A shining example

29 August 2012 is a day 19 year old Danielle Garratt from Sussex Downs College will never forget. Danielle was one of the 8,000 inspirational people from across the UK who lit the way to the Paralympic Games from Stoke Mandeville to the Olympic Park in London during the 24-hour Relay.

Danielle and her cricket team became Torch Bearers, after they were nominated by their coach as the UK’s first women’s, partially sighted cricket team. She could hardly believe it at first, but when her Torch Bearers’ outfit arrived there was no denying it. On 29 August Danielle was the first in her team to carry the Paralympic Flame from London’s Grove End Road to Lord’s Cricket Ground.

On the day

Danielle’s family were there to support her and cheer her on and she felt excited, but as the time got closer she started to get butterflies in her stomach. It was a big responsibility, the world was watching and there were cameras and film crews to prepare for. But Danielle didn’t need to worry. She said: “When I started carrying the torch the atmosphere was amazing. The crowd cheered me on and I felt incredible.”

I had one burning question to ask Danielle about the torch. Was it heavy? Danielle said: “The torch looks heavy but actually it is very light”.

A day to remember

As a souvenir of her memorable day Danielle bought her torch and it is now proudly sitting at home on display in her living room.

For more relay facts see www.london2012.com/paralympics/torch-relay

Contents include...

- Support for families ........................................ p2
- Things to do ..................................................... p3
- HOT TOPIC: Staying healthy in school ............ p5
- Health and well-being ................................... p6-7
- Money Matters .................................................. p8
- On the web .................................................... p9
- East Sussex Parent and Carers Council ........ p10-11
- What’s new? ................................................. p12
Story books with a difference...

Reading books with your child is fun, but with the right book it can also help your child manage anxiety, anger, the move from home to school and build social skills.

Kay Al-Ghani, a specialist teacher for inclusion support, has written a collection of fun storybooks for children with Asperger’s and their families. Each positive and practical book has an introduction for adults, explaining the issues for children and suggesting techniques to deal with them. The books are fully illustrated by Kay’s son Haitham who has ASD.

The stories let children to see situations from the perspective of others and to see themselves in characters. This opens the door to discussion to introduce strategies they can use in the future.

‘The Panicosaurus’ looks at children’s emotions and what to do when they feel their ‘panicosaurus’ rising, ‘Baby Blue has the blues’ provides a strong message for children who feel isolated while ‘The Red Beast’ is a fun way to talk about anger.

One parent said: “This book helped!...We have been able to talk about the Red Beast and how it affects my son at school and home...He is not alone, we all have a Red Beast in us. It can be tamed”.

Parents supporting parents

Would you like to talk to another parent who understands what you are going through and can offer emotional and practical support? Louise Brown from Crowborough who’s nine year old son Samuel has dyslexia was looking for support but couldn’t find a support group in her area. So she decided to set one up.

First she contacted her local children’s centre and her child’s SENCO for advice. Then she sent a questionnaire to local families, delivered through the schools, to measure local interest. She named the group, designed a leaflet and gathered the support of speakers to visit and share their experience.

The group is called SCREAM and the first meeting will be at Herne Junior School in Crowborough in January. If you are interested, contact Louise.

There are various parent support groups running across the county. To find out about existing groups or setting up your own, contact Information for Families.

Louise – SCREAM 01892 653511
Information for Families 0345 60 80 192
Spectrum helps children join the fun

Autism can make it difficult to join in but Spectrum which was set up in 2008 helps young people with autism try new sports and activities. The team have worked with over 400 families across the county, supporting young people to enjoy anything from youth clubs, scouts and football to fencing, drama and even scuba diving.

Pete Comper, Spectrum Manager, told us how it works. “We talk to the young person about their needs and interests. Then we find a club, talk to staff and if they need it, offer free training to help them understand autism, the person’s needs and how they can help. Then the mentor goes along with them for up to 10 weeks to help them settle in”.

Why not find out more:
01424 724700
spectrum@eastsussex.gov.uk
eastsussex.gov.uk/autism

“Spectrum is very good and has found a very fantastic club for me!”
14 year old from Bexhill

Saturday night sport
Fancy a swim, archery, badminton, boccia or basketball? Every Saturday, between 6 and 8pm, Wave Leisure Centre in Lewes runs a sports session for disabled individuals and families. It is fully accessible to all with disabilities and special needs.
01273 486000
info@waveleisure.co.uk
www.waveleisure.co.uk

Stimulate and soothe the senses

“She has gained so much through coming here”
Parent of four year old girl

A sensory room is designed with lights, sounds and textures to both stimulate and soothe the senses. This can be helpful for children with special educational needs or sensory impairment and can help carers take ‘time out’.

