

Parent & Carer Council Newsletter

June 2007



c/o

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Taking the PCC forward

In previous newsletters we have informed you of important changes in the way that the PCC is organised. The last 12 months have been very challenging for us as an organisation and we have had to take some tough decisions. Unfortunately, due to funding limitations, we were not able to sustain the chief executive function and consequently Julie finished her work for the PCC at the end of March. We wish her well as she pursues her interests through her own consultancy business. From the end of July, we will be unable to sustain the administration function and so Caroline will no longer work for us in a paid capacity. We would like to wish her well for the future too.

Despite these setbacks, we believe that the organisation is now shaping up for the future. We will be recruiting a city support worker in the very near future so we will have someone else working along side Jane. Despite the difficulties of recent times, the support to families has continued uninterrupted and we are grateful, to Jane and also to all of our volunteers who have worked tirelessly to ensure that parents have continued to receive the support that they need.

As we move forward, we are determined that the changes to the organisation will support and encourage the ethos of the PCC. We are an organisation run by parents, for parents. We seek to support each other and to work with partners in statutory and voluntary services to improve the quality of service for our families. There is always much work to do and so if you would like to become involved in any capacity as a volunteer we would be delighted to hear from you. We have our members meetings on 21st June, 13th September and 29th November. If you would like to attend these meetings, please contact Sue Harrison on 07986 857 598 to register your interest.

The Trustees

Support Groups:

Our support groups run both in city and county and are worked in partnership with Menphys SOS and Parent partnership in the county and with Menphys SOS and the Social Inclusion Team in the city.

The groups run in Loughborough, Castle Donnington, Coalville, Hinckley, Melton, Market Harborough, Syston and in the city itself.

For more information contact either:

Jane: 07870 688 973 or
Sue: 07968 857 598

County Take-a-break grant

Unfortunately, the allocated funds for this year have now been exhausted. If you were unsuccessful in your application, it will be kept on file and will be the first to be processed in the next financial year, assuming that the grant is again made available and that the same rules as this year are applied. This will be confirmed nearer the time. If you have not yet submitted your application, please still do so as this will help us to gauge the level of demand.

Your opportunity to have your say

Your views are being sought to help with research into two important areas that affect our members. If you are able to help, your time would be greatly appreciated.

Impact of Having Children with Special Needs or Disabilities on Parents' Experiences of Work: Questionnaire Stage

In the last PCC Newsletter there was an article introducing a project that I am undertaking to explore how parents' experiences of work are affected by having children with disabilities or special needs. Thank you to those of you who have already been interviewed and to those who have agreed to be interviewed over the coming months. In order to gather a broader set of views than can be obtained by interview, I have designed a brief questionnaire which would take approximately 10 minutes to complete. This questionnaire can be found on-line at www.clms.le.ac.uk/parentsexperienceofwork A link to this can be found on the PCC website.

I appreciate that finding any time can often be hard but if you can spare 10 minutes to complete the questionnaire this would be extremely helpful to the project.

The more views I can collect the better able I will be to really understand the complexities of working, or wanting to work whilst having a child with special needs or disabilities. The more comprehensive a picture that I can portray the more impact I hope that this research can have in trying to improve the situation for parents.

Thank you for any time that you are able to spare.

Dr Katharine Venter

Research to help children taking medicines for long-standing illness

At the Universities of Nottingham and Leicester we are designing better ways for the NHS to help children and teenagers take their medicines for long-standing illness.

We need advice from parents and carers about how useful and practical our ideas are. Your experiences and opinions are very important in shaping future services.

We would like you to contact us if:

- you are the parent or carer of a child or teenager between the ages of 7 and 18 who has diabetes, asthma, cystic fibrosis, epilepsy, congenital heart disease or chronic constipation;
- Your child is cared for by the hospital, a GP or a community paediatrician (or all three).

If you come to a meeting, we will cover all your travel expenses. If you would like to help but are not able to travel, we will come & see you, either in your home, or in a place convenient to you.

If you would like to be involved, or would like to find out more, please contact:

Rachel Elliott

Email: Rachel.elliott@nottingham.ac.uk

Tel: 0115 84 68596