

Go With Gaucher: taking forward the next generation

2nd full group meeting: 20-22 November 2015, Frankfurt (Germany)

Following the EGA's first 'Go With Gaucher' meeting in Frankfurt, we are now preparing a second meeting that will take place during the weekend of 20-22 November in Frankfurt for the same group that attended in 2012 to finalise the projects that these participants started.

The programme will include a presentation by Professor Timothy Cox (Cambridge, UK): 'Treatment of Gaucher disease – yesterday, today, tomorrow'; and we will also provide workshops with professional training (subjects such as public relations, fundraising, ethics, etc.).

As the participants were originally chosen by their national associations, we have written to their EGA representatives again to ask their permission to invite again. Invitations will be sent directly to GWG participants at the beginning of May. It is our hope that by inviting the same group again we will create strong relationships that the Gaucher community will benefit from in the future. Hopefully we will see most of the participants working in the Gaucher community at different levels in the future.

How has GWG already made a difference?

- Vesna Aleksovskaja (Macedonia) was appointed as a director of the EGA board
- International Gaucher Day was a concept developed from an idea in Frankfurt, 2012
- Thomas Biegler was appointed to the board of the German Association and is also part of the EGA's Best Practice working group
- Maddie Collin was appointed to the board of the UK Gauchers Association
- Daniela Zlatea (Romania) contributed to the 'Rare Lives' initiative.

6th Nordic-Baltic Gaucher meeting for patients and families



Almost 80 Gaucher patients, relatives and close friends met in Stockholm during the weekend of 18/19 April. A diverse group: from 6 years to over 70 years old, from non-symptomatic to severe Gaucher symptoms. "We all felt the presentations took us further; that we moved from the very basic on Gaucher disease to get a wider perspective on our disease" says Anne-Grethe Lauridsen, chairman of the Danish Association. Dr Allan Lund (Copenhagen) spoke about 'Genetic counselling' and Prof. Per Svenningsson (Stockholm) spoke about 'Gaucher and neurological symptoms, especially Parkinsonism'. The keynote speaker was Prof. Pramod Mistry (Yale University, USA) who gave the presentation 'Gaucher disease and its treatment; yesterday, today, tomorrow' and this brought us back in time when Prof Mistry told us about the very basic work done in Sweden since 1960 where the first cluster of Gaucher patients from the Norrbotten region in Sweden were described.

40th Anniversary celebration of the Swedish Gaucher patient association

The meeting also celebrated the 40th anniversary of 'Svenska Morbus Gaucher Föreningen', the oldest Gaucher association in the world. "The work done by the Swedish association is an ongoing inspiration for others, as they continue to develop their way of working for the benefit of Gaucher patients in Sweden" says Anne-Grethe. On the Saturday evening the participants were invited to celebrate the anniversary with dinner at the beautiful restaurant, Ulriksdals Wårdshus in Solna just outside of Stockholm.

Humanitarian Aid: good news!

At the end of January the EGA received a request from a desperate father from Rwanda whose son had been diagnosed with Gaucher disease, the child was just over three years old. Access to treatment in Rwanda is not available through the Ministry of Health and therefore the child's only hope was to be able to access treatment on compassionate grounds. The EGA contacted all of the pharmaceutical companies that manufacture or market enzyme replacement therapy (ERT) for Gaucher disease and asked for help for this patient. Pfizer came back to the EGA saying that they would be willing to look into helping this child and requested that the child's physician contact Pfizer and request their help.

We are delighted to announce that Pfizer have agreed to support this child and will be shipping ERT out to Rwanda as soon as all the necessary paperwork has been completed. As part of their commitment to this child, Pfizer have allocated additional resources to provide training to the child's physician ...writes Tanya Collin-Histed



Please visit <http://rarelives.tumblr.com/> to view stories from patients across Europe who suffer from a rare disease; their needs, their hopes, their difficulties, but above all their joys and their daily achievements.

Dates for your diary



International Gaucher Day 2015

Thursday 1 October 2015

More details will follow...

UK Gauchers Association's 7th nGD Family Conference

13-15 November 2015, Manchester (UK)

For more information, please email Sarah Allard: sarah@gaucher.org.uk. Closing date for applications is 2nd October 2015.