

## Fragile X Syndrome

The Fragile X Association of Australia in conjunction with QCIDD hosted a free one-day seminar on Fragile X Syndrome for more than 100 family members, health professionals and educators with guest speakers:

- ∞ Dr Jonathon Cohen (Medical Director Fragile X Alliance Clinic )
- ∞ Associate Professor Nick Lennox (Director, QCIDD)
- ∞ Rashelle Cohen (Behavioural Optometrist, Fragile X Alliance Clinic)



Fragile X is the most common cause of inherited intellectual disability but is hardly known. The seminar covered a wide range of topics including an overview of Fragile X Syndrome, behavioural issues, speech and language interventions, medications & behavioural issues, adult issues and genetic counselling.

A small number of families affected by Fragile X are keen to set up a Queensland based support network. Interested individuals or families who may wish to participate in planning this support group or network should contact Mel Mikkelsen, Fragile X Association, [mikkelsen\\_family@optusnet.com.au](mailto:mikkelsen_family@optusnet.com.au) or Lisa Bridle on 07-3163 2524 .



### Welcome to Dr Cathy Franklin!

Cathy is our new Consultant Psychiatrist.

She works at the QCIDD Clinic on Wednesday mornings providing assessments and management plans.

To enquire about how to refer to Dr Franklin, please phone 3163 2524.

# Talking Far & Wide

## Recent QCIDD staff presentations and activities

### May

- ☀ Disability Services Queensland, Goodna office
- ☀ QUT Disability and Human Services students
- ☀ Kyabra Expo
- ☀ Disability Sector Training Fund on *Challenging Behaviour: How Challenging is Challenging?*
- ☀ Halwyn Centre
- ☀ UQ Social Work and Occupational Therapy students
- ☀ Seventh Day Adventists Spanish-speaking group
- ☀ 2008 Special Care Dentistry Conference on *The oral health of people with intellectual disability*

### June

- ☀ Health for All? General Practice and Primary Health Care Conference in Tasmania on *Health assessments and health outcomes in hard-to-reach populations* Disability Services Queensland on *Impact of Developmental Disability across the Life Cycle*
- ☀ Mater Hospital Grand Rounds on “Research at the Mater”.
- ☀ Western Pacific Regional Meeting in Manila on the World Health Organisation first World Report on Disability, Health and Rehabilitation
- ☀ Child and Adolescent Psychiatric Registrars, ANZCP

### July

- ☀ Prisons Project at the School of Population Health, University of Queensland
- ☀ **MBBS First year students—*Living with a Disability***

### August

- ☀ QPPD (Queensland Parents of People with a Disability) Transitions Book Launch
- ☀ Australian Catholic Disability Council meeting in Alice Springs



Dr Lisa Bridle in Alice Springs

### August

13th World Congress of IASSID (International Association for the Scientific Study of Intellectual Disability) in Cape Town, South Africa on topics including:

- ∞ A trial of two programs to improve the healthcare of people with intellectual disability living in the community;
- ∞ Health Checks—A review;
- ∞ Research in Intellectual Disability
- ∞ Community Visitor Program: Challenging Behaviour



### September

- ☀ Social Work Masters students at UQ
- ☀ Down syndrome Family Camp

### October

- ☀ Mamre “Creating Meaningful Futures” event
- ☀ Ethical Genetic Counselling Panel



### November

- ☀ Rockhampton  
3 days of teaching and training for local service providers (photos on the right)



## Director Profile

*The latest on Nick's activities*

### Dr Nicholas Lennox — Associate Professor

Nick has been very busy these past months with lobbying, giving presentations, teaching GPs and medical students, providing clinic to his patients, supervising staff and being President of the Australian Association of Developmental Disability Medicine (AADDM). Nick is renewing research links with Endeavour Foundation and looking to do the same with Disability Services Queensland. Dr Nick is an active Chief Investigator on two large randomised controlled trials—the Ask Project here at QCIDD and the Passports to Health Project at the School of Population Health. Nick was recently invited to be a Chief Investigator for an Australia-wide collaborative Australian Research Council grant.

Among Nick's many presentations, he has presented at the key National Primary Healthcare conference in Tasmania and at the 13th World Congress of IASSID in South Africa. Nick was one of the guest presenters at the Queensland Office of the Public Advocate launch of their report on the health status of people with intellectual disabilities: In Sickness and In Health.

In his role as President of AADDM he has been actively lobbying, with the NSW Council of Intellectual Disability, the federal government to improve the health services for people with ID throughout Australia. This has included submissions to the National Health and Hospital Review Commission and direct contact with politicians and civil servants in Canberra.

