

Rapport ICPS

Dit is het rapport van de ICPS (Internationale Cerebral Palsy Society te Londen). In februari 2004 heeft het ICPS team een bezoek gebracht aan de SGCP (Selfhelp Group for Cerebral Palsy), het project dat wij ondersteunen, om te adviseren en te instrueren. Stichting "Holland Building" Nepal heeft de helft van de kosten van dit bezoek gefinancierd.

REPORT OF THE SECRETARY GENERAL ICPS PULA OCTOBER 2004

It is a great pleasure to be holding our Annual Meeting here in Pula Croatia and I take this opportunity to thank the Croatian Cerebral Palsy Society under its chairman Dr Miroslav Pospis and also the local organisers of the meeting, the Croatian Cerebral Palsy Society Pula and their chairman Gianni Kumar for all the hard work they have done in the organisation of this meeting, for their friendship and their warm welcome.

For ICPS it has been a year when projects we have been involved with and begun some time ago have continued and when new work and horizons have been opened up and I personally have found myself, as usual, in the role of co-ordinator.

Following the interesting workshops organised with Cerebral Palsy Greece entitled 'The Child as Educator' I went to Zagreb as the guest of the Croatian Cerebral Palsy Society not only to discuss the programme for this seminar but also to see some of the services they are providing for people with disabilities. I was privileged to take part in their 35th Birthday celebrations and surprised and delighted to find Miko and Tatyana Velickovic had joined us from Slovenia.

Services in Croatia for people, especially children with cerebral palsy, have been hampered in their development in recent years by hostilities and a resulting lack of money. This inevitably has meant that it has been difficult to implement many of the recent developments in thinking and approach to services, prevention, management, education and treatment, although staff working with children and parents here are making great efforts and achieving some good results. I was fortunate to see an excellent service developed for profoundly multi-handicapped children and adults which reassured me that the heart and soul needed to provide such support is alive and blossoming in Croatia. ICPS, as always, is at the disposal of everybody to assist in the development of practises appropriate to local needs.

Whilst in Zagreb I had the opportunity to visit an old friend who for many years has been an active supporter of ICPS work giving papers at many of our meetings, Ivancica Planinc who herself has cerebral palsy. Though only in her early 50s Ivancica lives in a home for the elderly where I visited her. We enjoyed a few hours together retelling mostly wild stories of daring escapades we had got involved in in our misspent youth! Ivancica had promised to be in Pula and to give a paper but I understand ill health has prevented her being with us. Can I take this opportunity on behalf of all her many friends within ICPS to wish her well and to say how much we miss her.

I suppose it would be fair to say that the main work of the year has been in responding to the request of the Self-Help Group for Cerebral Palsy Nepal for ICPS to help train their staff. For years people have joked that one day ICPS would find children with cerebral palsy to work with half way up Mount Everest but I have to admit that I never ever thought that ICPS would one day work in the land of that great mountain which we saw in all its majesty as we flew into Kathmandu.

For those of you who have visited the countries which comprise Asia, the sights and sounds of a bustling sprawling city like Kathmandu will be familiar. The constant noise of motorbikes and their exhaust fumes which pollute the air, of cars sounding their horns almost constantly and of priests dressed in saffron robes chanting in the narrow spice scented streets all form part of a picture of a country rich in heritage and history. Nepal is supposed to be one of the poorest countries of our planet and yet its people are rich in

kindness and warmth and the welcome we received mixed with curiosity was overwhelming.

There are two centres run by the Self- Help Group, one a rehabilitation centre the other a school, within easy walking distance of each other, that is if you discount the large holes in the roads, the sleeping dogs, motor bikes and clusters of curious local children. We were able to work with parents and their very young children in the rehab centre and were humbled by the circumstances many of these families live in and honoured that they were so willing to work with these 'three white ladies who had somehow dropped in out of the skies'

Most of our time was spent working in the school and we managed to persuade the therapists to join with the teachers for both our practical work and the teaching session we also organised.

In both facilities we demonstrated ways of handling the children which, on an individual basis, would involve both staff and parents working with the child. It involved discussing the need to assess each child and its family's needs, setting goals and planning towards achieving them and identifying the part each member of the team will play.

One of the highlights of our programme was a day spent visiting two families with the head of the Home Visiting Programme and the 'local' home visitor accompanied by Sabine Dreemann, a German Physiotherapist working part-time at the SGCP. We travelled for more than 2 hours out of Kathmandu in the direction of China! The first family we visited had a child of around 6 who was principally looked after by his Grandmother who had made huge improvements all round with this child. It seemed as if the whole village came to watch these 'white people' who 'played with' the little boy. The tea, which the family made for us, was delicious and the Grandmother had a quiet cry when we told her what marvellous things she had achieved with her grandson.

The second visit was way way in the countryside. We left the minibus and walked for nearly 2 kilometres down a steep pitted and muddy track to a house at the bottom of the hill in this farming village whose main source of income seemed to be farming and selling potatoes. There we found a beautiful 14 year old girl whom we taught to sit on a stool unsupported and drink ,unaided, for the first time in her life from a two handled cup we had brought for her. Here, not only the whole village joined in but the goats and chickens too! There was a heated discussion between two of the men of the village and the parents. One said that he was full of admiration for what the parents had done with their daughter because he said had it been his daughter he would have abandoned her out in the cold to die.....the second man told how they all worked hard as a community but made sure they kept an eye on the needs of the girl, toileting and feeding her when necessary.....it was indeed a day we shall remember for the rest of our lives....

