



NGO COMMITTEE FOR
RARE DISEASES

January 18, 2017

Subject:
Your Contribution to the UN Opening of the NGO Committee for Rare Diseases

Dear Friend,

Please accept our warmest and most sincere thanks, and those of all the colleagues involved at EURORDIS–Rare Diseases Europe and the Ågrenska Foundation of Sweden, for your contribution to making a success of the inauguration of the NGO Committee for Rare Diseases on Friday 11 November at the United Nations in New York.

Your video testimonial, which was displayed on the day, helped illustrate in no small measure the many significant challenges faced in real life by persons living with a rare disease, but it also underlined that rare diseases actually know no borders and therefore urgently require a global approach. Your words of encouragement to the Committee and to all participants on the day did, and will continue to, inspire us all as the Committee now moves into a new year and begins in earnest to develop plans for the continuation of its work.

For all of this, allow us to thank you so much. As a token of our gratitude, and maybe as a little keepsake too, please allow us to share with you in attachment a photo from the day on which you are appearing.

For a report from the event and further information on the next steps in the development of the Committee, please keep checking www.ngocommitteerarediseases.org – the website will be continuously updated.

With our very best regards,

Yann Le Cam
Chief Executive Officer,
EURORDIS-Rare Diseases Europe

Anders Olauson
Chairman,
Ågrenska