### **“Challenging Behaviour Mentoring Programme” - Update**

The mentoring programme has been going strong these last couple of months. The participants have not only received their usual modules relating to positive behaviour support issues, and their mentoring sessions but we have also held some workshops and teleconferences. Five teleconferences were held in May and all participants except one attended. Participants were organised into small support clusters of four to six people. Written evaluations regarding the usefulness of the teleconference were obtained. The second series of workshops were held on the 2<sup>nd</sup> and 3<sup>rd</sup> of June 2008. These workshops focused on more advanced training and with opportunities to reflect on learning and development so far. The content included choice making, restrictive practices, augmentative and alternative communication, reinforcement schedules, ethics and teaching of functional skills.

The last for the year was a one-day workshop which was held on the 13<sup>th</sup> of October 2008. It focussed on facilitating ongoing support for non-government staff. The content at the workshop included discussions on maintaining a successful mentoring relationship, the IBST view of challenging behaviour services and a hypothetical case where the participants used their knowledge gained throughout the programme to relate it to a case presented by one of our mentors...

Also last, but not least, the programme has been extended for another 6 months.. so stay tuned for another update in the next QCIDD newsletter...



## Working with the World Health Organisation

Our contribution to the First **World Report on Disability, Health and Rehabilitation** is the chapter on **General Health**. The report will be launched globally at the end of 2009.



## Visitors to QCIDD

- ∞ ASSID site visit
- ∞ Relationships & Sexuality Disability Network
- ∞ Stuart Kinner, Principal Investigator, Passports to Health Project, University of Queensland
- ∞ Michele Foster from Social Work and Social Policy, University of Queensland
- ∞ Professor Lesley Chenoweth and Associate Professor Jane Clapton, Griffith University
- ∞ Professor Tim Stainton, visiting Canadian Professor
- ∞ Maureen Fordyce from Amparo Advocacy Inc. for people with intellectual disabilities who come from non-English speaking backgrounds.
- ∞ Professor Robert Bush, Director of Healthy Communities Research Centre at Ipswich
- ∞ Adjunct Professor Ann Jobling from the University of Queensland, School of Education

## Farewell Sierra.....

Sadly for us, Sierra, the front face of our Clinic, is leaving us, but happily for her she is off around the world. Our farewell lunch was one Sierra won't forget!



Welcome to **Tania Patroa** who has been awarded a UQ School of Population Health [Vacation Scholarship](#). During early 2009, Tania will be working with Nick, Miriam and Rob, and conducting a pooled analysis of data from our previous randomised controlled trials to investigate the effects of the comprehensive health assessment programme (CHAP) on the health of adults with Down syndrome.



## Advocacy

The Queensland Shadow Minister for Health and Deputy Leader of the Opposition, Mr. Mark McArdle was invited to come and have a cup of tea with us in September. We chewed his ear for over an hour about how to improve the health of Queenslanders with intellectual disability. We also had afternoon tea with his colleague, Mrs Rosemary Menkens, Shadow Minister for Disability for Queensland, in October. Nick was in Canberra, speaking with politicians and civil servants about improving the health care of people with intellectual disability and with the Australian Institute of Health and Welfare about getting better national data on the health of people with intellectual disability.

The Australasian Society for the Study of Intellectual Disability (ASSID) is part of an international association which was established by a group of people united in their interest of intellectual disability. As such, ASSID has always operated along the lines of a professional association, a congregation of people committed to similar ideals and needing a forum in which to exchange ideas. ASSID holds events throughout the year and recently held a dinner regarding the Carter Report and the outcomes of that report entitled: "Challenging Behaviours - Bringing the Dream to Reality" . There was three key speakers at that dinner- the Hon. Bill Carter (the Carter Report), Ron Joachim (the new legislation), and Robert Heron (recently appointed as Director of Learning and Development in The Centre of Excellence for Behavioural Support) discussing the journey of challenging behaviours from the dream to reality. QCIDD staff Madonna Tucker and Lyn McPherson are very active in ASSID as Queensland President and Treasurer respectively. For more information on ASSID, please contact Madonna on [madonna.tucker@uq.edu.au](mailto:madonna.tucker@uq.edu.au)



## Therapeutic Guidelines

**Therapeutic Guidelines Limited (TGL)** is an independent not-for-profit organisation. Its aim is to promote the quality use of medicines through publication of its Therapeutic Guidelines series. Therapeutic Guidelines are written principally for prescribers, providing them with clear, practical, succinct and up-to-date information.

One of the Guidelines in this series is *Management Guidelines: Developmental Disability* which is a very practical and informative book, not only for health professionals, but also for care providers of those with developmental and intellectual disability. The focus is on the health needs of people with intellectual disability across their life-span. Topics include:

- ∞ Adult health care
- ∞ Assessment of developmental delay and disability
- ∞ Challenging behaviour
- ∞ Sexuality
- ∞ Syndrome specific information.

All of these titles are combined in the electronic versions **eTG complete** for desktop computers, and **miniTG**, which is for PDAs.

For more information visit [www.tg.or.au](http://www.tg.or.au)



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We stand up for...

**people from a non-English speaking background with a disability** who are being treated unfairly, abused or discriminated against.

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