clay Pigeon Shoot Day
- MAY 27 - Trek to Macchu Picchu
- .....
- JULY 2 - Stonehenge Trekathon
- .....
- SEPT 3 - Spire to Spire Trekathon
- .....

These legs are made for walking!



### The NCYPE has some fantastic opportunities to get fit, get happy and help children with epilepsy in 2011!

We are launching three 'trekathon' challenges across the South of England through the summer months.

Each one is a 26 mile walk through some stunning English countryside, starting in the South Downs on 7 May, Avebury to Stonehenge on 2 July and finally from Winchester on 3 September.

Registration is just £49 with a £150 minimum sponsorship commitment needed. To sign up or to find out more information, contact [fundraising@ncype.org.uk](mailto:fundraising@ncype.org.uk)

[www.ncype.org.uk](http://www.ncype.org.uk)

## Be a super supporter!



June 13-19 was National Epilepsy Week and Katherine Fowler from UCB Pharma decided to use it as a great way of raising funds for the NCYPE. She raised an amazing £2733!

She organised cake sales, an auction and a barbeque. Plus she got UCB to generously agree to match every penny raised.

And she didn't stop there! Katherine and nine friends tackled the Three Peaks Challenge – which meant climbing the highest mountains in Scotland (Ben Nevis), England (Scafell Pike) and Wales (Snowdon) in 24 hours! This raised another £1000!

**Katherine says,** "I'm really glad I took part and would definitely recommend it to others. I visited the NCYPE and really enjoyed meeting the people, having a guided tour and seeing where the money is spent!"

Huge thanks goes to Katherine for her enthusiasm, hard work and commitment to the NCYPE - you are a star! Also to UCB Pharma for its support.

**Could you be our next 'Super Supporter'?** If you or your company would like to get involved and help fundraise for the NCYPE we would love to hear from you!

Visit [www.ncype.org.uk/fundraising](http://www.ncype.org.uk/fundraising) for more info

## A wonderful evening awaits...

Join us for A Night at the Opera on 5 March 2011 at the luxurious Ashdown Park Hotel.

Tickets include a Champagne reception, sumptuous 4 course meal, and entry into a fabulous prize draw.

For more information and tickets, contact fundraising on 01342 832243 or email

**Tickets from £90 per person**

## Give it up for epilepsy!

**National Epilepsy Week is the perfect time to raise funds for the NCYPE**

Did you know young people with epilepsy often have to give up things that we would take for granted, such as trips to cinema, drinking alcohol and even driving.

### Could you give it up for epilepsy?

Why not get sponsored to:

- Walk everywhere for a week - no driving!
- Give up alcohol, chocolate or your favourite food

To get your fundraising pack contact us at [fundraising@ncype.org.uk](mailto:fundraising@ncype.org.uk) or call 01342 831 245.

## Feel good this Christmas!

Delight someone special with the treat of an exclusive Afternoon Tea at the House of Lords including fabulous views over the Thames. This fantastic event will take place on 17 May 2011.

Or why not indulge your loved one with a day out to remember at the NCYPE Clay Pigeon Shooting day on 20 May 2011? Held at the excellent West Kent Shooting Ground it's a perfect day for both novices and more experienced shots, with expert tuition, all equipment, clays, ammunition and refreshments provided.

For more information call the fundraising team on 01342 831245 or email [fundraising@ncype.org.uk](mailto:fundraising@ncype.org.uk)

*You could have tea here!*



## Christmas appeal...

The NCYPE Christmas Appeal is due to land on your doorstep very soon! To find out more and make a donation, visit [www.justgiving.com/ncypechristmas](http://www.justgiving.com/ncypechristmas)

Don't forget to pass the goodwill on and mention it to your friends and family too - Merry Christmas!

# Out and about w



## Odds on winners!

The NCYPE's annual Race Day with Lingfield Park racecourse was the most successful so far. Students from college attended and met NCYPE Ambassadors, Nathaniel Parker and Nicholas Owen as well as Channel 4 racing pundit, Lesley Graham. A record £27,000 profit was made, so a massive NCYPE thank you goes to everyone!

## Royal day out

NCYPE employee of the year 2009, Barbara Romaine, represented the NCYPE at a Royal Garden Party attended by the Prince of Wales this summer. While telling the Prince about the work she did, Barbara asked the Prince if he would support our next appeal to which he replied that he would 'do his best.' Well done Barbara!

[www.ncype.org.uk](http://www.ncype.org.uk)



# with the NCYPE



## Anyone for cake?

Students took part in the 'world's biggest coffee morning' for Macmillan cancer research earlier this year.

They raised over £400 for the cause and as you can see from the picture, the cakes went down extremely well!

## Pet therapy at the farm

The NCYPE farm has got some fluffy new additions to its pet enclosures on the farm.

