### Update from the Cerebral Palsy League of Queensland

### **Screeching into the Limelight**

In December 2004, more than 250 people flocked to Corinda State High School's theatre to witness the first performances of Brisbane's newest mixed ability theatre group.

The Cerebral Palsy League of Queensland established the Screech Theatre Group in 2004 with a grant from the Brisbane City Council (BCC).

League social workers Cristy Gough and Kathryn Ellwood collaborated with Chris Pye, from Interaction Drama, in a project to use drama to help reduce social isolation for young people with cerebral palsy and provide a creative and inclusive space for young people with and without disabilities. The team developed an eight-week pilot project in March 2004, which engaged twelve young people (nine with disabilities and three without) in a process of drama skill-building, which would lay the foundations for the group's further development.

The pilot project was a great success and BCC granted funds for a full performance project to take place later in the year. By December, a group of nine young people and support workers were nearing the end of a remarkable journey which had spanned three months and seen the group devise, script and rehearse a compelling piece of theatre, exploring the experiences of young people with disabilities and their relationships with the wider community.

Corinda State High School supported Screech, offering the use of its drama facilities and the committed support of the school's Special Education Unit (SEU) team.

Drama teacher, Maureen Billiau became an integral and invaluable member of the project team and is committed to creating further opportunities for greater integration of students with disabilities, through drama.

"As a teacher I wanted to actually get a better handle on how to include people with disabilities in the classroom and I thought this was just a fantastic opportunity to do that," Ms Billiau said. "They have so much to say, so much passion and they can really communicate using drama."

In 2005, plans are well advanced for a second series of drama skills

workshops, followed by a Theatre project later in the year to devise and present a performance.

For more information about Screech email Interaction Drama's creative director, Chris Pye at: mail@interactiondrama.com.au or contact Margo Wratten, Cerebral Palsy League of Queensland, ph (07) 3347 7200 or email mwratten@cplqld.org.au

MARGO WRATTEN CEREBRAL PALSY LEAGUE OF QUEENSLAND



Back row (left to right): Mark Halupka; Laura Solomon; Scott Waldren; Sally Foote; Erin Cowan. Front Row from left to right: Kirsten Miller; Melissa Howard; Heather Coupland; William Beanland. Photograph taken by Chris Pye

#### Update from the Cerebral Palsy League of Queensland continued...

# Landmark Achievement

The Cerebral Palsy League of Queensland celebrated becoming the first major, statewide notfor-profit service provider in Queensland to achieve ISO 9001 Quality Assurance Certification – resulting in more consistent and higher quality services for Queenslanders with cerebral palsy.

Minister for Disabilities, the Hon Warren Pitt, presented the certification to League representatives at an informal ceremony during March.

"The certification demonstrates the League's ability to provide quality services and showcases our leadership in the sector," CEO of the League, Bruce Milligan said.

"This is a great milestone for disability services and points to the start of a new level of service and thus, better quality of life for our clients. Although the Certification is not compulsory for organisations, it provides a good framework to ensure standards set by various funding bodies are met," he said.

To gain certification, the League was required to review all of its policies and practices to ensure they were of a quality standard.

"We developed a Quality Management System (QMS) clearly outlining the League's policies, procedures and various services across all regions," Bruce Milligan said.

According to Bruce Milligan, staff have received training to ensure a consistent standard of operation and the League will provide ongoing training opportunities in the coming months.

Both staff and clients of the League will benefit through improved communication channels, which will allow staff to focus more on service provision.

Achieving Quality Assurance will also enable ongoing improvement of the League's services.

The QMS will not only maintain the quality of services but ensure continuous improvement of these services.

Novella Martin Communications Coordinator Cerebral Palsy League of Queensland

## Queensland Cerebral Palsy Health Service

Last year, Minister for Health, the Hon Gordon Nuttall MP announced the allocation of \$1 million to establish a coordinated health program to help Queensland children with cerebral palsy.

