

REPORT TO THE AUCKLAND DOWN SYNDROME COMMITTEE REGARDING THE INTERNATIONAL DOWN SYNDROME CONGRESS – IRELAND 19-22 AUGUST 2009  
“Lifelong Living and Learning” – Bringing together the International Down Syndrome Community.

I would like to start with thanking the committee for giving me the opportunity to attend this congress. It was very inspiring and it opened my eyes to all the wonderful initiatives that are happening all over the world but it also made me aware that we do not have to reinvent the wheel but that we can tap into resources already available and ask for help from other countries.

I arrived in Dublin on Tuesday 18 August so had a few days to “acclimatise” and get my way around campus. Wednesday 19 August started with the first ever Synod for people with Down syndrome. Over 100 people with Down syndrome, from all over the world, attended this Synod, which was held as an interactive discussion by all who participated. Issues, affecting their daily lives, like independent living and employment, were discussed.

The most important issues that emerged were:

- how society still perceives people with Down syndrome. They spoke about being stared at or treated like children.
- the need for more meaningful employment and
- further education opportunities.

The synod has been recorded and the various issues will be analysed before a paper will be prepared.

Also on the 19th of August was a DS medical interest group meeting (DSMIG) <http://www.dsmig.org.uk> This is a network of doctors from the UK and Ireland who have a specialist interest in Down syndrome. Membership is open to interested healthcare professionals working with people with Down syndrome. There is also a DSMIG USA.

Topics discussed at this meeting were:

- Coeliac Disease: to screen or not to screen.
- Sleep related breathing disorders.
- Highlights from around the world.
- Case presentations + discussions.

At a later stage I will check again to see if the topics discussed at this meeting have been put on their website.

Thursday 19 August was the start of the main congress. It started with a tourist information movie, introducing Dublin, followed by opening addresses by Pat Clarke, chairperson 10<sup>th</sup> World Down Syndrome Congress, Mary O’Reilly, president Down Syndrome Ireland, and Penny Robertson.

The programme for the 3 days was set out as follows.

Day 1 – Life Possibilities & Achieving Full Potential until 11.00 am and then Positive Support in Early Years.

Day 2 – Promoting Good Health and Well Being until 11.00 am and then Supporting Best Vision and Good Communication, Language and Learning.

Day 3 – Effective Education & Inclusion until 10.15 and then Ensuring Good Quality of Life for Adults. Then for all 3 days, after lunch, there were “Meet the Expert Sessions”, where you could go and meet with/talk to the Keynote speakers who spoke in the morning sessions.

Then from 2.00pm onwards you could choose to attend Oral presentations of which there were very many and the problem was that they were held in two separate buildings so it was not easy to switch between the two.

These sessions were 20 minutes each and you needed to choose carefully (also where you were sitting) which ones to attend.

### **Day 1 – Thursday 20 August “Life Possibilities & Achieving Full Potential.”**

**Life Possibilities-**May Gannon – BSc Counselling and Psychotherapy, MA Dramatherapy, Ireland. May Gannon talked about her story with her son Michael, who was born in 1980. She talked about their journey from a state of helplessness to one of taking control. Disregarding all the advice given to them by parents and professionals (special pre-school, school and then a sheltered workshop) and how they changed their own belief system and how they accepted Michael’s difference. She talked about that we as parents need to look more at our children’s potential and not let our fear stop them from reaching their full potential.

**Self Concept-** David Hingsburger – M.Ed, International Speaker and therapist, Canada. David specialises in issues around sexuality and self concept. He talked about that we need to teach people with Down syndrome strategies how to deal with the social cruelty that happens to them on a daily basis. We have to teach them to be proud of who they are and that people that hurt you are wrong. David would be an excellent speaker and I believe that PFRC and Standards Plus (Lorna Sullivan) have already talked to David about coming to New Zealand. I think it is crucial to give young people with Down syndrome tools on how to handle social cruelty (see Synod).

