

Speech of the President of the European Huntington Association

Mowa Prezesa Europejskiego Stowarzyszenia Choroby Huntingtona

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First and foremost I want to thank you for inviting me and giving me the opportunity to celebrate this meeting together with you.

I also would like to express my thanks and respect to you all, also many thanks and appreciation to the board of the Polish Huntington Association and certainly to all the founders of this Association.

Your President asked me to tell about my own story and how I became involved in these voluntary activities. So here it is.

When in 1974 Marjorie Gunthrie was visiting Belgium she met in Louvain 2 young scientists, one was prof. Franz Baro, a psychiatrist and the other one prof. Herman van den Berghe, a geneticist, both attentive to Huntington's disease. They soon came to the conclusion it would be favorable to create, together with families involved, an association with as objectives breaking the taboo around and focus the attention of the medical world on Huntington's disease. They decided to go out and look for families affected.

Prof. Baro disposed of medical records of my grandfather, and two of my sisters tried to find out what kind of illness our mother had. The professor contacted us and asked if we were interested in meeting Marjorie Gunthrie and learn more about the disease. After a few meetings we then decided to set up an association to fight Huntington's disease in Belgium. This was in the year 1976. Later, due to the bi-lingual status of Belgium the vlaamse Huntington liga in the Dutch-speaking part and the League Huntington Francophone Belgian in the French-speaking part were created.

Nowadays the initial association has become a fully developed organization with a whole range of activities:

A social service

With a staff consisting of 3.5 employees paid by the Flemish authorities. Their main tasks:

- providing information about the disease, health insurance, social rights and allowances
- giving assistance when contacting competent authorities and appropriate services
- providing support in finding the way to predictive testing and during processing of the test result
- giving information to parents and their children
- assist when searching for settlement in specialized homes or registration on waiting lists.

Holiday week-ends with patients

Two times a year we organize holiday weekends for and with patients. These weekends are organized by volunteers with the support of the social service.

Assistance to partners

Partners of patients gather on regular time intervals, without patients. They can chat together in a relaxing environment, exchange ideas and find relief and support with each other.

Locally organized gatherings

In different regions of Flanders, the H. families meet, mix socially and relax together in order to reduce the feeling of isolation.

Dominant

We edit a quarterly published members newsletter.

Information evenings

Two times a year we organize information evenings in cities or regions where universities are located.

These evenings are attended by families as well as by professionals such as family caregivers, home nurses, social workers.

Seminars for professionals

Every two years in collaboration with the University of Louvain we organize seminars for professionals, both from home care organizations as from care centers that work with Huntington patients and their families.

In the morning medical information is given by professors, in the afternoon working groups per discipline are formed:

- Physicians
- Psychologists
- Homecare nurses
- Nurses in residential care facilities
- Speech and language therapists
- Physiotherapists
- Homecare service providers
- Family caregivers
- Patient's personal assistants

Those days are really appreciated by the caregivers, up to 100 and more individuals attend the seminars each time.

Only professionals are present, no family members. Doing so offers the possibility to speak freely and exchange ideas.

Gatherings of gene carriers

These groups exclusively consist of individuals with a positive test result. They know that one day they will develop the disease. The group members support each other and have meanwhile developed an intense friendship.

Relaxation weekends

This is for all members who are involved in care and want to get out for a few days without their patient.

Farm day

Once a year all members of the Flemish association are invited to our farm. They can come with or without affected family members, with friends and acquaintances and enjoy a relaxing afternoon. This day is made possible thanks to the generous contribution of volunteers who take care of preparing and serving a good meal and drinks.

Empathizing weekends for students

At the Louvain University an empathizing weekend is organized every year. Students of different medical and paramedical professions are confronted with testimonials of different clinical pathologies and handicaps. For several years now I give my testimony on Huntington's disease. This is in a nutshell what the Huntington league does in Flanders.

I was involved from the very beginning in 1976 as co-founder and board member and as a volunteer and member of an involved family.

I for sure do know very well the needs and problems faced by families affected by Huntington's disease.

In doing something about these needs and by trying to break the taboo around the disease I did and still do find my motivation.

During the E.H.A Congress in Boldern (Switzerland) in 2002 I was asked to join the management of the European lay association and to play an important role in it. After consultation I accepted this nomination and during the congress in Guerdrama (Spain) in 2004 I had been nominated and elected as president of the EHA.

EHA Congresses are organized every 2 years. Their objective is also to establish contacts between national associations and to learn from each other by exchanging experiences and ideas.

But solidarity is not only learning from each other. It also means supporting each other unconditionally, with knowledge, emotionally, and even with financial means. During our EHA meetings there is also a place for a laugh and a tear and this is also very important to me. We can meet on equal basis and as members of one big family.

Thanks to the EHA, several new Huntington associations have been founded and young associations did receive support. In Slovenia F.E. we are bringing together Huntington families and professionals around a project about swallowing and nutritional problems, this thanks to the financial support of The Dutch Huntington Association. And this is not their first project.

The West-German association has supported Huntington families after the unification with the former German Democratic Republic, and has made their knowledge and experience available to them.

These are just a few examples, there are more, but by mentioning them we could forget others and that is not the intention.

By always organizing the EHA congresses in different countries we create intensives for the local associations. They are encouraged to come out and get themselves known to the general public and official instances.

Organizing such a congress asks for important efforts, both of the EHA staff as from the national committees, but this is really worth it.

I wish you all a fruitful and pleasant congress and it is a real pleasure to me to be here and getting you to know.

All the best
Bea