Queensland Health was pleased to announce the current development of the Queensland Cerebral Palsy Health Service (QCPHS), which is due for operation in June 2005.

The QCPHS was funded to develop a number of specialist health services including:

- Hip surveillance and treatment program
- Botulinum Toxin Program Expansion (BTX-A)
- Single Event Multilevel Orthopaedic Surgery (SEMLS)
- Other new spasticity treatments, such as Intrathecal Baclofen (ITB) Therapy and Selective Dorsal Rhizotomy (SDR)

The QCPHS will work closely with staff from the League to ensure that its services are coordinated with the care that the League provides to Queensland children with cerebral palsy, and their families.

Dr Lynne McKinlay, Rehabilitation Specialist, and Ms Megan Kentish, Senior Physiotherapist with the Queensland Paediatric Rehabilitation Service, Royal Children's Hospital will coordinate the task of establishing the service. "We are pleased to be given this opportunity to improve specialist health services for children with CP and their families, and to continue our close working relationship with League staff," Dr McKinlay said.

"We are committed to improving the health of children with cerebral palsy in Queensland," she said.

Both Dr McKinlay and Ms Kentish are already familiar with some League families through their valuable work with the Botulinum Toxin program.

Queensland Health has also employed Nancy Hoyes as Project Manager for the QCPHS over the next 12 months, to work with Dr McKinlay and Ms Kentish, to help establish the QCPHS.

Ms Hoyes worked with the League during the 1980s and, after 20 years working with children through Queensland Health, was excited to be part of the project and the opportunities it would provide.

During the next few months the QCPHS will send information on its services to families on the League's mailing list.

This information will provide further details about the QCPHS and invite feedback, questions or concerns.

> Novella Martin Communications Coordinator Cerebral Palsy League of Queensland

#### Update from the Cerebral Palsy League of Queensland continued...

# **Queensland Cerebral Palsy Register**

AUSTRALIAN of the Year 2003, Professor Fiona Stanley, has spent decades researching the incidence of conditions like spina bifida and cerebral palsy through the use of state-wide population registers.

She advocated strongly for the establishment of good information systems to investigate the causes of conditions like these and, last year, the Queensland State Government agreed to help by providing ongoing funding for the establishment of a Queensland Cerebral Palsy Register (QCPR).

The QCPR would be used to aid progress towards the prevention of cerebral palsy as well as provide governments and service providers with information to establish better services based on outcomes and circumstances of people with cerebral palsy in Queensland.

Never before in Queensland has there been a comprehensive source of information where people with cerebral palsy live, their housing needs, education and employment circumstances, and the types of circumstances that contributed to their condition.

# Prevention and better services for people with Cerebral Palsy

The QCPR will provide information that will:

- Help researchers to find and prevent causes of cerebral palsy,
- Help clinicians to understand the outcomes of interventions by looking at long term outcomes, and
- Help services to plan and organise their services to meet the needs of people with cerebral palsy wherever they live.

# A secure register for the best information

The QCPR has a secure Web interface, which will allow people to see and update their own information on-line, 24 hours a day.

As a security measure, Information is protected by two firewalls to prevent unauthorized access, as well as a 128 bit encryption password protected access facility, which only

allows Queensland Database administrators and the password holder, to see their personal information.

# Good choices for people with cerebral palsy

As QCPR is consent based, participants can choose to place their information on the register, or not.

Once on the register, they can also choose to allow the registry staff to inform them of research opportunities.

Participants can elect to allow non-identifying information to be provided to the Australian Cerebral Palsy Register.

These different consents can be added to, removed or changed by participants through the QCPR web interface, or by calling the registry on 07 3358 8122.

There is no charge, no delay and no limit to changes.

#### National Cerebral Palsy Register

Once the National Cerebral Palsy Register begins, it will house nonidentifying information about participants with cerebral palsy in Australia.

It will never collect or hold identifying information which could

be used to identify individuals.

