



## Prader-Willi Association Newsletter November 2010

Hope everyone had a good summer and settled back to school.

### AGM

The Annual General Meeting was held on Saturday 24 July 2010 in Wexford. It was agreed we should approach some new parents to become members of the Association. Having considered those Parents who previously expressed an interest in becoming, we are happy to say that Anthony Carr, Tom Harty and Sean Kelly have become new Directors of the Association.

The strategic issues to be addressed in the coming year are as follows:-

1. Residential and Respite Care
2. Governance
3. Fund Raising
4. Communications including Website, Raising awareness and the Newsletter
5. Conference 2011

Ann Grassick pointed that as a result of conversations she has had with parents, it has been recognised that there is a need to provide help and support for parents. It was agreed to devote next year's conference to the needs of parents entitled "Help me to Help Myself". The conference is being organised by Ann O'Neill.

It would greatly help if as many parents as possible would contact us and inform us as to what topics they would like addressed.

### DVD

We hope those of you who purchased the DVD and Handbook for Educators found them helpful. We had some very positive feedback and would appreciate your comments on how

successful it was for you. If anyone needs to purchase or rent the DVD please contact Ann Grassick 087-9354914.

## ARCH CLUBS

We had some very positive information from one family whose teenage son joined the 13+ Arch Club in Dublin. The club is for all teenagers with disabilities. There is also a junior Arch Club dealing with the younger age group. The club meets twice a week for Drama, Dance and various other activities. They arrange outings during the summer and other school holidays.

As far as we are aware there are Arch Clubs all over Ireland. We suggest you make enquiries in your local area and would appreciate if you would let us know if you are successful in finding one.

## CHRISTMAS CARDS

We are happy to say that we have a new supply of Christmas cards. These cards are available by contacting Ann Grassick who will make arrangements to forward them to you. We would once again appreciate if as many people as possible would think of our "Very Worthy Cause" when purchasing Christmas cards over the coming weeks.

## RESIDENTIAL AND RESPITE REPORT

Thank you to everyone who took the time to complete the very detailed questioners forwarded to you during the summer. The response could have been better and we would appeal to you to please even at this late stage complete the forms and return them to us. We are desperately trying to act on behalf of all Prader-Willi people in Ireland and cannot help unless we have as much information as possible.

We are at present awaiting a meeting with the HSE and are hopeful that this will take place before Christmas.

## Colin Reilly

Some of you will remember Colin the Educational Psychologist who gave a presentation at last year's conference. He approached the Association some years ago hoping that we would consider collaborating with him on his research he was doing on four different syndromes one being Prader-Willi Syndrome.

Colin is now ready to complete his research and we have agreed to assist him in any way possible. The research focuses on three main areas with regard to provision for families and children affected by the four syndromes. The three main areas are

\*Parental and teacher views of educational provision for children affected by the syndromes.

\*Psychosocial impact of the syndrome on affected children and their families.

\*The support needs of families affected by the syndromes.

We will update you on the progress of Colin's research and hope that you will join us in helping him along the way.