

in **contact**



The newsletter of Contact a Family North East

www.cafamily.org.uk/northeast

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Winter 2015

Congratulations Pat!



Pat Bolton (second left on the photo) received an MBE in the New Year's Honours List for services to families with disabled children.

Pat is pictured along with Lynn, Claire and Carol, fellow members of Parents in Power, Gateshead's Parent's Forum. See page 3 for more details

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PIP

From 26 January 2015, young people on disability living allowance (DLA) who are turning 16 will be asked to claim personal independence payment (PIP) if they live in a Newcastle, Sunderland or Durham postcode area.

What is personal independence payment?

Personal Independence payment (PIP) is a new benefit replacing DLA for adults aged 16-64. It has replaced DLA for all adults who are making a new claim. The government is asking some existing DLA claimants to claim PIP rather than DLA including young people turning 16 in certain postcode areas. If you are invited to claim PIP you must do so within 28 days by phoning the PIP claim line on **0800 917 2222**. Your DLA payments will continue while your PIP claim is being assessed. However if you fail to claim PIP when invited, your DLA payments will stop.

In which parts of the country are young people turning 16 asked to claim PIP?

Young people are already asked to claim PIP in many parts of the country. This includes postcodes in the North East of England starting with DL or TD. Full details of all the current PIP assessment areas can be found in a "PIP postcode map" available at www.gov.uk However from 26 January, PIP will also be extended to young people who turn 16 on or after 26 January and who live in a postcode area that begins with NE, DH or SR.

Are any young people able to continue receiving DLA in these areas?

Most young people in these areas will be invited to claim PIP shortly after they turn 16. This includes where a young person's DLA award is for an indefinite period. However if a young person is claiming DLA under the special rules for the terminally ill, they will be exempt and can continue to get DLA.

I live in one of the designated postcode areas. My child turns 16 after the 26 January but has already been sent a DLA renewal form. Should we complete this?

Yes it is a good idea to complete the DLA renewal form if this has already been sent to your son or daughter. When PIP was introduced in other areas, the Department of Work and Pensions allowed young people who had already been sent a DLA renewal pack to claim this rather than PIP. However it is not yet clear whether this policy will apply in those areas where PIP is being introduced from January. Call Contact a Family's free helpline for detailed advice if this applies to your son or daughter.

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PIP

What about young people on DLA who are already 16 or over?

Alongside young people turning 16 years, other groups of adults getting DLA can also be asked to claim PIP if they live in one of the designated postcode areas. This includes anyone in one of the specific areas who is aged 16 or above and:

- who reports a change of circumstances that could affect their DLA award (e.g. their condition either improving or worsening)
- who volunteers to claim PIP
- whose existing DLA award is due to run out after a certain date (this date varies from area to area but is 15/6/2015 for claimants in a NE, DH or SR postcode); or

What about young people in TS postcodes?

For the time being, young people turning 16 in a TS postcode area will continue to fall under the DLA system. No date has yet been provided for the roll-out of PIP to Cleveland and other TS postcode areas.

What about younger children?

PIP only applies to claimants aged 16 or above. There are no current plans to extend PIP to children under 16.

Further information

If your child is approaching 16 you can get detailed advice about benefits including personal independence payment by calling Contact a Family's free Helpline on **0808 808 3555** (Mon-Fri 9.30am-5.00pm)

Congratulations Pat

As featured on our front cover, we wanted to pass on our congratulations to Pat Bolton from Gateshead on being awarded an MBE in the New Year Honours List. Pat first got involved in the 'disability world' in 2002 when her son was diagnosed with ADHD and after previously running a local support group for many years, she is now Chair of Parents in Power, Gateshead's Parent Carer Forum.

Pat said she was feeling very overwhelmed and honoured to be put forward and was keen to ensure Carol Hope, Claire Parkinson, Lynn Smare and Gail Duxfield the other parents who are members of Parents in Power's steering group were also recognised for their hard work. When asked what keeps her going, Pat said:

"Because we are needed, parents like to be supported by other parents that have been there, done that and got the T-shirt. It's about all of us not wanting parents to go through the challenges we went through and helping parents get the services they need as opposed to what services think they need." Pat's top tip to other parents is: 'Don't give up! There are people out there who can help & support you.'

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Counting the Costs

Counting the Costs campaign - Help us put pressure on government

In November 2014, Contact a Family launched its Counting the Costs campaign at the Houses of Parliament. Parents attended with their children and were able to talk directly to MPs about their lives and the financial challenges they all face. Contact a Family carried out research asking more than 3,500 UK families with disabled children for their experiences. The findings show that over the last two years, there's been a sharp rise in the number of families going without the basics like heating and food. This is leading to ill health, stress and debt. Shaped by what thousands of families say would help, the Counting the Costs campaign is calling on the UK government and energy companies to halt this alarming trend.



We need your help to make this happen. You can do this by writing to your local MP. On our website there is a template letter set up so you can do this easily. It will only take one minute, but it will make a huge difference. Nearly 1000 people have already taken action but we need your help too.

Take action at on our [website](#)

The campaign also wants more families to seek advice on their family finances from Contact a Family. We have produced two new guides for the campaign

[Money Matters](#) and [Help with Fuel Bills](#). You can download these from our website at www.cafamily.org.uk or call our office if you would like a copy sent out to you.



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SWAN UK Local Network

Did you know that 50% of disabled children having genetic testing in the UK won't get a confirmed diagnosis?

Many of these children have complex medical or learning disabilities but without a diagnosis, their families struggle to have their child's needs taken seriously, or access information and support. Without a diagnosis they have no idea what the future holds for their child. Many of these families don't link in to other support networks for parents of disabled children as they feel like they 'don't fit in' and don't know what to say when someone asks 'what's wrong'?

