

European Marfan Support Network

(AND RELATED DISORDERS)

Rare Disease Day 2013



Rare Disease Day[®]

The Rare Disease Day 2013 was marked world wide on 28 February. The EMSN did not have an official marking of this day, but there were several events going on in European countries which members of the EMSN attended. We have therefore asked our members to tell us what the national Marfan organisations were involved in this day and have tried to collect some of it here.

B. Lukovicova (left) and RNDr.R. Dusinsky from the Slovak Marfan Association at the "Rare Disease Day 2013 in Slovakia - Forum of Experts".



In **Germany** the organisation was present at events in some bigger cities where presentations of different rare diseases were organized, and where they met with other organisations and with Marfan people. A mother and her son met with a television team and talked about living with Marfan syndrome and how they were diagnosed. A doctor from the hospital described the symptoms of Marfan and how to manage it.

In **Norway** the day was marked with a big conference organised by the Norwegian umbrella organisation for rare diseases, FFO, in cooperation with the Norwegian Directorate of Health and the Centre for Rare Disorders at Oslo University Hospital.

The conference was fully booked with 150 participants from, amongst others, patient organisations, centres for rare diseases and FFO. The Norwegian Marfan organisation was represented by two participants.

The conference followed the international topic "Rare Disorders without Borders" with presentations and debates on topics like health care, transitions and life stages, and research, all without borders. The speakers included researchers, representatives from patient organisations and people holding political positions.

In the capital of **Slovakia** the conference "Rare Disease Day 2013 in Slovakia - Forum of Experts" was organized by EUCERD and Slovak Alliance of Rare Diseases in Bratislava.

Three representatives of Slovak Marfan Association attended this happening with a poster about Marfan and the patient organisation and participated in discussions with experts. We also take part in a Committee of Slovak Alliance of Rare Diseases.



At the "Rare Disease Day 2013 in Slovakia - Forum of Experts" (from left):
B. Lukovicova (Slovak Marfan Association),
RNDr. Dusinsky (Slovak Marfan Association),
MUDr.M. Ondrejcek (genetics/gynaecologist),
MUDr.K.Melissova (genetics).

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The other members of the EMSN have not reported attending any particular events in their country for the Rare Disease Day 2013.

In **Sweden** there was no Rare Disease Day this year as it is only organised every leap year.

In **Denmark** the umbrella organisation for rare diseases did not organise events this year, but instead used the day to start a discussion with the politicians about diagnostics and treatment across border. This in order to raise awareness about the Danish situation as the EU directive "Cross Border" is about to be launched.

Belgium Wallona reports that next year there will be a special Rare Disease Day in connection with the start of the Belgian "National plan of rare diseases". They are currently working on setting up of a centre of reference and expertise for connective tissues diseases.