Now the students can come and get to know our new rabbits, chickens and even a baby peacock. Some students find it very therapeutic to get close to and stroke the animals and the animals seem to like it very much too!

See more farm animal pictures on our facebook page!



A look inside...

## Reader Survey!

Click [here](#) to fill out the survey online:

Answer a few short questions and win £25 of high street vouchers to treat yourself or your friends.

What do you think of the Voice newsletter? We try to make it as interesting as possible and really value reader feedback on how to make it even better.

### 1: What type of reader are you?

- health/education professional
- supporter/fundraiser with the NCYPE
- parent of a young person with epilepsy
- other (please specify)

### 2: What articles do you like to read in the Voice? Would you like to see more:

- technical articles about epilepsy
- general childhood epilepsy information
- NCYPE activities
- student stories

### 3: Do you:

- flick through for a quick update
- keep the Voice for reference/coffee table
- pass the Voice on to friends/colleagues

That's it! Thanks for your help. Please cut along the dotted lines place in an envelope and return to:

The Editor, Voice Newsletter, The NCYPE, St Piers Lane, Lingfield, Surrey, RH7 6PW

Entry deadline December 23rd 2010. Entrants must be over 18. The first five entries chosen will receive £25 of high street vouchers. Winners will be notified by January 23rd. Entrants cannot be an employee of the NCYPE.

### The NCYPE campus

Over 100 years ago, the NCYPE was set up to help people of all ages with learning disabilities. Now it's a national charity and one of the largest providers of specialist paediatric epilepsy services in the UK. Over 750 staff and 170 students are daily on the campus, which is open 52 weeks a year.

The campus covers over 60 acres and 80 buildings (including the School, College, Neville Childhood Epilepsy Centre and 23 residential homes) and much of the original layout survives to this day.

It's not easy to keep it running smoothly, as Head of Facilities, Phil Rickett explains, "It requires a great deal of planning and commitment! Not only do we have to ensure that NCYPE students get everything they need in their homes, education facilities and medical centre, but also that our staff and visitors have everything they need too."

"There are 46 facilities staff looking after the campus covering everything from transport, to cleaning, to grounds maintenance. Our catering department produces over 90,000 meals a year and our fleet of mini-buses travels over 83,000 miles a year just taking students out in the local area."

"Many staff go above and beyond the call of duty too. When the snow hit last winter maintenance staff came in to hand grit roads and footpaths and food deliveries to our houses were kept up throughout."

"There can't be many places like the NCYPE, with a 200 year old farmhouse and state of the art medical centre within metres of each other.

It certainly takes some looking after but it's part of what makes the campus such an interesting place to be."



The 200 year old St Piers Farmhouse at the NCYPE

## My school day - Ben aged 7



Ben is looking at his wormery

**Ben started at the NCYPE as a day student in January 2010. He has epilepsy, autism and ADHD.**

**9.30am**

Ben arrives at St Piers school and goes straight to class with his support worker. Ben's epilepsy, autism and ADHD mean that he has emotional, physical and learning difficulties and requires constant one to one care. Ben starts the day, reading the symbolised timetable and greeting his classmates.

**10am**

It's a class trip to the local pet shop, Ben looks at the insects, especially the spiders!

**12pm**

Ben and his class return to school. Residential students go back to their houses for lunch while Ben joins the other day students in the school hall for his.

**1.30pm**

Following afternoon registration, Ben's class looks at Science, it's one of his favourite subjects. Together they observe worms through a magnifying glass and then make a wormery.

Ben uses a symbolised sequence sentence strip that enables him to make his wormery independently. He explores the texture of the sand and compost and uses a large scoop to layer them into the bottle, before adding the worms. The top of the bottle is covered

with cling film. (Ben reminds his teacher to make holes in the cling film so that the worms can breathe!)

**2.15pm**

Break time and Ben helps staff to make drinks for his peers.

**2.30pm**

The last session of the day is communication. Ben watches a presentation on worms and then joins in with the rest of the students pretending to be a worm! Ben enjoys sliding along the floor and wriggling like a worm very much.

**3pm**

Ben and his class also use their senses to feel things inside a bag and explains what he can feel.

**3.30pm**

Ben then collects his belongings and staff take him to his car for the journey home - see you tomorrow Ben!

### Ben's teacher says:

One of Ben's IEP objectives under economic wellbeing, is to be able to exchange coins for an item. To help Ben achieve both his personal and his lesson objective, we visited a local pet shop.

As a school we work towards the National curriculum. Our topic in science this term is 'plants and animals in the local environment'; PSHE&C is 'looking after the environment'.

Through these activities Ben purchased some worms to make a wormery and spoke to pet shop staff. This enabled Ben to meet people in the wider community as well as develop his understanding on how to look after other animals.