### **“Positive Support in Early Years”.**

**Caring Doctors-** Prof. Conor Ward PhD MD, FRCP, Langdon Down Centre Trust, Ireland/UK. Prof. Ward talked about the Rev. Andrew Reed, who was instrumental in the development of special services. The Rev. Reed helped advance the project of providing facilities for education and training. He talked about how Dr John Langdon Down was appointed to reform “The Earlswood Asylum for Idiots” and about him specifically identifying what came to be known as Down syndrome.

**Genetics-** Prof. David Patterson, senior scientist of the Eleanor Roosevelt Institute, USA. Prof. Patterson spoke of his research into the ill-effects of the extra copy of chromosome 21 which causes Down syndrome. The genetic research could help to develop postnatal drug treatments to help people with Down syndrome, including improving their learning and memory. Researchers are on the verge of using genetic information to help alleviate some of the difficulties people with Down syndrome encounter (memory, learning).

**Lessons Learned and Family Needs-**Prof. Juan Perera, PhD, Palma-Spain. I will report on Prof, Perera’s presentation separately. I went to his “meet the Expert” session Thursday afternoon.

**Early Intervention in Down syndrome-**Dr Sheila Macken M.B., B.Ch., FRCP(C), FRCPI, Ireland. Dr. Macken reviewed the general principles underlying early intervention with children and their families from the time of diagnosis through to school entry. She provided an overview of best practice, with reference to research and evidence supporting different approaches to the child with Down syndrome.

**Managing Life with Down Syndrome-**Ms Cora Halder, director of the German Down Syndrome Infocenter and president of EDSA (European Down Syndrome Association).

Ms Halder talked about how some people with Down syndrome managed their life better than others. Even when the environment they grew up in, their state of health and their developmental starting position were similar.

Ms Halder talked about the salutogenesis concept, which concentrates on the relationship between well-being, health, stress and coping.

It turned out that both boys had grown up in two very different family circumstances. The boy who lived in a family that had high expectations of him and a positive attitude towards life did much better than the boy who was not given the same opportunities and whose parents did not have high expectations of him.

After these keynote speakers it was time for lunch. I decided to go to the “Meet the Expert” session of Prof. Perera and Ms Cora Halder because I was very interested in hearing more about what they had to say indept about their presentations. This will be reported on in a separate report to parents.

The nature of the “Meet the Expert” sessions was more a Q&A-time for parents and professionals.

In the afternoon I attended “Parent Perceptions & Family Needs”.

3.00 – 3.20 pm <b>cancelled</b>	A Journey of Life and Independence	Mr & Mrs Graham & Annette Mayer, Australia
3.20 – 3.40 pm	Down Syndrome NOW Research. Lessons we have learned as parents involved in research	Ms Jackie Softly, Australia
3.40 – 4.00 pm	The Value of Parent to Parent Support	Sue Robbins & Mike Waddington, Canada
<b>4.00 – 4.20 pm</b>	<b>Parent of Children with Down Syndrome (POD)</b>	<b>Mrs Liana Vislan, Romania</b>
4.20 – 4.40 pm	Down Syndrome school behaviour clinic	Dr. Philip Mattheis MD, USA

I would like to bring to attention a resource that was developed by the following countries: Spain – Romania –Greece and Italy. It is a DVD entitled: “Professional Training for Parents of Persons with Down Syndrome”.

This in itself is not that innovative, except the DVD can be listened to in 5 different languages: English, Spanish, Italian, Greek and Romanian. It covers:

Presentation

From 0 – 6 years

From 6 to 18 years

Adulthood

I have the resource at the office for anyone who is interested in borrowing this.

## **Day 2 – Friday 21 August-“ Promoting Good Health and Well Being.”**

**Good Health and Well-being**-Prof. Hilary Hoey, Dept. Of Paediatrics University of Dublin Trinity College, Nat. Children’s Hospital Tallaght, Ireland.

Prof. Hoey talked about that the aims of health care for children and adults with Down syndrome are to achieve good health, good well-being and a good quality of life. They will need a healthy lifestyle including good nutrition, regular exercise together with health screening and care as recommended for the general population.