Where is my nearest sensory room? Children’s centres across the county in Eastbourne, Hailsham, Seaford, Sidley, Bexhill, Hastings, St Leonards and Rye have sensory rooms and offer free use.

The rooms, designed for children of all ages, offer an enjoyable, warm and safe environment and there is free training in how to use the equipment.

As well as sensory rooms, children’s centres offer a range of services, support and resources for families with children under five years old.

Find your nearest children’s centre
0345 60 80 192
eastsussex.gov.uk/childrenscentres
Last autumn young people 11-19 in Eastbourne and Wealden were given a chance to understand what it’s like to make difficult spending decisions when budgets are tight!

In Eastbourne members of the Youth Forum decided to fund youth projects through a ‘Dragons Den’ event. They saw presentations from seven youth groups and awarded £2,777 to those that showed their project was needed, would make a difference to young people and was good value for money.

Successful pitches included Eastbourne Police Cadets who gained £300 for an anti-bullying poster competition and Generate Art Group who were awarded £500 to run workshops in the community.

In Wealden 70 young people decided how to spend £10,000. They saw presentations from eight youth groups and voted on which offered the greatest benefit, value for money and youth involvement.

But with not quite enough money to go around, the three groups with the fewest votes had to come up with a £489 saving!

The day was part of National Takeover Day organised by the The Office of the Children’s Commissioner for England and gives children and young people the chance to make decisions alongside adults.

The funding for the projects came from Eastbourne Youth Partnerships and Wealden Targeted Youth Support partnerships group.

We are looking for young people with disabilities to make decisions on the ‘Life More Ordinary’ grant scheme which supports young people with disabilities to join in activities that other young people enjoy.

The closing date is 13 January.

Contact Tracey Johnson
tracey.johnson@eastsussex.gov.uk

Taking a break

One of those was Amy from Hastings. When 17 year old Amy, due to illness, spent long periods out of school, she lost her friends and her confidence. But since her first visit to Funky Teens she has regained her confidence and has hardly missed a session!

At the youth club she can chill out, relax with friends, do cookery, arts or play pool or Wii. Mum, Helen, said: “It is a really good experience and Amy always comes back in a good mood”.

Helen and Amy are together a lot and the break is good for both of them. With the free hours Helen is able to switch off and recharge her batteries, while Amy is socialising with people her own age.

For more on short breaks call 01273 336543
shortbreaks@eastsussex.gov.uk
eastsussex.gov.uk/shortbreaks

Short breaks allow disabled children and young people aged 0 to 19 to spend time away from their families.

From April to September 2012 about 500 children in East Sussex enjoyed short breaks adding up to 57,501 hours. And 98.6% of families said they had a positive experience.

Funky Teens!
If your child has health problems, they can receive support and care in school or pre-school, to help them stay healthy and take part in school life.

East Sussex County Council provides helpful guidance for schools, pre-schools and other settings. It covers any complex health need, including difficulties with mobility, breathing, eating, continence and medical conditions such as diabetes and epilepsy.

Here are parents and carers’ common questions, and our answers to them:

‘I like my local school, but they say they cannot take my daughter due to the help she needs in the toilet’

Children with complex health needs have the same rights of admission as other children. The school can use the time before your daughter starts to plan the support she will need, and any equipment. Your specialist nurse and the school nurse can work together to make sure staff are trained and confident.

‘I find it hard to trust the school. I have always been there for my son when he has an asthma attack’.

When you have discussed the support your son will need, you can ask for a written Health Care Plan. It will lay out procedures, who is responsible for what and how staff leave will be covered. You can review the plan regularly to keep your confidence up.

‘My son can’t go on the residential trip because his trained assistant is not available to give emergency medication for epilepsy.’

The Equalities Act 2010 requires schools to make ‘reasonable adjustments’ so that your son can be included in the trip. Ideally, the school should plan well in advance so that there is time to train someone up. If time is short, the school can get advice from the Schools Resilience Support Officer (Offsite Visits).

The East Sussex guidance can be found at czone.eastsussex.gov.uk, search for ‘complex health’.
Helping seriously ill children

WellChild nurses help seriously ill children with long term and complex health needs when they leave hospital and return home to their families. Andrea Ferns is the new WellChild nurse for East Sussex, funded by WellChild, the charity for sick children.

Andrea told us: “I bridge the gap between services so that the journey home is more streamlined for families and all the child’s needs can be met closer to home”.

Andrea is based in Lewes and works closely with local hospitals and community services as well as specialist hospitals in Brighton and London.

She ensures everything goes smoothly when children are discharged from hospital and works to reduce readmissions, helping them to live at home. She also provides emotional and practical support for the whole family.

