# Parenting a child and young adult with VCFS/22qDS

**By Anne Lawlor**

*Chairperson 22q11 Ireland*

February, 2011

My name is Anne Lawlor and I live in Dublin, Ireland with my daughter Áine. For many years, 15 to be precise, we lived without a diagnosis for her. Genetic testing and the FISH test in particular was not readily available during the 1990's and even if it were it is quite possible that she might never have been tested. I still believe that her diagnosis only happened because we had chosen to put her into special education and there was a clued-in doctor on the premises who suggested the genetic test.

With the diagnosis at 15 however came some answers, answers as to the whys of the puzzling medical, educational and behavioural issues that both of us had been struggling with. Although Áine had had a clinical psychological test at six, diagnosis 'mild mental retardation, cause unknown' it in no way enlightened me as to what we were really dealing with. And sure I thought that 'mild' was, well mild, as in a mild sunny day or a mild cold. Experience over time has taught me that there is in fact nothing 'mild' about this condition. Mild is only mild when compared to something worse.

Her official diagnosis at the time was DiGeorge Syndrome and I vaguely remember something being mentioned about a micro-deletion on the long arm of her 22q chromosome. I was given the diagnosis along with the name of a UK support group and very little else. So, she went from someone who was quite frequently sick to someone with a syndrome and there was no-one to tell me, as a mother and a parent what this meant in real terms. All I knew was that for fifteen years my child had been ill and now suddenly she was ill because she had a syndrome - that was a very frightening place to be.

Looking back at parenting her as a child I realise now that my confidence in my own abilities as a mother was undermined right from the start. Áine was born with a sub mucous cleft palate which was not picked up on for three months. My worry and concerns about feeding issues were brushed aside, I was described as over-anxious. The assumption from the experts was that I was most emphatically *not* an expert, I was merely an inexperienced mother whose knowledge of such matters was to be dismissed. I now know with a quiet certainty that every mother is an undisputed expert when it comes to her child with VCFS/22q.

Diagnosis answered some questions but raised many, many more and so the quest for knowledge began driven by my insatiable hunger to find out what was this thing that they had labelled my child with. No one I spoke to had ever heard of this syndrome. Oh sure, the genetic consultant was able to tell me that she had a deletion on the long arm of her 22nd chromosome and that that was the reason she had been born with a palate problem and it explained all the other more minor medical and behavioural problems too, but what did it mean in real terms? What did the future hold? Did this mean she was different in some radical way? What were the differences? How was I to help her come to terms with this and how was I to come to terms with it myself? Although Áine has 22q11.2 deletion, she is very self-aware and looking at her you would not easily guess she has a syndrome, but she knows she is 'different'- when you get to grips with the medical problems you're then faced with the psychological and emotional ones.

As parents of children with VCFS/22q there are very many things for us to worry about, as our children grow we grow increasingly fearful about what will happen to them when we are gone. Over time therefore my main concern began to center on Áine's own self-image and what I could do to ensure that she lives into her abilities to live her own life, as an independent and valuable citizen with a lot to offer.

I have 'grown into' this syndrome as Áine herself has grown. In very many ways I simply adapted to her quite unique ways of being. Long before CBT ever became recognised as the useful therapeutic tool it is today I had read some of the work of one Dr. Abraham Low who devised a self-help care plan for his patients who suffered from a variety of 'mental illnesses'. Acutely aware of the significance of language and how it subconsciously educates us Dr. Low set up Recovery Inc and

devised slogans or mantra's for his clients one of which is to learn to 'excuse rather than accuse'. Maternal instinct, more than anything else, told me that because I had no real idea of what was going on with Áine, that it would be better for me to 'excuse rather than accuse' her sometimes inexplicable moods and quirky behaviours as I had no knowledge of the cognitive/ behavioural profile of VCFS/22q. So mostly it was a hit-and-miss affair and having stated that I knew very little of what was going inside her head I can with assurance say that now that she is grown-up nothing much has changed in a lot of respects.

She used get tired very easily as a child, she still does. She had problems finding things, she still does. Constipation was a feature, it still is. Ear infections were a problem, they're still a major feature. She was a concrete literal thinker, she still is. She couldn't tie shoelaces, now she won't wear shoes with laces. Math was a problem, now she has difficulty with understanding money. I could go on and on citing countless of daily relational interactions that might make no sense to anyone else, unless of course I'm talking to another parent of a child with VCFS/22q. We live in this 'other' world you see, in a place where only we can make sense of what is happening because unless you are immersed in the daily, lived, felt reality of this syndrome your knowledge is theoretical. This is not a judgement, just a statement of fact. This is the reason why parents say that the chit-chat after a conference is so vital to them and they very often gain *more* valuable information than from the presentations. It is wonderful of course to be given the information and the latest research findings but other parents have either been where you are about to go, or you have been where they have not reached yet. We are a rich source of information and solace for each other, nothing beats the feeling of blessed relief to be able to sit with someone without having to 'explain' your child to them. It is the precise reason why parents also flock to those professionals with specific 'syndrome' knowledge – they know they will be understood.

Parenting a child as opposed to a young adult merely brings different challenges. When younger, bad and all as some of us have it, we at least had a measure of control over our children. Very often when the 'child' passes the 18 mark we hear the "but I'm 18 now, I can do what I want" refrain. Our hearts sink because we know deep down that our children with this syndrome are extra vulnerable, we are torn between wanting their independence and protecting them. Issues around sexuality

and relationships come to the fore, in this respect there are some very difficult decisions to be made especially if we are raising girls. How on earth are we to negotiate this tricky and oh so important phase of our children's lives? Did anyone tell us that we would be facing issues in their finding friends, relationships, jobs or independent living?