The health care is slightly different for different age groups:

Infancy and childhood: general health, growth (incl. height and weight gain), heart, thyroid and gastro-intestinal disorders, cervical spine, vision, hearing, speech, psycho-social development and effective education.

Adolescents: their health and well-being needs vary but should include development of puberty and sexuality.

Adults: mental well-being, behaviour, intellectual and functional capabilities.

Every person with Down syndrome is unique and with good health and mental well-being they can lead a happy and fulfilled life.

**Child Health**-Dr Liz Marder, consultant paediatrician, Community Child Health.

Dr Marder spoke about promoting health and well-being in children with Down syndrome and that this started with an awareness of the medical problems that may be associated with Down syndrome during childhood and how important it was to identify problems early on.

She then spoke about the work they are doing in the UK to help increase awareness amongst health professionals and to provide parents with appropriate information.

She also showed cardiac guidelines for medical surveillance for people with DS. This was developed by the DSMIG UK and Ireland ([www.dsmig.org.uk](http://www.dsmig.org.uk)).

**Health Issues in Adolescents with Down syndrome**- Dr J. Murphy, RCN MSc, Dip. Stats, PhD, Ireland.

Dr Murphy talked about adolescence being a time of rapid change with significant physical, emotional and social development. In addition to the health needs of childhood, issues around puberty, sexuality, weight management and mental health wellness are more evident now.

The challenge for health professionals and parents is to identify their specific needs which are vital for developing their self esteem, personal identity, and to have understanding what having Down syndrome means for them as they prepare to enter adult life.

**Nutrition and Lifestyle**-Joan Guthrie Medlen-RD, LD, dietician with private practice in USA.

Talked about the importance of creating healthy life styles for individuals with Down syndrome. She talked about that you needed a blend of science, education, creativity and tenacity and how important it is to promote healthy eating habits and independence.

Dr Medlen is the author of “The Down Syndrome Nutrition Handbook”.

**Mental Wellness Adults & Ageing**-Dr Dennis McGuire, PhD, USA

Dr McGuire spoke about how teens and adults with DS have some unique and interesting behavioural characteristics (self-talk, repetitious “grooves”, visual (photographic-like) memory, emotional radar and sensitivity to others and how these characteristics easily can be misinterpreted by the uninformed.

**Sexuality – Relationships Require Skills**-David Hingsburger, M.Ed, Canada.

David talked about how important it is to keep an open line with your teenager with Down syndrome and let them know that they can come to you and talk about anything pertaining to sex(uality).

Once again I would like to say that David would make a wonderful speaker and that we should look into inviting him for a series of workshops here in New Zealand.

**“Supporting Best Vision and Good Communication, Language & Learning.”**

**Ensuring Best Possible Hearing**-Mr. Patrick Sheehan, MB BCh, M.Phil., FRCSI, FRCS(ed), FRCS(ORL-HNS), UK.

Mr Sheehan talked about that hearing difficulties and other ear, nose and throat medical issues are relatively common in children with Down syndrome. He talked about the current best practice in managing hearing loss in children with Down syndrome.

I went to his “Meet the Expert”-session and will report separately about his address.

**Promoting Clear Speech**-Dr. Clothra N. Cholmain, PhD, Ireland.

Dr. Cholmain gave a brief overview of the role of speech in facilitating language development and language use for living in communities.

**Supporting Language & Communication**-Jean-A. Rondal, Emeritus Professor of Psycho-Linguistics, University of Liege, Belgium

Prof Rondal talked about language stimulation and intervention in people with Down syndrome. That this has to be conceptualized according to a life-span perspective. This does not mean that the same thing should be done and repeated over the years. Early and continued intervention pursue different goals and need to be conducted differently according to age and developmental level.

**Ensuring Best Possible Vision**-Prof. M.Woodhouse, Special Needs Optometry at Cardiff, UK.

Prof. Woodhouse outlined the most common visual problems and described ways of overcoming the deficits.