SWAN UK (syndromes without a name), an initiative of the charity Genetic Alliance UK, offers support and information to families of children with undiagnosed genetic conditions. It is the only specialist support available in the UK for these families. Established in 2011, the SWAN UK community already has over 1,000 members and is still growing. Through multiple Facebook groups, families can access support 24/7 and make contact with others who understand how difficult life can be having test after test come back negative. Their quarterly newsletter, monthly e-news and regularly updated blog provides a wealth of information from tips for your first genetic appointment, information on the different types of genetic testing available and how to access it, to other families stories.

They have also recently started piloting a new Local Networks project in this area. Coordinated by one of their local members, Rachel Jeffares, they hope to develop a community of families to share the highs and lows of raising a child with an undiagnosed genetic condition. Offering opportunities for the whole family to enjoy days out, such as a recent meet up at the Alan Shearer Centre, the Local Network is a way for parents of children with undiagnosed genetic conditions to meet in person, make friends locally and share experiences and information.



If you are the parent of a child with an undiagnosed genetic condition living in the North East why not drop Rachel a line? Her email address is rachel.jeffares@undiagnosed.org.uk You can also call Rachel on her SWAN mobile number **07824668655** (not staffed all the time but if you leave a voicemail or text, Rachel will get back to you as soon as she can).

You can also find out more about SWAN UK by visiting their [website](#)

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Percy Hedley

School for Parents at Percy Hedley

What is School for Parents?

School for Parents is a free service providing Conductive Education for young children with cerebral palsy and other neurological disorders within Tyne and Wear. Children attend the group with their parents/carers and work alongside qualified Conductor/Teachers and support assistants.

What is Conductive Education (CE)?

CE is an educational approach to the development of children with cerebral palsy. CE teaches children the skills they need to learn to function as independently as possible. The best way to learn is to be motivated to achieve and for babies and young children, motivation comes from a desire to learn to play and to communicate with their caregiver.



Who is it for?

Families with young children with cerebral palsy and other neurological disorders, from age 3 months to pre-school. School for Parents aims to work in partnership with parents to provide high quality early years education. Parents are supported to learn to play together with their child and to develop motor, social and communication skills.

When and Where?

The session currently runs on a Wednesday morning during term time, beginning at 9.45am until 11.30am, at Percy Hedley Lower School, Station Road, Forest Hall, Newcastle upon Tyne. They hope to increase the number of sessions per week in the near future.

How do I find out more information?

Referrals can be from parents and carers, health visitors, therapists or GPs. Parents are invited to visit the school for an initial consultation and to gain more information about the Conductive Education approach used with School for Parents.

For more information or to arrange a visit, please contact Rachel Smith on **0191 2665491** or email r.smith@percyhedley.org.uk

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Local Support

Autism Northumberland

Autism Northumberland are a family run charity based in Cramlington, but they support families from the whole of Northumberland who are living with Autism. They offer 2 different parent/carer support groups, sibling support groups, teenage support, training and workshops, exclusive activities for families and lots more. They have a huge network of support on social media sites and are currently trying to raise £5000 to earn charity status. They welcome families who have a diagnosis and those who are still going through the process who live in Northumberland.

Founder Lesley Cole has two autistic children and knows exactly what it is like to be in the system without any support, so decided to create it herself and launched Autism Northumberland. There are lots of exciting things planned for 2015, their only requirement is that you complete a membership form which can be found on their [website](#) or contact them and they can send you one. You can call them on **07772208622** or email

autismnorthumberland@gmail.com Also find the group on Facebook by searching "Autism Northumberland" and on Twitter **@wereautastic**

Action for Blind People

Action for Blind People have recently appointed Children, Young People and Family Coordinators to work with families and organise Actionnaires activities for young people affected by sight loss. Emma Dawson is supporting the South of the region from the Middlesbrough office and Aly Turner is covering the North of the region and is based in the Wallsend office.

Parents have said that Actionnaires is a great chance for their children and young people to try new activities, build on skills and meet others. Priority is given to visually impaired children aged 4–16 years, with places then offered to siblings; in most instances siblings can be accommodated. Under 8s must be accompanied by a parent or carer at all events and all children/young people must be registered with Actionnaires.

They have a full range of activities coming up over the next few months so to find out more, please contact either Emma (for the South) on **01642 233439** or email **emma.dawson@actionforblindpeople.org.uk** or Aly (for the North) on **0191 262 0869** or email **alyson.turner@actionforblindpeople.org.uk**

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North East Support Groups

Calling all Support Groups

Did you know - Contact a Family has a Local Groups Network?

Benefits of joining include:

- Free copies of Connected, our national magazine
- Invites to our North East Groups Days - Supporting You, Supporting Others
- Inclusion on our Local Support Groups map - coming soon on our website

We also have a designated Local Groups Officer, Adele Meader and a range of publications in our Group Action Pack guide which you may find helpful. See our [website](#) for more information or email adele.meader@cafamily.org.uk or contact us here at the North East office.

National Freephone Number - 0808 808 3555

Contact a Family's **National Freephone Helpline** for parents of disabled children is open from Monday to Friday 9.30 a.m. to 5.00 p.m.

Our **SEN National Advice Service** and **Benefits' Advisors** are available through this helpline so please give them a call if you need specialist advice.

Language Line is available for parents whose first language is not English.

help us help more families like yours

The need for our services is growing all the time. Families with disabled children are more likely to struggle financially and often feel isolated and exhausted. With your support, we can help change this. Contact our fundraising team to see how you can help on **020 7608 8786** or email fundraising@cafamily.org.uk

If you did not receive this newsletter at your own address and would like to be added to our mailing list, please give us a call or write to us at Contact a Family, The Dene Centre, Castle Farm Road, Gosforth, Newcastle upon Tyne NE3 1PH.

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