When learning about worms, students were encouraged to wriggle around on the floor (like a worm). This develops motor/movement, as well as encouraging physical activity.

Working in a group challenges Ben. Making drinks for his peers helps develop these vital life skills, required for accessing education in a group setting.

# In Principal..!



**NCYPE's new Principal, Jon Sharpe**

A big welcome has been given to the NCYPE's new Principal, Jon Sharpe. He has taken the helm of both the NCYPE's St Piers School and the Further Education College this term. Jon was previously Head Teacher at a special needs school in Lewisham and comes to the NCYPE with over 25 years experience in special educational needs. He said, "I aim to capitalise on the excellent reputation that the NCYPE has for special needs education and make it even better for both the students and the staff already here and those who are yet to come."

"It's a really exciting time to have joined the NCYPE. The school and college staff work extremely hard to ensure that our students get the very best they can from their education. This is where our personalised education plans come in to play. For some students, learning to recognise a picture



of a cup is a huge achievement - as this means they will be able to ask for a drink when they're thirsty. For others the aim is to achieve the maximum independence possible when they leave, so the emphasis is on work experience, learning life skills and completing vocational courses."

"The NCYPE works with many local schools and colleges. This includes inviting students in to do work experience with the organisation, sharing sports facilities, sending our students to do courses such as hairdressing and IT. The learning experiences gained and shared best practice by all concerned really are invaluable."

Our school and college Open Days have been highly successful. Five more are planned for the coming year and I look forward to welcoming everyone who attends.



## Open days...

If you know a young person with complex epilepsy or other neurological condition and you'd like to find out more about the NCYPE's school, college and medical facilities, why not visit us at one of our Open Days?

**2011 dates are : 19 January, 16 March, 11 May, 13 July and 12 October**

All open days run from 10 am until 2pm. Attendees will get to meet key members of staff and receive presentations from education and care teams, as well as go on a tour of the campus. Refreshments and lunch are also included.

**Email [openday@ncype.org.uk](mailto:openday@ncype.org.uk) for more info**

## Students speak out



*The Outreach students outside Westminster with MPs*

### Members of the NCYPE's FE College Outreach Group attended an adjournment debate at the House of Commons recently.

They represented all young people with epilepsy and helped promote the Joint Epilepsy Council's call for a 'fair deal for epilepsy'. The call was supported by MPs from all parties including Laura Sandys and Paul Maynard who both declared publicly that they too suffered from the condition.

Senior Lecturer and Outreach Group organiser, Frankie Caffyn said, "As one of the most commonly misunderstood conditions it's vital that politicians see how epilepsy affects real people in every day life. Everyone who attended the debate felt how important it was that the issues surrounding epilepsy were brought to the attention of the government and really enjoyed the experience."

## Me and the NCYPE by Matt

**Matt came to the FE college in 2004 and left this year. He was a proactive member of the Student Council, the Outreach Group and an Equality and Diversity Representative.**

Polite and thoughtful, Matt was popular with both staff and students. He made the most of his time at the NCYPE, making many friends and joining the Lingfield Running Club, among other activities.

As part of his vocational education, Matt chose to study hairdressing at a local college and gained work experience in local salons. Matt aims to get a job doing this and is now continuing with his hairdressing course at East Surrey College. He has gained various vocational qualifications.

When asked about moving on from the NCYPE Matt said, "I want to be more like other men, to be myself and mix. I want to stand up for people with a disability. I have done lots of work experience and have benefited from this. I have been really happy here - it has been my second home."

He continued, "The best thing about the NCYPE for me was working with staff and friends. I have made so much progress."



*Good luck with the hairdressing Matt*

## Celebrity voice



Norman Pace

**This issue we welcome comedian and actor Norman Pace as our celebrity voice. Norman is best known as being one half of comedy duo Hale and Pace. His daughter, Holly previously attended the NCYPE's FE College.**

**How do you think epilepsy is viewed by modern society?**

I think that epilepsy is highly misunderstood in general. The sight of a full tonic clonic seizure is very disturbing to the average person. In my experience, people don't know how to deal with epilepsy and they are rather scared of it.

**As a parent of a child with epilepsy and other special needs, what more do you think should be done to help parents in the same situation?**

Support is the key word here. When you have a child with epilepsy, you are on call 24 hours a day, 7 days a week. Parents need respite from this situation as much as their children. Unfortunately, some respite facilities are well below par. It is very difficult for a caring parent to let their child go into these places and they should be brought up to acceptable standards.

Support in our case usually comes down to family and close friends and these are hugely important, but not everyone has that network to fall back on. Having someone who understands the social care system is also vital, and children need access to someone to advocate for them as a matter of course. As Holly's parents, we always feel responsible for her to try and use all the services available to us.

