

PWSAI Newsletter Summer 2010

Conference.

The Prader-Willi Association Ireland held its annual conference in April 2010 at the Red Cow Hotel. This year's theme was "Education". The conference provided information to parents with a view to helping parents to make an informed decision based on the needs of their child and on the choices available in their locality. We believe that there is no right and wrong decision as the choice of school is dependent on both the child's needs at any particular point in time and on the facilities available from which to choose.

The conference was well attended and the speakers gave generously of their time to share their experiences of providing support, working with and teaching our children in both mainstream and special school settings. From feedback received from parents, we believe the conference was very successful and that people learned from listening to our chosen speakers.

The morning session was chaired by Maria Meyler, who gave the opening address, with Donnchadh Clancy acting as MC. It was given over to presentations from speakers with expertise in special needs education. We had four presentations from five speakers:

*Martine Butler, Resource Teacher in a mainstream / integrated setting.

*Teresa McGann, Principal of St Michael's House, Special Needs National School, Dublin with Assistant Principal from the same school.

*Colin Reilly, Educational Psychologist with St. Michael's House, Dublin.

*Se Goulding, Head of Operations, National Council for Special Education (NCSE)

Martine shared her expertise and her experience of teaching a child with PWS (Dara Meyler) for 7 years in a special class in mainstream setting. She outlined the methodologies used when helping special needs students in this context and painted a very encouraging picture of what can be achieved when schools and teachers have the right mindset.

Teresa and Aine gave us a revealing and heart-warming presentation on the functioning of a special national school and showed how this can be a very positive option for some children with PWS and their families.

One of the main issues highlighted by these teachers from both integrated and special schools was the need for good communication channels and the difference it makes when that is working well.

Building that culture and developing a successful relationship within school environment and beyond to include people like the bus escort is what parents, in partnership, with schools to nurture. This is what makes the difference.

The main theme covered by the Educational Psychologist, was managing behaviour. In particular, Colin Reilly spoke about developing skills and tools because we need to use many skills and tools in understanding and managing challenging behaviour. Examples would include the need to develop skills such as empathy to try to understand and see a situation from our PWS child's perspective and to work on our detective skills to be able to go back and see what triggered a behaviour and learn from these. Colin's presentation resonated strongly with all our families present as he described the complex world of the PWS child in the educational context and beyond. He demonstrated a great professional understanding of key behavioural issues for PWS persons, their families and carers.

Se Goulding occupies a key position in the NCSE. In his presentation he described the role and function of the NCSE. He also gave an outline description of the process of resource allocation to school in order to support children with special needs with particular emphasis on the allocation of Special Needs Assistants (SNA) hours for students. He also spoke about the need for information and transparency in relation to the allocation of resources. He mentioned the standard of assessments and reports and whether there is room for improvement in clearly setting out the educational, social, care and behavioural supports that our children may require.

During the morning, extracts from two very relevant DVD's were shown and these are available as follows ;

Contact Ann Grassick: 087-9354914 or Email: anngrassick@iol.ie

€10.00 to rent per month or €40.00 to buy together with Handbook.

While the conference was taking place, our very important PWS people headed off to the ZOO and a trip on the Viking Splash. Everyone had a great time. This year we had an amazing team of professional carer's, allowing parents to relax and make the most of the day.

We are already planning next year's conference and we would ask parents to come forward with ideas or issues that they would like to see addressed. Please bear in mind that to ensure that the conference runs smoothly, there is very significant planning involved and if anyone feels they can help in any way, contact me at 087-9354914.

Thank you to everyone who sent cards, texts, e-mails and donations following the Conference. They were very much appreciated.

Ladies Marathon.

Thanks to all the Ladies who requested sponsor cards for this year's marathon. As always all cards (including unused cards) and funds must be returned to Lena Lawlor, Kilmurray, Bray, Co Wicklow by 30 September 2010.

Special Olympics

This year's Special Olympics were held in Limerick in June 2010. Well done to all who participated in the various sports. It takes a lot of dedication and very hard work leading up to the games and so you should be very proud of your achievements.

Good luck to those who are now progressing to the Games in Poland, please let me know how it all goes.

PWS Adult Week-end in Derby in June 2010

Sheila Mooney and her daughter Siobhan went to Derby to take part in the over 18's week-end organised by the PWSAUK. The aim was to give our adults a chance to talk about their syndrome together. The week-end was open to all over 18 PWS people once they were accompanied by a carer. Carers and Parents did not take part in the talks, this gave the adults a chance to express their feelings amongst themselves.

This idea proved to be very successful and enjoyable. We might perhaps join with the PWSAUK to offer another person(s) an opportunity to take part next year. Thanks to Sheila for the positive feedback.

Progress on our meetings with Minister John Moloney and the HSE.

We had a further meeting with the Dept of Health and the HSE last month. Again we provided information about the syndrome and in particular we spoke about the challenges that parents face daily relating to diet and behaviour. We outlined our reasons for looking for PWS specific residential and respite care as against shared accommodation with other special needs people and this is being considered.

While we believe we have made progress, further progress can only be achieved by providing data in relation to

- (a) the level and extent of help that parents need and
- (b) the level of help that PWS children and adults, receive currently from any agency or care provider.

To enable us to compile this data we are asking parents to complete a questionnaire which will be posted to you shortly.

The information will remain confidential to PWSAI and only statistics based on the information will be provided to the Dept and the HSE.

We do need to be able to provide accurate and specific details relating to adults and teenagers in need of PWS specific residential care or respite care both at this point in time and in the coming 2/3 years. We need to have details of difficulties being experienced by PWS adults and teenagers, their parents, carers and care workers. We had asked parents of PWS adults to provide consent to discuss such issues and we have some consents but more of our children have reached this stage now and we need to be able to represent all those in this category who need or may need more help than is

currently available. Parents in this category will receive a consent / questionnaire form with this newsletter as well as the general questionnaire / consent form, please contact Ann immediately.

It is really important to help us to help you and we are asking you to make a real effort to supply the information and to get it back to Ann within the next two weeks but no later than August 27th.

Information Booklets and Educational DVD's

We were experiencing a delay in getting the books and DVD's to all of those who placed orders. If anyone has not received their order please contact Ann Grassick at 087-9354914.

PWSAI, as always, are working hard on your behalf and if we can be of assistance to anyone who needs further information or just a chat, feel free to contact Ann or Lena or indeed anyone of the committee. If anyone has any stories or tips to share please let us know.

PWSAI COMMITTEE