That's Rare!

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

The Newsletter of the NI Rare Disease Partnership **Issue 1 – December 2012**

Welcome to our first Newsletter! If we look back a year, we were working and planning to get the Northern Ireland Rare Disease Partnership incorporated; and for Rare Disease Day 2012.

We have made tremendous progress, thanks to the commitment and contribution of our members- now over 120, and growing. As we've moved forward we've discovered and developed new skills and strengths, learning from each other; building relationships with our elected representatives, responding to consultations, planning events and so much more. All this makes us more effective in our work on behalf of those living and working with rare diseases!

It's really exciting to look ahead to all that is underway or planned for the next year. There are the projects we are taking forward on Patient Pathways; involvement in the Neurological Conditions Network; our role in the review of Paediatric Services; plans for a survey of Community Care, and for modules for education and training in rare diseases.

Alongside this there is our continuing work on consultations- making sure that the policymakers hear our voice, and genuinely take account of what we are saying. Most important and immediate is the Transforming Your Care consultation, which we must respond to by mid-January: so watch out for details on it.

And there is our Rare Disease Day key event, jointly hosted with our counterparts in Dublin, picking up on the "Rare Disorders Without Borders" theme of the 2013 International Rare Disease Day. There is detail elsewhere in the Newsletter on this, but let's see if we can build on the success of last year's event! Let's put Rare Disease on the map right across Northern Ireland, and Ireland, in 2013!

Wishing you all a very Happy Christmas, and a safe and peaceful New Year!

Christine Collins

Chair, Northern Ireland Rare Disease Partnership

In this Newsletter, we hope to bring you a selection of patient stories of people living with a rare disease. Below, Carol McCullough gives her experience of being involved in the Northern Ireland Rare Disease Partnership…..

WHAT IS SUCCESS?

In 2010 I was diagnosed with probable Wilson's disease in the absence of using any ophthalmic opinion; not Ophthalmologists or current doctors' fault. I am under the care of three Consultants and, regardless of problems posed by several chronic illnesses, receive excellent care. Wilson's disease patients, and their families, can suffer greatly due to lack of understanding of this rare disease and the road has not been all plain sailing. However when I discovered, and joined, Rare Disease UK in 2010 it became very apparent that Wilson's disease was not alone - but times were changing and here were people who wanted change. People who were prepared to support each individual regardless of their diversity. My own small voice had an opportunity to join many others during consultation on 'Experiences of Rare Diseases' and 'Improving Lives, Optimizing Resources'.

The next big event was Rare Disease Day 2011; I was going to Stormont. It was a blessing that I did. Now I was not only face to face with people who wanted to see change they, like me, knew from experience and knowledge of rare disease that it had to happen. I was hooked and began meeting up with likeminded individuals who planned to form a group that represented the needs of those affected by rare disease in Northern Ireland. There was much discussion; ideas thrown around – what would we need; how might we go about things; who could do what? I was always allowed a voice but not certain what I could actually do. I mean … I have ideas but are they any good?

I aired my thoughts at meetings; lobbied MLA's on the need for improving the plan for rare diseases and had a chance to help during planning stages of the Patient Client Council's survey. The months flew by and Rare Disease Day 2012 fast approached. Fellow members worked tirelessly to make the event in the Pavilion at Stormont the success that it was - and what a success!!! It once again validated just how much interest there is in rare disease. The Northern Ireland Rare Disease Partnership was launched; the PCC report 'Experience of Diagnosis' was launched; discussions were serious but there was also fun and laughter and …… is food important? It is to me; there was food.

Mr Poots, The Minister for Health, was there and I joined the queue to speak to him about the challenges of rare disease. He listened to everyone. Since then I have attended general meetings to discuss the group's strategic direction over coming years. I have also accepted the role of Consultations Lead and a meeting is currently being planned to systematise how we work together in forming consultation responses. We have completed five consultation responses and the very important 'Transforming Your Care' is next on the agenda. Whatever I have been involved in with the NIRDP the experience has been positive, constructive, interesting and rewarding. I am looking forward to Rare Disease Day 2013; the new UK Rare Disease Plan and in anticipation – no certainty - that the NIRDP shall make as much progress in 2013 as we have done in 2012. So that eventually no one is left behind.

Wishing everyone a Happy New Year. ***Carol***

OLYMPIC TORCHBEARERS!

Over the summer, the NIRDP was well represented in the Olympic Torch Relay!! A massive thanks to the lovely staff and pupils at St Colman's in Lambeg, who inventively, paid £1 to run a lap with the torch and raised £415 for NIRDP…Well done!

