From small acorns (or pecans?)...

...trustees set out plans for the future



In this issue -

- Welcome from Page 2 a trustee Page Parents help 3 plan new health service Page Join the chat on Facebook 4 Page How you can 5
 - get involved





PCAN's trustees have set out aims and plans for the forum for the coming year, and beyond. Here are some of the headlines:

- newsletters to members every half term
- a big event for parents in the Autumn, focused on good information
- termly events and activities across Kirklees for you and your family
- a working system to make sure parents voices are heard in the planning of services for our children

Our big themes are good information, support and a strong voice. Kirklees Council and central Government are supporting PCAN with grants. Read on to hear about PCAN's latest work on each theme.



Support and Friendship

Welcome

Over 70 families are now members of PCAN. Forum trustee Jenny Young welcomes everyone and gives an insight into life as a trustee.

Firstly, welcome and thank you for those of you that have recently joined our quickly growing forum. Please pass the word - we will always welcome new members.

As I am sure you are finding out, a large part of our role as trustees is to provide information. We have an ambition that all families of children with additional needs should have the right to access information that enables them to make their own judgements as to what suits their family needs. We strongly believe in sharing information and our website and Facebook page are really helping us to do that.

Along with being a trustee, I am also a parent of two children with additional needs, so I am right at the heart of knowing what is important to us, where are drive comes from and what leads us into discovering support like PCAN. Parents need to have a way of linking together; for me, being part of PCAN has helped make my family life better through the people I have met. I feel I can fairly represent the needs of families and can add an individual perspective that will strengthen our collective voice. Our recent trustee meeting has been about setting a business plan. This has been crucial as we need PCAN to be sustainable and be long lasting - we are pleased to say we have great plans for the future, so watch this space!!

My role as a trustee and parent has also led me to contribute to developing the new CAMHS service (see page 3). I attended a very positive meeting with the PCT and other parents where I was able to make suggestions and express thoughts about how the new service could work. I am very proud to have had this opportunity and I would urge any of our members to come along to future meetings. We are always approachable and will give you a warm welcome. It feels very empowering to say we contributed to a service that in the future will be there for our children.

I would like to see my role as a trustee delve deeper into finding harder to reach families and families with children who do not have a diagnosis. I know from personal experience that not having a diagnosis can be very isolating and many of the support groups didn't quite fit our situation, so for me finding ways we can welcome those families will be extremely rewarding. I feel privileged to be a small part of the development of PCAN and I look forward to connecting further with our members and friends.

Allotment event kicks off PCAN support role

PCAN and the Holme Valley Gardening Network have got together to give families an afternoon of outdoor fun at the Wooldale Allotments

PCAN wants to give every family the chance to get together to have fun, to give and receive support, and to make friends. We're planning at least one PCAN event every term to bring families together. Wherever we can, we'll spread events around Kirklees. Our first event is an afternoon of Easter Egg hunts, arts and crafts and good food at the Wooldale Allotment and Wooldale Methodist Church. This will be first of a series of sessions for families at the allotment, so keep an eye open for news of the other sessions if you can't make this one. The event is free and starts at 1.30 on Saturday March 31. **Hope to see you there!**



A strong voice for parents

PCAN is aiming to put your concerns and views at the centre of the planning of services for children with additional needs, and find the best way of having real conversations with the professionals who support our children. We've had a great start to this work with two projects with the NHS.

Planning a new mental health service

PCAN parents came together recently with NHS commissioners to help plan a new mental health service for children with learning disabilities.

Parents suggestions have led to specific changes to how the new service will run – see below – and a request from the NHS to help develop a good practice charter and evaluation for the service. The ideas suggested which the NHS will now act on are:

- Early morning and evening appointments to increase accessibility for parents, particularly fathers
- A 'Choose and Book' system to give more choice over appointment times
- Each child to have a named key worker and the service to adopt a 'Team Around the Child' approach as needed
- Group work to be available to parents to provide education and support
- Hand held notes to be developed and incorporate a single assessment
- Session by session evaluation to take place so that parents get the most out of each session
- The service to be delivered in accessible, age appropriate environments i.e. schools, children's centres

- The service to deliver training to other providers such as schools.
- The service to ensure smooth and timely transitions
- More targeted support for siblings through group work and young carers network

Helping nurses to do better consultation

PCAN has developed a 'Participation Guide' which helps service providers to plan and deliver good quality involvement work with parents. The Learning Disability Nursing Team within the NHS volunteered to help pilot the Guide.

The Guide works by taking staff through a simple series of steps and questions which encourage them to think about why they wish to involve parents, what they wish to do, and how they will do it. For the Nursing Team, who wished to consult with parents who use their service about the most suitable content and practical arrangements for a potential series of training events for parents, working through the steps helped them to come away with a clear action plan for how they would talk with parents.

Reaction to the Guide was positive from the team, who felt the process had been useful in clarifying their planning. This successful pilot means PCAN is now well placed to support other providers.

Upcoming chances to get involved

Short breaks review -

PCAN has been asked by Kirklees Council to help in the future planning of Short Breaks activities for families. We'll be in touch through the website or by email to let parents know when and how they can get involved.

Parental involvement working group –NHS Kirklees and the

council have agreed with PCAN to work out a new, practical and effective system which brings parents and planners together constructively to work together to benefit families. This work is in the very early stages, so watch this space!

Good information for parents

Facebook making connections for parents

PCAN's Facebook page is proving to be a big hit with parents. We have a closed group on the social networking site, meaning only other members of the group have access to the site, not the wider public.

The page is a great way of passing on information about places, activities, groups or resources that you've found helpful, and to pick up knowledge from other parents. Follow the link on the PCAN website to find us, and **enter a prize draw** – any member who posts a comment which tells other parents about their positive experiences of using local businesses, venues, organisations or activities will be entered into our prize draw!



Essential information – a single database of children

PCAN is working with Kirklees Council on the creation of a single database for children with additional needs in the district. Nothing to write home about perhaps, but a good system could revolutionise what information reaches you and your family.

Presently, there is no one place where information about children with additional needs in Kirklees can be accessed. This means, for example, that better information about activities for children can't be targeted at those families who need it most, services for children find it hard to reach families who would benefit and parents will find it hard to find other parents whose children have similar needs to theirs.

A good database of details about children and their needs is the foundation on which the building blocks of information, support and a strong voice can be built. For the first time in Kirklees, work is underway to create one place for this information to be held. PCAN parents have helped in this process already, giving feedback to the Council on early drafts of the form which parents will be asked to complete to add their details to the database. The Council is listening to us: the new forms are in everyday English and questions linked to benefit entitlement have been removed at parents' request.

Over the summer, you will receive a request to join the database. We hope you will choose to do so, as a good database will mean better information for parents and, ultimately, better services and activities for children. It doesn't matter whether you are beginning to have concerns about your child or whether you have had a formal diagnosis for some time – for the database to work well it needs to have details from all the families in the district who are concerned that their child or children need support due to additional needs. We'll keep you updated through the PCAN newsletters and the website.

How you can get involved

Join us on Facebook

You've already read about the Facebook page – it's a great way for Friends and Members 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 <u>pcankirklees.org</u> 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.

PCAN – we could be just what you need!