Many of us feel that we are dealing with a never-ending childhood. My daughter will be 28 this year. She started an educational course and I had to get a new psych assessment done so that she could get one-to-one resource hours. I still attend hospitals with her because I know something gets lost in the communication process if I am not there. Whilst semi-independent she still needs care and supervision with certain tasks – there are some things that she will never do, like driving a car. Adulthood brought with it a diagnosis of osteo-arthritis, this will gradually impinge on her quality of life, and mine for that matter as I am her carer. Personal wellness has become a goal of mine, I know if I am not physically and mentally fit both of us will suffer. As parents of children, young or older, we are in permanent anxiety-mode. Self–care, often at the bottom of our always lengthy lists, is no longer a luxury, it's a necessity in order to keep the relentless anxiety at bay, to keep one step ahead.

Perhaps the most difficult aspect over time of parenting a child with VCFS/22q is the attempt to get to grips with the perplexing behavioural profile that our children have. Of all the many anomalies associated with the syndrome this is the one that undoubtedly causes the most distress both for the child and the parent. When young this aspect of the condition is far more manageable, our children are usually kept in close proximity to us and there is a level of support that we can rely on in relation to their behaviour. It is here that the importance of accurate information can make a crucial difference to parents and care-givers.

We know that many children born with VCFS/22q are on the autism spectrum and some will have ADHD. This all goes some way in giving us a greater understanding of our children's behaviour but what gives most cause for hope for parents is the neuro-imaging scientific research currently ongoing. Also, evidence in the literature indicating that early intervention may improve the outcome of mental health disorders and in particular psychotic disorders is very heartening.

The fact that Campbell and Kates state that although “children born with VCFS have brains that may look different from typically developing brains, their brains are as amazing, as plastic, and as is increasingly being understood, to some extent as malleable to outside influences” is truly an exciting and hopeful viewpoint from a parental view. Our own Irish educational psychologist Colin Reilly speaks to me in terms of “learning delay” as opposed to wholly “learning deficits”. I can see the logic of this, my own daughter has at aged 27 learned to play the fiddle. Where once she could not ‘get’ sarcasm now she is not so bad at dishing it out! When our children’s strengths are focussed on and they are given the support and understanding that they need they can achieve great things. Most of all, when they are viewed and treated as first and foremost *a person*, and their condition is viewed as incidental to their personhood they are in with the best chance of living a good life.

Personally and in my voluntary capacity with the Irish 22q Support Group I have adapted the VCFS slogan ”*Knowledge is Hope”* and now as a parent, believe that *“Knowledge is Power”.* I see a movement from total reliance on professional expertise to a welcome recognition that parents also have an enormous contribution to make to the growing body of research on VCFS/22q. My desire, also personal is to now see a third group enter the picture and that is those affected by 22q themselves. There is much to be gained by doing participatory active research with our older children and young adults and a lot we can learn from them. Along the way Áine gained her own ability to articulate the experience of what it’s like for her to have a 22q/VCFS, her insights are hugely valuable. She herself has always taught me the most of what I know in real terms about this condition, she has in fact taught me many things, and not least the fact that having a ‘syndrome’ is an inherent part of who she is. She has made me question what it means to be a ‘whole’ person and because of her I learned what is *not* in the books – I have become a life-long student.

In conclusion I would like to say that parenting a child, young or older, with or without VCFS/22q is never going to be plain sailing, parenting is not like that. What we need with our ‘different’ children however is perhaps advanced parenting skills, we need to learn how to advocate for our children and then in turn teaching them self-advocacy. We need to learn how to negotiate first the medical and then the educational

systems to ensure our children get the best services possible. Very often this is very frustrating, a time-consuming effort on its own *without* the parenting piece. For all that is written about VCFS/22q there are very many people who have no clue as to what it is so along with everything else we become awareness raisers and champions for our cause. How many of us have started support groups?

We need to get ourselves into parent training programmes to help us understand and cope with the behavioural difficulties that will inevitably arise. Most of all however, what we need as parents is to never lose sight of our children's struggles with themselves in trying to adapt to the world around them and in the words of Harilyn Rousso "to communicate appreciation and respect for the child's unique often different-looking ways of doing things". As always, our parenting starting point is love.



***REFERENCES.***

Disabled yet Intact: guidelines for work with congenitally physically disabled youngsters and their parents. Harilyn Rousso (1984)

Mothering Special Needs: A different maternal journey. (2007) Anna Karin Kingston. Jessica Kingsley Publishers: London

Missing Genetic Pieces: Strategies for Living with VCFS, The Chromosomal 22q11 Deletion. (2004) Desert Pearl Publishing: Arizona.

Putting the Patient at the Heart of Clinical Research: Powerpoint presentation to Irish parents, Saturday 29th jan 2011 Professor Kieran Murphy, Dept of Psychiatry, Beaumont Hospital and RCSI.

The Mental Health Needs of Young People with 22q DS. Powerpoint Presentation to Irish parents Saturday 29th January, Trinity College Dublin. Dr. Elizabeth Parks, Senior Reg, North Galway CAMHS Team.

The Psychiatric Health of individuals with 22q11.2 Deletion syndrome (22q11.2 DS). Presetnation to Irish parents, Saturday 29th Jan 2011, Trinity College, Dublin. Dr. Sarah Prasad. Beaumont Hospital & RCSI.

The Brain and VCFS; what we know. Linda Cambell & Wendy Kates. 30/01/11

The Everything Parents Guide to Children with Special Needs. (2009) Lynn Moore. Adams Media:USA