Pictured left; Leigha Coade, who has cystic fibrosis with supporters and right, Robbie Crouch, whose mother in law died from PSP last July.

SOCIAL MEDIA – BRINGING PATIENTS TOGETHER

Whilst many people are wary of social media, I would like to share some very positive stories about our Facebook Page, Parents of Disabled Children Northern Ireland. We are all parents of disabled children who have known each other through various disability groups that we have come into contact with over the years. Parents of disabled children do not often get the opportunity to speak to other parents in the same situation and attending support groups is often not an option for many who lead very busy lives because of caring, working or attending the multitude of appointments that so many parents' lives are tied up with. Last year, I notched up a total of 120 appointments!

Many of the parents on our page have children with very rare conditions and most of these parents will not have access to a local support group. Most support groups in NI are condition specific and we wanted to create a pan disability page for parents, to come together to simply talk about the issues that affect their lives. Our first task was to invite parents who we would know from existing networks that we were involved in from neo natal wards, hospice stays, conferences, clinics or consultation events. As admins we believe that is it absolutely vital that this is a closed group, thus anyone who joins the page is linked onto it by the admins or by parents already on the page who can verify the friend request is from a parent of a disabled child. This is regarded as a safe space for parents, who can talk about matters that affect their daily lives and it is important that parents feel confident to share their lives with others. Our rules are quite simple, we will not tolerate any abusive posters and we do not allow anyone to name any professionals who work with them. It is really quite enlightening, just how respectful and caring all our parents are towards one another. There is a feeling of community on the page even though this is all in a virtual world. And the great thing is this – disability is normal in our virtual world, and parents do not have to explain things the way they would have to others whose lives are not involved with disability.

Bernie and Roma Drayne with Edwin Poots, Minister for Health

We cover so many issues but there are recurring themes – which come around so often - disabled facilities grants, housing problems, Social Work and OT provision and DLA. But we also talk to each other about equipment, wheelchairs, toys and practical issues around sleeping or bathing. We also have many parents who are newly diagnosed, and those waiting on diagnosis. Parents like myself who have older children are able to talk to parents to help them come to terms with their new lives, and to try ease the way for them. Many of the children here are actually life limited, and sadly since our page was started just over a year ago, we have lost two little lives although

the parents have stayed with us. We are often asked to pray for children, who are ill, and so many parents will join in and send messages of support – it really is lovely. We have had long discussions about coping with diagnosis, and everyone has shared how they deal with things with great honesty and compassion. Very few people outside of our world actually appreciates how diagnosis affects parents – the effects of this lasts for years – but parents are thrown into a what is a new world for them of SEN statements, AHP assessments, and all the various medical appointments that follow whilst at the same time grieving for their child. Our aim is to help parents understand the processes that they find themselves thrown into - no-one is born knowing these things, thus parents often do not understand what professionals and services can and should be doing for them. We can sign post parents onto other groups that we feel have worked for us, and indeed we can also compare how groups, trusts and services perform.

We also use poetry and humour too, a recent post relating to how parents would spend the DLA Christmas bonus brought some amusing replies. Our page is also used to advertise public consultations and we link surveys and newspaper articles so that parents can participate if they wish to do so. Ultimately we hope to reply to government consultations but at the minute a Facebook page is not recognized as a 'legitimate' group.

We now have over 170 parents with us, and the page is busy from early in the morning until very late at night. If anyone has problems that cannot be aired on the page we can to talk to them by private messaging. I must say we are really surprised at how well this has all gone. I just wish this resource was around when I was struggling in the early years to understand the new world of disability that I was thrown into. I do applaud all the parents we have, their sensitivity and generosity is striking. We are driven by passion for what we are doing, we don't need funding or scoping exercises, and we can define our own problems, and work out solutions. **We understand each other, we hold each other's hands and it works.** ***Bernie***

SAVE THE DATE!

"RARE DISORDERS WITHOUT BORDERS"

An all-Ireland meeting of patients' organisations to mark International Rare Disease Day. Please email sarah.mccandless@hscni.net or phone 02890 321230 if you are interested in attending.

Date: 28th February 2013
Time: 9:00am
Venue: Wood Quay
Civic Offices, Dublin 2.

NOW THAT'S RARE!

In 1963, Gaylord Perry (a baseball player) remarked that "they would put a man on the moon before I hit a home run." In 1969, a few hours after Neil Armstrong made history by being the first man on the moon…..Gaylord Perry hit his first and only home run of his career!