

IOYR



International Organisation of Youth with Rheumatism
Newsletter no. 12 - Special Edition

www.ioyr.org
12. October 2003

MOVING!

- The World Arthritis Day 2003

Organisation work in another age

- by Tina M.-L. Mortensen, Denmark

I travelled for the second time many time zones away. I really had to cross some barriers. And when we reached Nepal, it was also like we had been travelling back in time with years. Later I found out that it was not only a matter of moving myself physically but indeed also mentally. Everything was so strange to us. Absolutely filthy and incredibly beautiful at the same time. It is really difficult to imagine, before you actually see it yourself.

I had tried to organise these meetings with disabled people in Nepal several months ahead. The plan the first time, when I was there in November 2002, was that I should help them with some assistance for a workshop on accessibility for disabled people in Nepal. And the second time in March 2003 was more direct organisational work for disabled people in Nepal.

It was really interesting for me to plan this workshop with disabled people in Nepal by email. I had never met them, so it was a challenge to co-operate with them in this way. Sometimes I felt like we were having some culture problems between us. Every idea I came up with was "a perfect idea". They never seemed to be unsatisfied. In my world that is a problem. It's hard to co-

operate with people that never give you feedback. I also enjoy when people tell me what could be better.

I did not believe that all my ideas were perfect, so I spent a lot of time explaining that to them. In the end I didn't trust they were honest with me, so I told them to choose some of the ideas and trust themselves a little more. That problem was even worse when I came to Nepal.

They were all over me. People travelled for hours in poor busses on poor roads to talk to me. Everything seemed so overwhelming for me. It took me many days to get use to this big interest. It was like they thought I would have all the answers to all their problems. But no one else but themselves can or should come up with the answers. I had no clue about anything in their country. How do things work there? When I don't know those simple things, I cannot do anything other than come up with ideas that might work for us in Denmark.

It was really hard in the first days. It was a lot of work and frustration. It was difficult to see what I could do there. And it was frustrating to turn so many people down. There is a great need for some help in Nepal. It is a very poor country with very

difficult possibilities for especially disabled people.

After I started focusing on the people I COULD help, I got more energy and excitement. It was so fascinating to see the hardworking disabled people. They climbed up on a top of a mountain, helping each other on the way every day in order to get their education. I was wondering why in the world they had an education centre for disabled people up there. Until I found out that that was the cheapest area. In a poor country like Nepal it is either this or nothing. They were just so happy and proud of their education centre which for me looked like a bunker.

It was that day, I fell in love with Nepal and its people and felt embarrassed for my complaining over things in Denmark.

For the people there it's a huge thing that a European came to their country to help them out. For me it's normal thing that one country helps another. I often thought about all the help we supply each other in IOYR. For us it's normal to share the knowledge. I had some knowledge about making workshops and some personal opinions about accessibility. And DSI – The Danish Council of Organisations of Disabled people - is involved with this kind of work because we in Denmark have a long history of organisation work.

Danish disability organisations have been involved in development assistance since the early 1990s. Organisations and individuals became committed to this field, new contacts and working relationships were established, a great deal of experimentation was undertaken and some important lessons have been learnt. DSI has succeeded in establishing an overall strategic framework for the mini-framework agreement, and has defined fundamental development issues in relation to disability work.

In short you can say that DSI wants to ensure full participation, equality and human dignity for disabled persons in developing countries on equal terms with their fellow citizens in society. DSI's principal focus is on support to the initiation, establishment and development of democratic organisations of disabled people in developing countries and on managing projects, mainly in cooperation with such organisations.

These main objectives and strategies are why I will happily travel to Nepal again in the fall.

If you are curious to know more about these issues, you can visit www.disability.dk.

Moving on the scooter - 850 kilometres scootering through the Netherlands

*by Lucinda Blauw, The Netherlands -
Lucinda is also a board-member in IOYR*

We have made it: Lucinda from Hoogeveen and Marjolein from Utecht. Saturday afternoon, the 2nd of August, we ended our journey on the scooter through the Netherlands under the 'Domtoren' in Utrecht.

During the last 17 days we were on a special journey. First it was a holiday for 2 good friends and second it was a kind of promotion tour to show people that even with a disability you can have a great holiday. To make this journey we had a lot of support. From a scooter manufacturer from the Netherlands (Revatak) we borrowed 2 fantastic scooters: the Solo TS120, with excellent springs, a maximum speed from 19 km/hr and a range of 75 kilometres. Behind one scooter we got a cart for our luggage. The only thing they asked from us was that we made the journey this year because this year is the European year of Disabled People and

people with chronic disease and we would be able to get some PR for it.

We drove from Wapenveld in the north-east straight to the south. Alongside the rivers the IJssel and the Maas, sometimes next to the dike, sometimes on top of it. In Maastricht, in the deep south of the Netherlands, we stayed for four nights, so we had some time to visit the wonderful city. We also visited the marl caves where we could actually join an excursion in our scooter to enter the caves! From Maastricht we drove to the west, one part by train, to the sea. In Zeeland we drove over lots of dams and dikes with marvellous views. From Zeeland we drove to the north through the dunes, what a wonderful landscape! We also visited cities like Delft, The Hague, Scheveningen, Leiden and Haarlem. From Haarlem we drove to Purmerend and then to Amsterdam, alongside the IJsselmeer (lake) and through real Dutch villages like Edam, Monnickendam and Volendam. Our last day we drove from Amsterdam alongside the rivers the Amstel and the Vecht to Utrecht. There awaited us a warm welcome with lots of family, friends, flowers and champagne!

During our journey we did get lots of PR! More than one newspaper article per day, two local radio interviews, two national ra-

dio interviews and twice filmed and interviewed by a commercial television broadcasting station. During our journey lots of people recognised us from the television or a newspaper, so every day we had nice talks with total strangers. And even people who hadn't seen us were very interested.

Off course we also encountered some problems. On the first day we were stranded after 45 kilometres. The scooter with the luggage cart didn't have the same range as the one without. So from that day we planned a two-hour-lunch break every day to charge the battery of the scooter and to eat and rest. And when we are planning our next journey we will do it differently. We will plan shorter distances per day and stay at our bed & breakfast addresses at least for two nights, or stay in one place and make short trips from there.

But in the end Marjolein and I concluded that we succeeded in having a great holiday and in spreading the news that as a disabled person there might be more possibilities than you think!

When you want to see pictures, look at www.leefwijzer.nl and go to the part 'wandelen op wielen / 800 km door Nederland')

This newsletter – a special one...

About MOVING!

The 12. October is World Arthritis Day
This year IOYR is marking the day with the headline MOVING!
This newsletter is published this day.

Next newsletter from IOYR

The next newsletter from IOYR will be published in December.

Please send your article to ioyr@ioyr.org latest at 20. November, thanks. We are looking forward hearing from you.

The Aims of the IOYR

The main aims of IOYR are to:

- exchange information and experiences and to learn from and help each other.
 - encourage the development of self-help in each of the countries.
 - empower young people with rheumatism and enable us to get our voices heard.
 - raise public and professional awareness of the situation of young people with rheumatism and change attitudes.
 - exert policy influence, both internationally and nationally.
 - develop links between medical professionals and young people with rheumatism and increase understanding.
 - encourage more research into the experiences of young people with rheumatism.
-

More information about IOYR

c/o FNUG • P.P. Ørums Gade 11, bygn. 10 • 8000 Århus C • Denmark
Phone + 45 86 11 85 21 • Fax + 45 86 11 73 88 • www.ioyr.org • ioyr@ioyr.org