**As a well known funny man, do you think there's a place for 'special needs' in comedy?**

No. I think comedy is about choosing your targets wisely. There was an example quite recently in the news when Frankie Boyle took the mickey out of people with Downs syndrome. I was surprised and disappointed in him as I'm a fan. I hope he's now dropped that section from his act.

**How is Holly getting on since leaving the NCYPE's FE College?**

Holly is at home and has been for a year since leaving the NCYPE. Her time at the college was so enjoyable that she has come to expect a full and busy schedule, and quite rightly so. At the moment, she is doing some work experience in her old special needs school where she helps young children with reading and maths. Her social life is full and she is generally happy. She gets bored sitting at home and is not willing to accept this as her lot. The local council have promised that Holly and five friends all of whom have special needs will go into purpose built supported living accommodation. This was meant to happen this summer. Unbelievably, the council has not been able to get planning permission from its own planning department. Heaven knows when it's going to happen. It's very frustrating.

**What's coming up for you in the next few months?**

At the moment I am on tour in a play called Murdered To Death in which I play Inspector Pratt. Can you tell it's a comedy? I then go into a musical called The Secret Garden. That will take me through until March 2011. After that who knows? You never know with the business of show.

# And the winner is!



**The Neville Childhood Epilepsy Centre has won a national LABC building excellence award for 'Community Building of the Year'!**

The LABC is a national body for Local Authority Building Control issues. The centre had already won plaudits as 'an inspiring transformation' from the LABC when it won the regional heats of the competition earlier in the year.

Hayley Bath, the NCYPE's Head of Health Services, said, "We are delighted to win the national Community Building of the Year award. The NCYPE team worked hard together with the architects, Lee Evans Partnership, to make sure the airy, modern design was focused on young people's needs. This award is a great tribute to all concerned."

## Welcoming new friends!

**Ketogenic diet charity, Matthew's Friends, will soon be using the Neville Childhood Epilepsy Centre as the base for its new Treatment and Training Service.**

Launching early next year, the charity aims to offer a fully comprehensive service to both patients and professionals wishing to find out more about the ketogenic diet.

Around 100 years ago, it was discovered that starvation may help to reduce seizures. The ketogenic diet is a high fat diet that can cause the same metabolic effect that occurs in the body when it is starving, namely producing ketones.

Matthew's Friends founder, Emma Williams, said, "We are delighted to be launching our new service at the Neville Childhood Epilepsy Centre. The friendship that has been forged between the NCYPE and Matthew's Friends

is a true example of how different charities can work together to give the best possible service for those who need them and in the most cost effective way."

The NCYPE's Head of the Health Services, Hayley Bath, said, "It's great to be working together with Matthew's Friends to be able to offer an even wider range of services for people with epilepsy. The ketogenic diet is a successful treatment for some people with epilepsy and I wish the new service every success."



# Epilepsy medication update

**There are approaching 20 licensed antiepileptic drugs (AEDs) in the UK. Four of these drugs have been introduced in the last five years but the oldest antiepileptic drug still used is phenobarbital (introduced in 1912).**

Epilepsy types and syndromes respond to different antiepileptic drugs. Ideally treatment with one AED is preferred, but typically many NCYPE students may be taking 2 or 3 AEDs at any one time (called polytherapy) and some may even have 4 prescribed for them. Some evidence suggests that more than 3 AEDs prescribed concurrently can increase the number of side effects without improving seizure control. Research into quality of life and how this improves by reducing polytherapy is ongoing. Much work is done by the medical team at the NCYPE to optimise drug treatment for students at the NCYPE who experience poor seizure control.

New and better formulations of some of the older AEDs have been released in recent years. For example, modified release granule formulations enable medication to remain

active for up to 24 hours inside the body. These preparations only need to be given once daily which aids compliance and may be taken sprinkled on food which is an added bonus to those who find solid dose forms difficult to take.

Another big issue with epilepsy therapy surrounds the prescribing of generic pharmaceutical products. Once the patent on an AED runs out, generic manufacturers can apply for a generic licence for that product which will be considerably cheaper than the cost of the branded drug. The generic product has to demonstrate a very similar profile to the innovator drug, but there can be variation between different generic brands of the same drug. This variation can lead to fluctuating blood levels of the AED if the same generic product is not maintained and so seizure control can be compromised.

Where possible at the NCYPE we try to keep a student on the same branded product rather than have them yo-yoing between different generic products.

For more information about medical services at the NCYPE visit [www.ncype.org.uk/health](http://www.ncype.org.uk/health)



Sandra Bale

## About the author

Sandra Bale is the pharmacy adviser at the NCYPE. Her diverse role encompasses liaising with NCYPE staff, parents and allied professionals around medication issues, delivering medication training, conducting audits and monitoring and advising on clinical governance matters.