07795 060756
Andrea Ferns
www.wellchild.org.uk

Children eating well with diabetes

“Cheryl helped me to learn about diabetes in a fun way.”
Parent of an 11 year old

About 100 children in East Sussex have type 1 diabetes. To help manage their lifelong condition the NHS Trust has appointed Cheryl Paul as Specialist Paediatric Diabetes Dietician to their diabetes team. Cheryl works with all children with diabetes up to age 15 giving them and their families advice about food and eating.

Cheryl is aware receiving a diagnosis can be a difficult time for families and there is a lot of information to take in. In one to one meetings she tailors learning to suit each child. She knows people learn at different rates and offers support on a rolling basis, not a one off lesson.

You can contact Cheryl on 07785 577741
Top toileting tips

Toilet training can be emotionally and physically demanding. Here are Dr Laura Tinkl’s top tips.

Is my child ready for toilet training?

Your child may be ready to start when:
• they seem to know if they need the toilet. They behave differently at these times e.g. they squat or hide;
• they dislike being wet or soiled;
• they can last at least 2 hours without wetting or soiling; and
• they seem interested in toileting activities.

Developing a toileting routine

• Start when the time is right for your family.
• Work with school for a consistent approach.
• Use symbols to create a step-by-step schedule e.g. pull pants down, sit on toilet, etc. Do not take any step for granted.
• Display the symbols in the bathroom for your child.

Your child may find it easier to start at the end of the process, flushing and hand washing, before working towards the earlier steps.
• Create a visual timetable with drinking, eating and toileting to reduce anxiety.
  • Ensure your child has loose clothing they can easily remove.
  • Reward your child for successes, however small.

Other things to consider

• Can my child communicate when they need the toilet?
• Consider using symbols or signing.
• Does my child have sensory sensitivities?
• Consider clothing and bathroom environment.
• Does my child have difficulties sitting or co-ordinating their movements?

Consider supports, footrests and alternatives to toilet paper, e.g. wet wipes.

If you are struggling, you are not alone and there is help available. Speak to your Health Visitor or GP, your child’s teacher, or school nurse, if your child has a moderate to severe learning disability call the Child and Adolescent Mental Health Service – Learning Disabilities / Family Intensive Support Service.

01323 741717
CAMHS LD / FISS
Dr Laura Tinkl is a Clinical Psychologist for CAMHS LD / FISS

Changing places in Lewes

Wave Leisure Centre in Lewes has a new accessible changing area.

You can now find two separate showers and the large changing area has a hoist, adjustable changing trolley, toilet and shower.

01273 486000
info@waveleisure.co.uk
www.waveleisure.co.uk
On the buses

Disabled adults and children can travel free off-peak on buses throughout England.

**Harry, age 11, who has autism and ADHD, has a bus pass.** His dad said: “It’s great using the bus as I can interact with Harry instead of concentrating on driving. We can talk about what we are seeing on our way.”

You can get a free bus pass if you live in England and are ‘eligible disabled’. This includes people with a learning disability. See [eastsussex.gov.uk](http://eastsussex.gov.uk) and search ‘disabled bus pass’ for eligibility.

To get a bus pass for your child, apply in person (you don't need an appointment) to any East Sussex library or some district and borough council offices and bring along:

- proof of disability
- proof of your address
- a photograph of your child if you are applying at a council office.

At libraries, staff will take the photo (free of charge). Your pass will be sent to you within 10 working days.

Companion passes

If your child sometimes needs help to travel, you can apply for a companion pass allowing a carer to travel free. Your child does not have to always travel with a companion.

**To get a companion pass also take a letter from your doctor stating that your child needs help.**

Paul aged 16 has a bus pass and his dad has a companion pass. Dad said: “Having the pass has taken the stress and expense out of going to regular hospital appointments. We can also have a family day out in the summer holidays.”

Any questions?

- visit your local library or council office
- 0345 60 80 194

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**True Colours Trust**

**Does your support group need a financial boost?**

The True Colours Trust provides small grants of up to £10,000 to small organisations in the UK that help disabled children, their siblings and families. There are no application deadlines. You can apply at any time.

The Trust is particularly keen to fund hydrotherapy pools, multi sensory rooms, minibuses, young carers' projects, sibling projects and bereavement support.

For more information visit [www.truecolourstrust.org.uk](http://www.truecolourstrust.org.uk)

For general funding advice for voluntary groups call Veronique Poutrel on 01273 336616.

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**MacMillan benefits**

Macmillan Welfare Benefits Advice Service is for people affected by cancer, their families, carers and support workers.

The service works to increase your overall household income and lessen some of your financial concerns. They give one-off advice or on-going support.

01323 635989
macmillan@moneyadviceplus.com
Information and advice for families

As well as by phone and email, you can contact us on Facebook and our website for information and advice on...

