PCAN newsletter January 2012

PCAN website up and running!

New trustees get to work...

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PCAN now has seven volunteer trustees working hard to take the forum forward. One of the first tasks for the group has been the creation of the new PCAN website and Facebook page – two great ways for parents and carers in Kirklees to find information, get (or give) support, and make views count.

You can use the new site by visiting pcankirklees.org or find PCAN on Facebook.

The first trustee meeting had a packed programme, confirming there is plenty for the forum to do. Turn the page to meet the new trustees and see the projects they are working on as PCAN gets busy!





Meet the trustees...

<u>Carol Thomas</u> - following a successful sales career in the textiles industry, Carol became a carer following the birth of her son Jamie (now 12) who was born with a rare and complex syndrome. As a result, Carol has accumulated a wealth of experience in many areas in health, education and social care including sensory support, special education, and alternative communication for hearing/vision/multi-sensory impaired.

Carol has an active voluntary role with the CHARGE Family Support Group (national charity) and has worked for Carers Gateway in Kirklees. Having listened to the varied experiences of other families with children with additional needs Carol is passionate about the involvement of parents in shaping services for children and families. Carol is married, has another son Adam aged 9, has two dogs and loves walking and reading. She currently works part-time at the University of Huddersfield.

<u>Diane Boustead</u> - my parenting life began over 16 years ago; all three of my children have had various challenges to overcome from an early age, but I see this as a really positive part of our lives; we live, grow and become stronger as a result of the day to day challenges we face as a family. I am a single parent and live in the Holme Valley out in the hills of Holmbridge; where I can be found digging in the garden, walking or drinking coffee and watching the world go by.

My daughter is at college studying A levels, my middle son studying for his GCSEs and my youngest is happily settled in junior school. I served in the Army, and then took up teaching later in my career. I am currently on a sabbatical studying a Masters in Modern English at Huddersfield University, which keeps me out of mischief! I got involved as a trustee of PCAN because I saw the potential to create something different, something new to support parents of children with additional needs. I am particularly passionate about supporting parents who are just beginning to realise that their child is different in some way, and those who have no specific diagnosis to use as a signpost to access support that is often really

John Egan - as a recently diagnosed Adult ADHD sufferer and I.T. professional of 25 years, my goals and aspirations changed suddenly with the birth of my 2 children, both of whom have Down's Syndrome. I quit my Computing BSC Hons Degree and switched to Health and Community Studies BSC Hons in order to fight for disability rights and champion diversity and inclusion and fight discrimination. My intention is to become a disability advisor and fight the bureaucracy and red tape for the disabled. A highly motivated self opinionated individual, with a highly defined sense of justice, who believes that everybody should be given a second chance and you are never to old to learn or change, but believes that more people need organisations and help to do this.

Continued...

Hi, I'm <u>Erika Farey</u> and I am a single mum to Toby who is ten. The experience of having a child with medical, learning, social and emotional additional needs has been a complicated journey, full of one way streets, dead ends and no entry signs! However, there have been other fantastic moments along the way where a map has taken shape and helped us navigate this challenging journey a little more successfully. Many times I found the really useful bits of the map came from other parents and families. My career has spanned both Education and Health, and I would welcome the opportunity to use these skills to support the work of PCAN. I really believe we can and should work together to improve opportunities for our children, and improve the experience of families with children with additional needs

Jenny Young - I am very much a child-centred person and I am extremely enthusiastic about improving the well-being and quality of life for children with additional needs. In my personal life I am fortunate to have two lovely boys both with a range of complex needs, so I understand and experience the many challenges parents face in their fight to enable their children to lead a happy and fulfilled life.

In my working life I have strived to work with children with additional needs, so working in a school with a resource provision has enabled me to develop further my knowledge of how a range of difficulties can affect children. Alongside my work I have sat as a chair of governors at a Kirklees school and now as a parent governor at my son's school. I am also well on the way to completing my degree in Childhood and Youth studies. My personal and professional experiences have led me to be involved with PCAN. I became a trustee because I want to support parents facing challenges. I am particularly passionate about supporting those parents who are still on the road to discover exactly what additional needs means to their families.

Hi, I'm <u>Angie McCormack</u> - I live between Dewsbury and Huddersfield and am married with a teenage daughter who has physical disabilities. I work and study part time in adult education. I have a strong interest in all issues concerning disability and a special interest in communication. For many years I have been a passionate consumer of services for children with additional needs and their families so I am delighted to be on board with PCAN to help put "parent power" to good use!

Hi, I am <u>Lesley Neve</u> and I am a parent of two young boys. I moved to Huddersfield nearly 20 years ago for work and enjoy living in this area. I work part time at Leeds University supporting students in my department's analytical laboratories. I would like to ensure that PCAN gets information about support and services available in Kirklees out to all parents who need it. Not having local family meant that finding the support network I now have is a hugely important part of my life and I would like to help others create this.



PCAN Projects

Good information

A single database –

getting the right services and information to the right families is a real challenge in Kirklees as there is no single database of information about the needs of children. PCAN is helping the Council to put parents interests at the heart of the planning for the new database.

PCAN Pages –

PCAN's own 'Wikipedia' with everything (well, most things) a parent or carer may need to know about activities, support and services in the district. You can access PCAN Pages through the website.

Collective Voice

Getting ourselves heard – a big

task for PCAN is to ensure that parents and carers views are listened to, and that service providers like the Council and the NHS get better at involving parents in planning. PCAN is working with the parent's forum in Calderdale to learn from their experience to find the best system for our district, then give local parents the support and resources to get involved, making your voices heard and getting good information back to you.

Participation Guide – PCAN has written a simple 'how to' guide for service providers who want to involve or consult with parents. The NHS Nursing Team for Children with Learning Disabilities has volunteered to help pilot the guide with their staff.

CAMHS new service planning –

the children and young people's mental health staff in the NHS are planning a new service for children diagnosed with learning disabilities and who have mental health needs. The NHS staff planning the service are working with PCAN to make sure the voices of parents are part of that planning. We'll let you know more about how to get involved as the work develops.

Talk and Support

Our next PCAN event

- after the success of the launch, we want to provide regular chances for parents and carers to come together. Watch this space for news of the next PCAN event, which will be in the New Year.

Supported Gardening sessions – The Holme

Valley Gardening
Network are working
with PCAN to create
activities for families to
come together with a
trained horticultural
specialist at their
adapted community
gardens near
Holmfirth. Thanks to
those of you who let us
know what you'd like
from the sessions.
Watch the website for
updates.

How you can get involved

Join us on Facebook

We have created a Facebook group because we want to give all our Friends and Members an opportunity to share information with each other about activities and events in Kirklees. Please help others to benefit from what you know by posting up messages. You can do this by...

- if you are not already a Friend or Member of PCAN please sign-up by following the link on our website (or call us on 07754 102336)
- find PCAN on Facebook and request to join our group

We will then join you up and you are free to read and post messages.

Become a **Member or a Friend** of PCAN

If you are a parent or carer of a child with additional needs, it would be great to have you involved as a member. If you work with children with additional needs in Kirklees, or you're not a parent but want to support PCAN's work, you can become a Friend. Go to pcankirklees.org and follow the links. You'll be very welcome!

Call us on **07754 102336**

Email us at info@pcankirklees.org

Pass it on!

Please send this newsletter on to...

- any organisations, parents groups or services that you think would like to become Friends of PCAN
- any parent or carer who you think would like to know more about PCAN or become a Member.