If consent is given, the state registries will send relevant birth and health care details to the National Register when children turn five years old.

The National Register is a huge database, which will be used to identify the various causes of cerebral palsy and greatly assist the progress towards prevention.

Novella Martin Communications Coordinator Cerebral Palsy League of Queensland

### From The Spastic Centre of New South Wales

## **Hospital Partnerships in New South Wales**

The health status of young people with cerebral palsy is of international concern as highlighted by Young et al in the 2004 AusACPDM conference paper, "Health status of youth and young adults with cerebral palsy".

The Spastic Centre welcomed NSW Health's 2000-2005 Strategic Directions for Health, which included a strategy to 'Develop and implement a disability action plan in each Health Service in order to ensure the provision of services appropriate to the needs of people with disabilities and their carers'.

Feedback from The Spastic Centre's service users highlights the paucity of medical and allied health services for adolescents and adults with cerebral palsy and similar physical disabilities. Also at issue is the transition of young people with disability from paediatric to adult health services, the lack of knowledge and health personnel sufficiently skilled to meet the needs of this group in the areas of acute care, aged care rehabilitation, women's health, screening processes, nutrition, and dental and optical health.

The Spastic Centre has targeted health care services for people with a disability as a priority in its current *Strategic Plan*; including the outcome of 'Available and Appropriate Health Services.' To this end, The Spastic Centre has recently joined with New South Wales Health in a number of pilot projects. These are outlined below:

Westmead Hospital Adult Physical Disability Clinic - The Spastic Centre is now providing an occupational therapist for the Westmead Hospital Adult Physical Disability Clinic. A physiotherapist is also available to patients of the Clinic and referrals are made to speech pathology staff as needed. Clients who have a physical disability with a specific medical need are able to access the Clinic either through The Spastic Centre or directly through Westmead Hospital's Outpatient Department.

The Clinic has been successful in meeting the specific needs of many of The Spastic Centre's clients and in developing partnerships with other specialist clinics (e.g. dysphagia, spasticity) and with individual specialists. It is envisaged that a positive outcome of this project will be the gradual familiarisation of the medical community to the needs of people with cerebral palsy and similar disabilities.

*Fairfield Hospital Partnership* – For a number of years, staff from The Spastic Centre have joined in the Fairfield Hospital Community Participation, and Health and Disability working parties. A new group is now examining ways to ensure that clients with severe and multiple disabilities receive the level of care they require when in hospital, and pre and post surgery. This group will then pilot these procedures with a client who has cerebral palsy, complex medical and communication needs, and is awaiting orthopaedic surgery.

Although the short-term aim is to ensure a smooth admission, surgical procedure and rehabilitation for this client group through a collaborative partnership with The Centre's allied health staff and the Fairfield Hospital's medical staff, the long-term aim is that clients requiring orthopaedic surgery can be referred to this hospital for treatment. It is envisaged that both parties will learn from the partnership and the model can be extended to other hospitals through case studies, communication and collaboration.

Cecilia Gray Manager, Adult Resource Program The Spastic Centre, South & West Sydney Region

## **Modified Mealtime Consistencies**



A new poster on modified mealtime consistencies has been produced by The Spastic Centre. The poster is designed to assist staff and carers in the correct preparation of food and drink for people with dysphagia.

The A3 poster depicts four diets: standard, soft, minced-mashed, and pureed - with helpful checklists on food types and consistencies for each type of diet. Four types of fluids are also featured with accompanying descriptions. Under the direction of Senior Speech Pathologists at The Spastic Centre, a professional food stylist and photographer were engaged to create and photograph the menu. The result is a poster that is attractive enough to be placed in a home or work kitchen.

The poster is available for \$12 plus postage and handling. Details are available on The Spastic Centre's website at www.thespasticcentre.com.au

ROBYN CUMMINS INFORMATION MANAGER THE SPASTIC CENTRE OF NEW SOUTH WALES