19 July 2004

FOR ATTENTION: ALL STAFF IN THE REHABILITATION DEPARTMENT

Dear Colleagues

STUDY: Parental perceptions and experience of rehabilitation services for children with cerebral palsy in poorly resourced areas.

REQUEST FOR INFORMATION REGARDING SERVICES FOR CHILDREN WITH CEREBRAL PALSY

I am a full time Ph D student in the Physiotherapy Department at Wits University. The focus of my research is on caregivers’ experiences and perceptions of rehabilitation therapy in public service hospitals in Gauteng and Limpopo Provinces, and the impact of rehabilitation on the caregiver and family. I will also be exploring the role of mother-to-mother support activities as a moderator of maternal stress and worry, especially mothers of children with CP living in poor areas. The findings of this research will have wide generalizability and should lead to interventions which are cost-effective and implementable.

The study has received ethical approval from the University’s Ethics Committee, and permission to conduct the study in Limpopo has been received from the Limpopo Health Research Committee.

Findings of the research will help to strengthen and improve services for children with CP in Limpopo. The benefits will include assessment tools which rehabilitation departments can use to assess the impact of therapy on caregivers, as well as a tool which measures caregivers’ perspectives of aspects of the rehabilitation service. All these measures will be available in the local languages.

The study will be done in two stages. The first phase will test out the questionnaires and scales which have been designed to measure caregivers’ attitudes to their child, their support networks, their quality of life, mental health and their perceptions of the therapy service they have received. One hundred and twenty caregivers from Limpopo will be included in this phase. These caregivers will be attending hospitals
where only one approach to therapy is offered e.g., children are only seen individually on a one to one basis. The reason for this is that the purpose of this phase is simply to test out and validate the questionnaire, and a convenience sample can be used.

The second phase will be conducted at hospitals where more than approach to therapy is offered e.g., some children are seen individually; some children are seen in groups; some children attend support groups facilitated by Community Based Rehabilitation Workers.

In order to plan the logistics of the study, and to decide which hospitals will be eligible for the study, I need to understand how the rehabilitation services for children with CP operate in each hospital – who treats the children, what groups, if any are there for parents, on which days the children come for therapy, and how many children come. Hospitals must have clinic records for the children and the service needs to have been in existence for at least three years.

I would like to start Phase 1 in mid-August, and I need to draw up a plan of which hospitals I will visit and make the necessary travel arrangements. Three field workers, all mothers of children with CP, have been trained to conduct the interviews and we will travel together.

I am attaching a one page table which I would be grateful if you could complete as soon as possible and fax it back to me at (011) 892-3893. If you have any queries, or suggestions, please do not hesitate to contact me on 027 483-5766 or (011) 726-1555.

This study will not be possible without your assistance, and I really do appreciate your time. Thank-you!

Yours sincerely

GILLIAN SALOOJEE