Since leaving Nepal we have been in constant touch with the SGCP as they follow up on recommendations made in our reports. I would like to take this opportunity to thank Professor Batuk Rajbandhari, his staff, and all the children and their parents with whom we worked for the warm welcome they gave us together with their time and commitment to our project which was at times overwhelming. Particular thanks are due to the Stichting 'Holland Building' Nepal who financed half the costs of this project for without them the project would not have happened at all....and last but not least my fellow team members, Olive Surtees a physiotherapist and Carol Hehir a special needs teacher.

I said at the beginning that I acted as project leader and part of my responsibility is to ensure the safety of my team members. I have to admit to you that I nearly failed. One morning, Suzi Groeli, a Swiss volunteer at the SGCP, decided to take us on a rickshaw ride. There being four of us, we had two rickshaws, As we careered through the narrow streets of Kathmandu, clinging on for dear life, the chariot race in Ben Hur came to my mind as our drivers systematically overtook each other in what seemed to be totally

impossible circumstances. However I am pleased to report that although both shaken and stirred we all arrived safely at our destination.

The work begun by the Society to train staff working at the Sesobel Centre for those with cerebral palsy in the Lebanon continued this year and was funded by the Lebanese themselves. This is an indication of the important role ICPS specialists play in helping others to develop their services and enlarge their expertise. ICPS is particularly grateful to the Percy Hedley School in Newcastle England for the training programme they provided for Sesobel staff.

I had thought that maybe the fallout from the famous Vari meeting had finally died down but how wrong I was! EUCLID is the UK cultural contact point of the EU Culture 2000 programme. They held a meeting in London entitled 'Cultivating Cultural Co-operation - the impact and future of the Culture 2000 programme of the EU.' at which I was asked to give a 10 minutes presentation of our project. I talked for 5 and showed 5 minutes of the Vari video. This project was the only project concerned with disability on the programme. The presentation was a great success not only because the Vari video is so good but because I was the only speaker all day who kept to time!

Two things followed from this meeting, firstly I had a chance conversation with a participant who turned out to be organising a 90th Birthday party for Professor Paul Polani, an ICPS Gold Medal recipient, which I was delighted to attend, and secondly, another participant, Ciaran Gillespie from Glasgow, had been so impressed by even 5 minutes of the Vari video that he invited me to speak at an Inclusive Arts Seminar and Festival in Glasgow. I begun by showing part of one of Daphne's videos of her drama group enjoying rehearsals, then I spoke about the Vari project and showed the video, which was followed by an animated discussion, and I ended with the famous Finnish Dance video.

Participants were eager to know if the Vari project could be repeated and I suggested they find somebody to sponsor and organise such an event. It was also emphasised that it is ESSENTIAL that videos made of projects should be made by professionals so that the quality is very good and not by somebody just holding and pointing a camera.

Cerebral Palsy-European Community Association has had a busy year continually responding to information from the European Disability Forum of which it is a full voting member. CP-ECA was represented at the Annual Meeting of the Forum held in Warsaw by Francois Bonnet (France) and Catherine Carr (Wales).

I find keeping in contact with ICPS members very important and was delighted to have lunch with Dr Grace Holmes and her husband Fred from the USA when they visited London during the course of their researches at the British Museum Library and dinner with Ceri Lascombes from Argentina and her husband John. It seems there is always a possibility to put people in touch within the world of CP through our contacts. Recently I was asked for a contact in Alexandria. A swift email to Jean Calder in Gaza came up with two names and I believe the parties met last week in Alexandria...Rob White, the Chief Executive of the New South Wales CP Association Australia lunched with the Chairman of SCOPE Gerald McCarthy during a recent visit to London, Joan-Mary Majali from Jordan often visits ICPS members as she travel extensively with her husband.....and so it goes on.

I had the opportunity to attend the 5th World Congress on 'Conductive Education - science and Quality' held in Budapest. It was an event not to be missed, to visit my Alma Mater, meet many old friends and make several new ones from all across the globe.

So you see it has been a year of great contrasts and hard but rewarding work, and much is planned for the coming twelve months.

I would like to take this opportunity to record my thanks to Daphne Economou, Maria Andrada, Claudette Bonnet and Ulrich Aebi who retire from the Executive Committee for all the hard work they had undertaken for the Society and for their total support of its work and also me personally.

The high points of my year have to be a phone call from Dr Marcel d'Avignon, now in his late 80s, the first Chairman of ICPS, ringing from Stockholm to congratulate ICPS upon its work; tea with Ivancica Planinc talking about old times; meeting Paolo Kumar from Pula, a very special young man; **and lastly of course Reshav the little boy from Kathmandu whose parents came to the centre to see us on our last afternoon. They were very curious. Reshav is 7 years old, and a highly intelligent athetoid whom we had taught to sit independently and to shut his mouth so he did not dribble and also begun to show him how to walk. He had gone home and told his parents all about these 'three white ladies' who had told him what to do AND he demonstrated it! For the first time their son was sitting independently and unsupported! Mother and father had come to the centre on a motorbike. They left, all three on the same bike, for now Reshav had learned to sit independently; he sat in front, his feet placed firmly either side of the seat giving his trunk stability and therefore balance, grasping firmly with his hands onto each wing mirror, then Father then Mother on the back!! What a sight as they bumped off down the dusty road on their way home.**

ICPS has bumped continuously down many a dusty road but with the support of its membership worldwide, its Executive Committee and particularly its Chairman Carol Hehir, as she successfully completes her first year in office, it holds on tightly to the wing mirrors in which it sees where it is going, remains independent, stable and balanced as it continues on its journey determined to ensure that Reshav and all those children with CP worldwide achieve their full potential..