* services for children and families
* childcare and activities (0-25 years)
* special educational needs and disability (SEND)

www.parentlinksussex.org.uk
For changes and how they affect you, SEND help and information, newsletters and opportunities.

www.facebook.com/InformationForFamilies
‘Like’ our page and find out what’s on, and for specialist activities, competitions and discussions. We are also happy to answer your questions so do get in touch.

ON THE WEB

Each edition we feature a website or two. Let us know which disability websites you like, and why, so we can share them with other families.

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Online disability lifestyle magazine

www.disabilityhorizons.com
Disability Horizons is a website set up by two disabled Londoners, Martyn and Srin, offering a modern approach to disability. It has:

- readers’ stories on employment, sport, travel and relationships,
- contributions from politicians, celebrities, entrepreneurs and more
- a questions page
- classifieds to post unwanted disability items and ‘Travel Zone’.

Challenging Behaviour

www.challengingbehaviour.org.uk
The Challenging Behaviour Foundation website offers information and support for families of children with severe learning disabilities. It is organised in three age groups, 0-11, 11-17 and 18+.

You can find support, resources that include a wide range of information sheets and real life stories.

Martyn and Srin on their travels
Progress update

East Sussex Parent and Carers’ Council membership continues to grow and so does our chance to influence the policies and practice that affect our children. Here are just two of the projects we have been working on:

- **Pathfinder project**
  At termly meetings with the project leaders our Parent Reps are influencing how single plans for Education, Health and Care will be delivered. Also three of our members attended an event in London on applying the new legislation, which Ministers have announced will be extended to September 2014.

- **Children’s Integrated Therapy Service tender**
  Two of our parents gave their views in the tender interview process for the new service for the next three years. One commented, “It was lovely to be a part of something so exciting”.

Training

**Parents Participating Confidently**

Recently we held our first training session for parents and carers in Eastbourne. The one day course strengthens your knowledge and skills. It builds the confidence to be heard in meetings about your child and to help to shape services.

One parent who came said, “I now have more belief in myself to positively affect my daughter’s education, leisure time and future”

*See opposite for future dates.*
Profile

Hi my name is Emma Godson.

I have been a member of ESPaCC for over a year and am currently the parent representative on the Local Offer for the SEND Pathfinder.

I attended an Insiders Guide parent resilience course in early 2011 which was a really positive experience. The course has enabled me to see how to move forward and access appropriate support for both of my children and reduce my feelings of isolation and despair.

I feel as individuals in a society, we need to support one another. So I made a promise to myself that, after putting myself and my children first, I would then in some way look at tackling the bigger picture. So I joined the ESPaCC and in addition to that I am looking for funding to run Insiders Guide resilience courses for other parent carers in East Sussex.

Date for your diary!

23 January – ‘Meet the ESPaCC’ Information Day at the Congress Suite in Eastbourne

• Hear presentations about local and national projects that will affect you and your child
• Meet and speak to us and professionals about our work
• View information stands
• Hear about our new award

Book your FREE lunch with Yvonne. (details opposite)
Disabled children and the law

There are many laws affecting children and families and it can be confusing.

To understand, see ‘Disabled children: a legal Handbook’. It is a reliable and easy-to-read guide to the legal rights of disabled children and their families.

The education chapter has information on current and proposed changes to legislation relating to SEN and disability.

For your free online version, visit www.councilfordisabledchildren.org.uk/legalhandbook

Coming soon...

Information for Families and Rockinghorse are developing a ‘leisure card’ for children and young people with disabilities. We are working to improve:

- access to facilities, such as leisure centres
- information about leisure opportunities and discounts, and to
- provide concessions.

Families are helping us to develop the project. We are looking for more families to trial the card, identify venues and to feedback on the project.

The card will eventually be available from libraries and we will keep you updated on our progress.

For more information or to get involved contact Information for Families.

0345 60 80 192
kate.gare@eastsussex.gov.uk
www.rockinghorse.org.uk

Free Makaton app for Apple devices

MyChoicePadLite is a free and easy way to help children and adults communicate using Makaton on an Apple device such as an iPod, iPhone or iPad. The app doesn’t require internet access, so you can learn and practise whenever you want.

The app was created by The Makaton Charity with schools and speech therapists and can help support memory, recall and visual learning as well as focus and attention.

To download, go to Apple’s AppStore and type in ‘mychoicepadlite’.

Parent Voice newsletter is for you.

Tell us what you would like to see.

0345 60 80 192 (local rate)
07797 870317 (textphone)
informationforfamilies@eastsussex.gov.uk
www.parentlinksussex.org.uk

If you no longer wish to receive the newsletter, contact us.