



Newsletter from the Cerebral Palsy Consortium Vol. 1, no. 2, September, 2005

A word from the editors

A recent conference on Cerebral Palsy leads us to believe that research in this area is at a crossroads. To improve social participation in children with Cerebral Palsy, we have identified the following four priorities. First, we must **document** the most common interventions and establish their effectiveness in the children treated. Researchers, practitioners and families must **come together** and **share** their expertise to facilitate this task. The information gathered will permit a better understanding of the issues, help **organize** the data, and establish research priorities and actions within the community. The documents presented at the colloquium in June, of which several appear in this newsletter, demonstrate that Québec researchers understand well the issues at hand, and are participating fully in the necessary research. Enjoy your reading!

*Line Nadeau Ph.D.
Francine Malouin Ph.D.*

New on our Website!

Forum

The Cerebral Palsy Consortium (CPC) forum is now open to members of the CPC. You can find it at our Website (www.consortiumpc.ca). Don't hesitate to communicate your expectations for the forum. The goal is to provide a place for researchers, school and health practitioners, and family members to exchange information and ideas.

Social and cultural events

The new social and cultural events web page is now ready to publish information from organizations and associations about up-coming activities and/or services, specifically targeting people with Cerebral Palsy. Let us know what events will be taking place in your region!

Coming soon

27-28 octobre 2005 :

A conference entitled *Naissance à risque : Éthique, interventions et nouvelles avenues de recherche*, will be held at The Manoir Victoria in Québec. To register or for further information please contact Ms. Annie Fraser at annie.fraser@psy.ulaval.ca

For the entire program, you may consult the Website of the Cerebral Palsy Consortium (www.consortiumpc.ca).

Research File

Mainstreaming and Social Participation of Children with Cerebral Palsy

Line Nadeau Ph.D. et Réjean Tessier Ph.D. Fonds de recherche sur la Société et la Culture. CIRRIIS.

The object of the study was to create a portrait of social adjustment using a group of children living with Cerebral Palsy (n=60), who are mainstreamed in schools throughout 7 regions of Quebec. The study results indicate that children with CP (particularly the girls) have fewer friends, experience more feelings of social isolation, and report more incidents of verbal and physical intimidation than their peers. A full report will soon be available on the CPC Website.

Do not hesitate to contact us if you have any information regarding events or projects concerning the social participation of children with cerebral palsy. We will be happy to add this new information to the news bulletin or to our website.

Thank you and have a great autumn!

The following will appear in our December 2005 newsletter:

- **Conference Report:** Conference *Naissance à risque : Éthique, interventions et nouvelles avenues de recherche*, October 27-28, 2005.

Conference Report

The following is a brief résumé of the objectives and results of research projects presented during the Cerebral Palsy Conference, held June 8, 2005 in Montréal. Please note that summaries from all presentations are available in the section *Current projects* on the CPC Website.

Registre de la paralysie cérébrale au Québec (REPACQ)

Pigeon N., Koclas L., Lamarre C., Desjardins C., Dagenais L., Shevell M.

Objectives :

1. To assess the prevalence and distribution of Cerebral Palsy (CP) in Québec.
2. To identify the risk factors.
3. To document the difficulties in children with Cerebral Palsy in order to improve the quality of care.

Results :

- Many children are already registered (104 in Montréal, 15 in Hull, 21 in Sherbrooke, 30 in the Laurentides /Lanaudière areas, and 15 in Québec).
- At this time, they hope to register all children born between January 1, 1999 and December 31, 2001.

CPEngine

Snider L., Korner-Bitensky N., Richards C., Malouin F., Gorter JF., Thomas A., Kloda L., Levin M., Saleh M.

CPEngine is a Website designed to summarize the effectiveness of rehabilitation interventions in children with Cerebral Palsy.

CPEngine :

- Is a virtual terminology data bank whose overall objective is to include the most effective therapeutic interventions for children with CP.
- Is for practitioners, students, administrators and families.

Note: The CPEngine is not yet online. The launch of CPEngine will be posted on the Cerebral Palsy Consortium Website.

Étude québécoise sur les services de réadaptation dispensés aux enfants avec paralysie cérébrale : résultats préliminaires chez les enfants d'âge scolaire

Malouin F., Snider L., Korner-Bitensky N., Dumas F., Roy M.A., Lepage C., Kennedy E., Mazer B., Saleh M., Levin M., Gisel E., Lamarre C., Bilodeau N.

Sample: 161 therapists (88 occupational therapists and 73 physical therapists)

Little information exists concerning the evaluations and therapeutic interventions given to school-age children with Cerebral Palsy by occupational and physical therapists. The objective of this study was to create a profile of therapeutic services given to the children based on two case studies.

- Preliminary analysis reveals that occupational and physical therapists identify a comparable number of problems but that the nature of these problems differs
- This preliminary result illustrates the complimentary roles physical and occupational therapists play in the treatment of CP.

Determinants of life quality in children of school age with cerebral palsy

Majnemer A., Shevell M., Law M., Rosenbaum P., Poulin C.

Sample: 80 children with CP

Objectives:

1. To determine the quality of life of children affected with CP, particularly from the point of view of the children and their parents
2. To identify the factors associated with the physical and psychological well-being of children with CP.

Results:

- About half of the children reported a very good quality of life.
- The type and severity of CP impacted the child's level of function but not the quality of life.
- Physical well-being is significantly associated with severity of impairment and functional limitations.
- Children with hemiplegia demonstrated a greater degree of physical well-being than those with diplegia.