



Dear Friends

I hope you are all keeping well and busy with your important duties. I have had a very intense period but also very exciting and positive. I am happy to tell you that there are a lot of things happening in the Bureau and I would like to mention some important steps that we have taken on the road to better quality of life for people with epilepsy.



IBE has applied for consultative status as A Non Governmental Organisation (NGO) in the United Nation in order to influence the ongoing work of a convention for people

with disabilities. I have met with Special Rapporteur on Disability of the United Nations Commission for Social Development, Sheikha Hessa Khalifa bin Ahmed al-Thani from Qatar, and discussed epilepsy issues with her.

The task of the Special Rapporteur is to monitor implementation of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities, adopted by the UN General Assembly in 1993, and to advance the status of people with disabilities throughout the world. I am curious to explore in what way IBE could link human right issues to epilepsy in our daily work with legislation and political activities.

For the first time ever IBE has been visible at the World Congress of Neurology with the performance of a play called "Brain Storm". The

**World  
Premiere of  
Brainstorm**



play dramatizes the effect that seizures have on the lives of people with epilepsy as seen through the eyes of an epilepsy specialist. The aim of the play is

to improve communication between people with epilepsy and their medical service providers.

A panel discussion followed the performance, on which IBE was represented by Michael Hills (New Zealand). This was a very successful event and received good media attention. If you are interested to learn more, you will find a news release about Brain Storm on our website [www.ibe-epilepsy.org](http://www.ibe-epilepsy.org).

Recently you will have received messages from Philip Lee,



Immediate Past President, relating to the IBE 5-Point Plan. This initiative aims to bring attention to the importance of continuity of supply of AEDs for people with epilepsy and encourages medical professions to sign up to the initiative by way of a Pledge Card. The Pledge Card is available on the IBE website and we would encourage as many people as possible to submit their pledges online. You should do this before the closing date of **31st December 2005**.

Best wishes

Susanne Lund  
President  
International Bureau for Epilepsy