



NGO COMMITTEE FOR
RARE DISEASES

Dr Min Chieh TSENG
Taiwan Foundation for Rare Disorders (TFRD)
6F, No. 20, Changchun Road, Zhongshan District
Taipei City 104, Taiwan (R.O.C.)

Monday 12 September 2016

Subject: Invitation to UN Opening of NGO Committee for Rare Diseases

Dear Dr Tseng,

Taiwan stands out in the concert of nations today for the historical recognition and support your country has lent to the cause of rare diseases and to the advancement of the well-being and integration of all persons living with them. This remarkable achievement is due in no small measure to the tireless work of the Taiwan Foundation for Rare Disorders, which deserves to be saluted and praised.

This is why we would be honoured if you would kindly accept to join us in celebration on Friday 11 November 2016 for the inauguration of the new NGO Committee for Rare Diseases at the United Nations in New York, an initiative launched by EURORDIS–Rare Diseases Europe and the Ågrenska Foundation of Sweden. This special event will mark the first time ever that rare diseases receive proper consideration as a global public health priority for action within the United Nations.

As part of this unique occasion, we would feel extremely privileged if we could welcome yourself or one of your colleagues of the Taiwan Foundation for Rare Disorders, but also involve you as speaker during the morning session – particularly during session number 5 on



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the attached programme: “How it all started: The Contribution of the NGO Community to Advancing the Cause of Rare Diseases”.

The purpose of that session should ideally be to go back in time at the very origins of the rare disease movement worldwide, and to shine a light on the foundational groundwork delivered by pioneering organisations like EURORDIS in Europe, NORD in the United States but also and most certainly the Taiwan Foundation for Rare Disorders in Eastern Asia to create a fuller understanding of rare diseases as well as a greater awareness of the needs and challenges of the persons living with them.

Let us reassure you that the format and content for that speaking opportunity can be tailored in close coordination with yourself, and that we stand at your entire disposal to discuss and help in any possible way.

Should you or your colleagues be unable to attend the event in person for any reason, we would be then willing to explore any means to still have the Taiwan Foundation for Rare Disorders represented at this important gathering. A written statement of support or a video interview come to mind as possible fallback options which could be put in practice, and which would make a formidable difference for all participants on an occasion of such global significance.

We look forward to your kind response, and we will be in touch with your office in the coming weeks to discuss further.

With very best regards,

Terkel Andersen
President of the Board,
EURORDIS-Rare Diseases Europe

Jean-Louis Roux
Committee Secretariat