I will report separately about this address.

In the “Meet the Expert” session I attended Ensuring Best Possible Hearing and as stated previously I will report separately regarding this issue.

In the afternoon I attended the “Education” and “Friendships” oral presentations.

3.00 – 3.20 pm	More academics in regular school?	Mr Gert de Graaf, Netherlands
<b>3.20 – 3.40 pm</b>	<b>Accommodations and Modifications for Including Students with Intellectual Disability into the Mainstream Classroom</b>	<b>Mary Frances Edwards</b>
3.40 – 4.00 pm	Mastering the art of Multi-level teaching ... the key to lifelong learning	Mrs Azette Engelbrecht, South Africa
4.00 – 4.20 pm	Stepping in Cinderella’s shoes, A Young Girl’s Quest for Identity and Empowerment	Esther Joosa, Singapore
4.20 – 4.40 pm	The Rarely Heard Voice	Dr Michael O’Keeffe, Ireland

The highlighted presentation was very interesting and I will report on this separately to our members.

### **Day 3 – Saturday 22 August “Effective Education & Inclusion” and “Ensuring Good Quality of Life for Adults”.**

**Benefits of Inclusion & Keys to Success Preschool/Primary/Secondary-**Dr. Ursula Doherty, Department of Special Education, Ireland.

In recent years, there has been a significant increase in the number of children with Down syndrome attending mainstream primary schools in Ireland.

A study explored the experiences of inclusion for pupils with Down syndrome in mainstream primary schools in Limerick city and county.

Findings indicated that inclusion can be a positive experience for pupils with Down syndrome and for the entire school community. It can contribute to the creation of a more caring and tolerant ethos where diversity is understood and accepted. When provided with the necessary supports, pupils with Down syndrome have the capacity to participate, learn and achieve in an inclusive learning environment. The opportunities afforded by inclusive education for pupils with Down syndrome to make friends and to learn with and from their peers were highly valued by the parents and teachers who took part in this study.

However, it also highlighted a number of issues that need to be addressed to enable pupils with Down syndrome to realise their potential in mainstream primary schools. These include:

- the availability of multi-disciplinary assessment and support;
- the provision of professional development courses for teachers;
- building partnerships with parents;
- inclusion in the mainstream curriculum and
- approaches to the organisation of support teaching.

Results have important implications for the ways primary schools are resourced and supported. In particular, they underline the need for primary teachers to be provided with opportunities to develop their expertise and skills in educating pupils with Down syndrome in mainstream schools.

In response to these findings an Education Resource Pack for primary teachers has been devised and was distributed to all primary schools in Ireland this September.

**Encouraging Literacy at Home and School-**Gillian Bird, director of Education and Information at DownsEd International, UK.

Gillian presented an overview of research into reading achievements and suggested expectations for achievements for children of differing abilities across the age range.

Effective teaching methods at different stages in literacy development were summarised with practical examples for learning to read and write with comprehension at home and at school. She also talked about how to use reading activities to promote speech and language development .

**Encouraging Social Inclusion and Managing Behaviour-**Prof. K Feeley, Assoc. Prof. of Education, USA.

Prof. Feeley talked about how for pupils with Down syndrome, who present with challenging behaviour, this can prevent them from accessing inclusive opportunities within their schools and communities. Training educators in the functional assessment process as well as providing them with strategies to develop positive behaviour support plans can drastically reduce problem behaviours, helping to ensure their success in inclusive schools and communities.

(This lady would be an excellent speaker. )

**Transition from School/Adult Ongoing Education-**Dr. Patricia O'Brien, Foundation Director of National Institute for Intellectual Disabilities, Trinity College Dublin.

She shared the experiences of students with intellectual disabilities gaining access into a university setting, specifically Trinity College Dublin, to complete a two year course entitled “ Certificate in

Contemporary Living”. The perceptions of students, family members and tutors were captured through focus groups, questionnaires, use of photo voice and document analysis.

