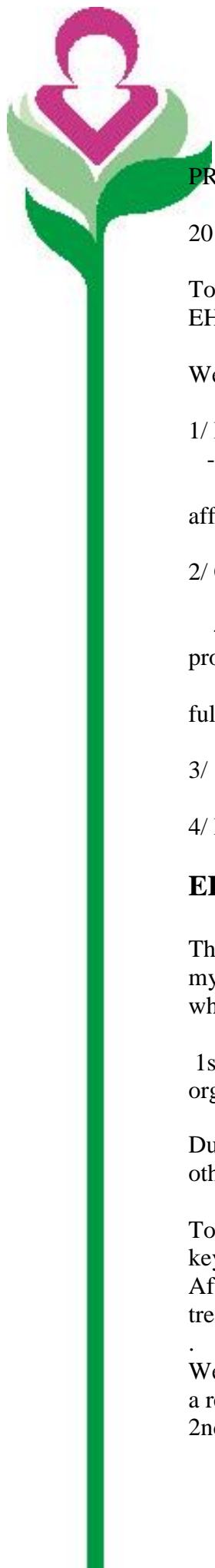


European Huntington Association EHA



PRESIDENTS REPORT EHA 2016

2014 - 2016

Together with Astri Arnesen and Svein Olaf Olsen, I worked on the expansion of EHA.

We continued to support the HD organisation and all its initiatives.

1/ BULGARIA

- together with the Bulgarian HD Association, we organised an information day. 48 people attended our workshop, mainly professionals but also some families affected by Huntington

2/ CYPRUS

- support was given to found an H.Association.
- in Nicosia, present at first information day attended by families and professionals.
(Cyprus now also has an Huntington Association and they have asked to become full members of the EHA).

3/ LITOUWEN : we continued to advise them.

4/ ROMANIA : several contacts , especially with Ramona

EHA CONGRESS IN WARSCHAU SEPTEMBER 2015

This congress was organised by EHA , more specifically by , Astri, Svein en myself and the support of the Polish Huntington Association, especially Danuta Lis, who provided practical local support.

1st European Huntington Association congress about the care for HD patients , organised for caretakers, nurses and families.

During the congress we focused on the exchange of experience, learning from each other and how to give support.

To enable this congress we contacted sponsors, checked contracts, looked for keynote speakers, made deals with the hotel and contacted all the participants. After the congress we paid all the bills, controlled the expenses together with the treasurer and checked that all the contracts had been fulfilled.

We received a lot of positive reactions during and after the congress . There was also a request to keep up this kind of work. And therefore we have decided to organise a 2nd congress in Sofia , Bulgaria.

European Huntington Association EHA

We focus on these countries because huntington is still a hidden disease there and because the knowledge about it, and the care for HP patients needs more public attention.

Present at the National Huntington Congress in Warschau and contact made with the VISGRAD group to set up a Huntington Association in Hungaria and Slovakia.

Together with EFNA and the Danish Huntington Association organised an "awarness day" , during the E.A. N congress in Kopenhagen. It was a day filled with testimonies , a much appreciated speech by Prof.Landwehmyer and very interesting courses on nutrition and care.

I'm also engaged in the workgroup BioPontis Alliance for rare diseases, and in EFNA, lobbying with the government for better support for Neurological diseases.

In EHDN I am still a member of the Genetic Testing workgroep and the Quality of Life workgroup.

I have been president of EHA for 12 years now (2004 till 2016) and after all these years I feel it is the right time to make room for a new president, Astri Arnesen,.

We have been working together for 5 years yet.

I know she is very competent and highly involved

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Thanks to all of you who supported me during my presidency. I hope and wish that Astri will receive the same support.

I will not totally disappear from the scene . I will stay in contact as LIASON OFFICER .

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