

FIRST OF ALL, THANK YOU MISTER VOTTA FOR THE INVITATION TO SPEAK AND THE OPPORTUNITY TO ATTEND THIS MEETING.

I AM BEA DE SCHEPPER AND MY FAMILY IS AFFECTED BY HUNTINGTON DISEASE.

Huntington disease is a progressive neurological disorder that causes uncontrolled movements, emotional problems, and loss of thinking ability (cognition). its a dominant hereditary disorder which means that if ONE parent has huntington, then each of their children has a 50 % risk of also developing the disease..

On the screen you will see pictures of a woman living with huntingtons disease. Look carefully at the changes over the years, she went from being a very independent person with a lot of interests, holding down a job to a dependent person requiring full time care (day and night).

Huntington's patients have a range of neurological problems, physical and mental health issues manifesting in uncontrolled movements, difficulties swallowing, cognitive problems, loss of speech and the ability to communicate . Communication is a necessity : losing it means that you can no longer express yourself and that others can't understand you anymore. And they become more isolated.

ISOLATION is the worst loneliness in the world.

It is a paradox : you live but you are not alive.

Huntingtons is a family disease not only affecting the person with the disease but it impacts on the whole family. The burden on

family and friends can be enormous as they seek to support and care for their loved one. There is a huge need for appropriate treatment, and care tailored to the individual at whatever stage of the disease as it progresses. The work of huntington patient organisations (both european and national) is to raise awareness and to ensure these unmet needs are catered for.

Suffering knows no borders so the work of the European Huntingtons Disease Association is to champion the needs of the patients and families by ensuring this rare disorder is diagnosed, managed and treated by well educated healthcare professionals whilst encouraging research for the future.

As a respresent of the European Huntington Association, I want to promote the advantages of cooperating with other european umbrella organisations. . The European Federation of Neurological Associations share many of our concerns and as I said Huntington Disease is a rare disease so our voice is stronger. EURORDIS , represent a lot of rare diseases . They know different diseases have many different symptoms yet there are so many areas of mutual interest.

Collaborating in the following areas of medical research. exchange of experiences, improved support based on actual lived experience of those affected by Huntingtons shoula make the work more effective and relevant. Leading to improved quality of life for all.

I am convinced that for all of these reasons the necessity to include centres of excellence across Europe and to promote the setting up of these in each member state should be a matter of policy.

There is no need that all of us stay in our own corner working in isolation.

Together, -WE ARE STRONGER ESPECIALLY WHEN WE SPEAK WITH ONE VOICE!

thank you