**Fourth Newsletter**

**14th July 2017**

It seems so long ago that I put pen to paper or should I say put pick and peck to paper? It has not been intentional nor due to lack of concern but rather due to finding a new webmaster and a very busy work load. I want to send ongoing thanks to Brendan’s mum; Ann Earle for stepping up to the plate to help whenever asked. She has a busy secretarial business and her assistance is greatly appreciated. I am hoping for success with a local person taking over the website this week.

I have been thinking about the difficulty that exists in our Leukodystrophy community when we need to replace an existing worker or find someone who is prepared to volunteer and thereby helping us ensures that our voice is still heard, our organisation runs efficiently and ultimately, we can maintain the best quality care for our loved one. It is not always that easy as rare diseases are less known and usually only attracts those family and friends who have a link to it. There are of course exceptions to this and the world has its hidden angels. I have been looking at what activity has occurred lately around the world in all the Leukodystrophies and it is very apparent that it is all community driven. It occurred to me that we all live in a variety of communities in our life time and that they change and some are far more supportive than others. Some we chose to live in, some we evolve from and others can leave us stranded.

We moved to the Leukodystrophy community because one of our loved ones has had some terrible news and this news compounded and affected the community we lived in at that time. Most of us find that the commonality of interests that created that community has had its structure challenged. Not all the participants remain the same people that we thought we knew. I would suggest that nearly all of us lose some “friends” and that experience is painful. We are hurt by the lack of understanding and acceptance of our changed circumstances. Often some of the lesser known participants become friends of great substance and we are surprised by this revelation.

We discover multiple communities existing within our own and they support us in all the varying ways to meet those daily needs that help us just to manage and get out of bed every morning and very often many times before the morn.

There is the disability community from which we gain life membership. Possibly the most powerful community on this planet and formed from the most improbable and unlikely group of mismatched, socio economic opposite, multi ethnic, disorder different, group of mums, dads, grandparents, sisters, brothers, aunts, uncles, cousins, nieces, nephews and sundry other souls. They achieve the impossible with ease and have a complete understanding of each other, stranger or otherwise and communicate with perfection in the most potent ways and often never speak a word. If you think I exaggerate I suggest a visit to the parents’ room in any children’s hospital or if you are game find the fogged area designated to those getting some “fresh air” by having a “destressing” fag.

If we made this the model from which our countries were governed what a glorious world we would live in! A world where we all knew that we belonged, shared the equality of inequality, could access our functional needs and always feel safe.

There is the community of special education. One that constantly amazes me for it is made up of those that create a living experience for our children, often with no personal link to disability and all structured in the binds of a bureaucracy. Another stunning example of how a loving functional essential community works from elements that would not seem compatible.

The medical community is the most ambivalent one we encounter. We often get bogged in this one for far too long before we meet other vital members. The reason a large number get caught in this morass is mostly due to ignorance, arrogance, egotism a total lack of concern or care for the affected family member/s which of course creates a contagion of fear, pain and anger throughout that family system. Others are most fortunate and enter this community and get to meet the broader community in a timely and acceptable fashion.

This community also has a large number of people with varying learned skills, understandings, attitudes, backgrounds, goals, ambitions and they are not by design synergistic. This is its tragedy. We meet many different clinicians, therapists, hospital volunteers and hopefully the palliative care team. It is a community we enter where our fervent wish is that we can find answers, learn about this catastrophic condition and find the elusive miracle of a cure. Most of this does not happen as we would like and of course our hope remains for the miracle. As there are many different participants so are there many different experiences. Lifelong friendships grow from the depths of despair. This becomes another “family” for most and like all families there are those that are remembered for not honourable reasons. So, it is with this community. One way or the other they remain in the Leukodystrophy family for ever.

Our Community of hope – research. This is where we place our trust and hope. I am reminded of the words of St Augustine on this subject when he said that; “Hope has two beautiful daughters – their names are anger and courage; anger at the way things are, and courage to see that they do not remain the way they are.” It has been my great pleasure to see the enormous progress in this area across a lot of the Leukodystrophies. There is an energy and personal commitments from scientists, biogenetic companies and clinicians. Trials are being undertaken with much more confidence, knowledge and purpose. There is a fire that has been lit under the belly of big business and this encourages more research. Whilst we may not think there is a lot happening or perhaps that we are not making new discoveries on the Leukodystrophy that impacts our life the difference in research activity is dramatic from what it was say 5 years ago. Leukodystrophy Centres of Excellence have been developed from this growth because the family’s needs and wants were listened to, understood and acted upon; the families are the real experts in Leukodystrophy.

Our domestic Community is the one wherein we have the most of our struggles, troubles and triumphs. It is where we live, love, laugh and lament our lot. We watch our loved one as they battle through the insidious inevitability of this illness. We see out partner in torture and wonder how we will be able to survive. Sometimes we do not seem to be dealing with the same situation as our antenna is snowed in by sorrow. Often our children confuse us because we are never sure just how they are absorbing this uninvited and frightening future. We wrestle with finances, bureaucracy, work issues, schooling choices, belief systems, general ignorance to name but a few.

Our neighbourhood Community which in broad terms involves all those around us contains our non-government support system and I doubt if most of us would survive without it. Our fundraising and our fun raising mostly elevates from here as does the cooked meal, supportive shoulder and restorative respite from the reality of our circumstance. We experience the truth of how; many people let their kindness be discovered and how that creates a lasting belief in the inherent goodness of people. They honour our loved ones and themselves and hopefully they find the internal happiness that comes as a bonus from their actions and not from something sought.

Until next time

Bob😊