



Hungarian Williams Syndrome Association¹

Charity Organization, 1089 Budapest, Orczy út 2.

Tel: (36-1) 326-7492, (36-1) 788-3881, Fax: (36-1) 438-0739, <http://www.williams.org.hu>



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Dear Delegates, Colleagues, Ladies and Gentlemen,

Thank you for coming to our Conference jointly organized by FEWS and the Hungarian Williams Syndrome Association, with support of the Visegrad Fund!

As you know, there were only a few similar event organized during the previous years. Some of us could participated in Williams Syndrome Conferences with international participation in Rome in 2004, or in Paris in 2008. Therefore, the member associations of FEWS realized this long gap which made necessary to organize a real European meeting, as the development of science is rapid in the area of Williams Syndrome (WS) as well. As you can see, we were successful! More than a hundred people registered for this event, from more than 17 European countries, so I think that is quite an achievement! It is wonderful to see so many people from all over Europe!

I think this underline the fact that although the Williams Syndrome is a rare disease, it can bring so many people together! We were able to attract some of the most recognised speakers of Europe, who will exchange ideas with not only the experts of European Countries, but also with the families, coming mainly from the new EU Member states.

I would also like to thank our collaborators in organizing this event, because a lot of people have been involved, particularly the FEWS and its member associations, and the Visegrad Fund. On behalf of Hungarian Williams Syndrome Association, I would like to thank all of those partners and supporters and programme committee as well who have brought this day to pass!

In 2014 HWSA reached the milestone of celebration our 15th anniversary of our existence, together with the same year of 1999, when the initiative was taken to start the European Federation. We know that 15 is an interesting age, but it is also an age when we are growing up a maturing. During this 15 years, that this organization has been in existence, we had the support of a very active, very focused and very determined voluntary membership. Without their basis, our further work would not have been possible. On this way, we could participate in the initiation and foundation of the FEWS as well as the Hungarian National Federation for Rare Diseases (HUFERDIS) or recently the Hungarian Alliance of Patient Organizations (HAPO). Together with others



HUFERDIS

Member organization of Rare Diseases Hungary and the Hungarian Federation for Persons with Mental Handicap



ÉFOÉSZ

Mailing address: H-1022 Budapest, Pajzs u. 5.
Office: H-1091 Budapest, Üllői út 119. 3. em. 49.

Tax No.: 18249255-1-42

e-mail: info@williams.org.hu

we could reach the formation of Hungarian Rare Disease National Plan and the transposition of Cross-Border Health Care Directive in our national legislation.

During the conference, our main focus is to share good practices and knowledge on the disease between European Countries with a good expertise and other European Countries with lesser experience on the syndrome. The ultimate goal of the Conference is to help patients with WS have a better life by promoting or improving better care, including those elements which may integrate with the EU policy on rare diseases.

The Conference targets professionals in different areas from different countries, who, by their professional position, have an impact on spreading the awareness and knowledge about Williams Syndrome. We would like to establish a network with the leader European experts of the area with high international reputation as well.

Participants to the Conference are relevant stakeholders, e.g. representatives of healthcare professionals and caregivers, politicians, patient organisations, researchers and academics, national authorities, medical societies, media, etc. We especially target professionals in countries with rather limited knowledge about the syndrome to spread awareness. Therefore, a Fellowship program was available for Central/Eastern European member countries of FEWS.

Together with the majority of rare diseases, the WS remain untreated or untreatable, we continue to see significant delays in diagnosis, and we see huge discrepancies in access to treatment both between and within EU Member States.

Our future depends on you, and your interaction, so we do need to hear from you and we do need to hear your voices and your experiences, because that is the only way we can learn from each other!

We hope that this Conference will provide edification for all participants in the interested fields. I wish you all an excellent conference and fruitful discussions over the next two days. Thank you!