The students themselves found that inclusion within a university setting led to see themselves more alike than different to their same aged undergraduate peers. They felt more accepted, more competent and more socially networked. Vital to the development of friendships was a mentoring programme. The aspect of the Certificate programme that supported students to participate in a range of undergraduate classes was described as well as the role that service agencies have played in supporting the programme. Being included within a university setting opens up a whole new way of being for students who have previously experienced marginalisation. Inclusion like this is a convincing way to promote **ability**. The programme will be rolled-out throughout Ireland.

**Providing a Range of Living Options**-Prof. Roy McConkey, BA, PhD., Prof. of Developmental Disabilities School of Nursing, University of Ulster, Northern Ireland.

Although a range of living options is required to meet the diverse need of people with Down syndrome, the greater challenge is ensuring that these deliver the outcomes that people desire. There is growing evidence that a better **Quality Of Life** is more often found with individualised, community based support options. He presented research on cost-beneficial support services in the modern era.

**The Application of QOL (Quality of Life) Principles**-Prof. Roy Brown, Prof. Emeritus University of Calgary, Canada, and Flinders University, Australia.

Prof. Brown talked about the concept of **Quality Of Life** and what it means over the life span to adolescents and adults with Down syndrome. It included: individual choices, inclusive opportunities, and the development of friendship, partnership and marriage, He also considered the issues of family quality of life and the relationship between parents and the young person as they develop and experience life. The balance between care, risk taking , with opportunities and lifestyle were presented across life domains.

**Independent Community Living**-Prof. Steve Eidelman, president of the American Association of Intellectual and Developmental Disabilities, USA

Prof. Eidelman talked about how people with Down syndrome bring value and diversity to communities everywhere and how policy makers, advocates, family members, professionals and people with Down syndrome are seeking improved methods of supporting adults in communities worldwide.

Old notions of continuum of care and varying programme models are continuing segregation, isolation and separation. In many places people with DS are institutionalised needlessly and presumptions of competence and capability are ignored.

The research is clear that people with intellectual disabilities prosper when they live in places of their choosing and that congregate care, regardless of how it is labelled, diminishes quality of life and functional capabilities over the long run.

Article 19 of the UN convention “Living independently and being included in the community”, has a strong bias towards supporting people in community.

**Increasing Employment Options**-Ms Anne O’Bryan

Ms O’Bryan presented 4 initiatives aimed at increasing the likelihood of people with learning disabilities getting and keeping valued careers.

1. Valued in Public action learning events (<http://www.efd.org.uk/events/2008-02-valued-public-action-learning-events> ) is a workshop for public sector employers aimed at improving the way they attract, select and employ people with learning disabilities.
2. SEARCH– Cincinnati children’s Hospital model (<http://www.cincinnatichildrens.org/svc/alpha/p/search/> ). This is an internship for young people in their last year of school in a large prestigious employer such as a hospital, local authority or bank.

3. Employment awareness raising and signposting service for people with learning disabilities and their families. It helps individuals develop their own employment pathway using the existing employment opportunities and services in their local area.
4. Family Led Jobs, is an initiative for families who are not finding the career support they need for their family member. It is a series of workshops with individual support that combines Personal Futures Planning and Customised Employment to individually negotiate successful careers.

In the “Meet the Expert” session I attended Social Inclusion & Managing Behaviour and I will report separately regarding this issue.

In the afternoon I attended The “Education” presentations.

2.00 – 2.20 pm	Transition – A Story of Success	Ally Attwell & Debbie Rickard, New Zealand
2.20 – 2.40 pm	Modern Approach to Child Inclusion in Russia: from parents initiative to professional care for children with DS	Ms Natalia Riguina, Russia
2.40 – 3.00 pm	Peer Interaction in mainstream classes	Ms Anne-Stine Dolva, Norway

General Assembly and Closing Ceremony was from 3.15pm.

**Christel van Baalen**  
**Community Liaison Officer**  
**28 September 2009**