

**PR Keynote Address
at the Rare Disease Day Policy Event**

Thursday 21 February 2019, 09.45 - 10.45 hrs. at Conference Room 8

His Excellency Mr. Sven Jürgenson (สเฟ่น เยอร์เกนสัน), Ambassador and Permanent Representative of the Permanent Mission of Estonia,
Excellencies,
Distinguished delegates,
Ladies and gentlemen,

1. It gives me great honour to be among you today at this policy event, dedicated solely for rare diseases, and this year I understand that the discussion will focus on how addressing rare diseases will contribute to the achievement of universal health coverage as a whole.
2. First and foremost, let me begin by thanking the NGO Committee for Rare Diseases and the other organisers for having me here today. This comes in very timely since Her Excellency Ms. Katalin Annamária Bogyay, Ambassador and Permanent Representative of Hungary, and myself, have just been appointed by the President of the General Assembly as Co-facilitators for the negotiations of the political declaration of the High-level Meeting on UHC, to be held on 23 September this year.
3. Let me also share with you a bit of background information. The High-level Meeting on UHC was proposed by the Foreign Policy and Global Health Initiative, or the FPGH, which consists of seven like-minded countries promoting greater discussion on health at the UN: Brazil, France, Indonesia, Norway, Senegal, South Africa, and my own country, Thailand. The FPGH presented its annual resolution in 2017, during the chairmanship of Thailand under the theme “Addressing the health of the most vulnerable for an inclusive society”. Indeed, the topic of rare diseases is very relevant in that aspect.
4. We must work together to ensure an equitable and affordable access to quality health services and medicines for everyone, especially people who are most in need, which also includes people living with rare diseases, among others, while ensuring that they do not face financial hardship or fall back into poverty because of their catastrophic medical expenses. This is in line with our commitment in the 2030 Agenda to leave no one behind. Millions of people around the world are suffering from rare diseases or disorders, which require some of the most advance and expensive forms of treatment and interventions. As a result, these people and their families carry very high burden in many aspects of life – physically, financially and socially.

5. Having achieved UHC since almost two decades ago, my own country, Thailand, is working to do more. Currently, patients with Type One Gaucher (เกาเช้) disease is covered under our UHC scheme. They are entitled to treatment by imiglucerase (อิมิกลูเชอเรน) and also to bone marrow transplantation in severe cases.

6. The High-level Meeting on UHC will be an important and historic milestone as it creates a space for all of us to discuss on how each country can achieve universal health coverage, which is an overarching umbrella for the success of the whole SDG3.

Excellencies,

Distinguished delegates,

7. However, UHC is not only about access to health. It involves a much broader spectrum than health alone and requires a strong and resilient health system as well as adequate financing to sustain it. Above all, no one can deny that in order to drive this agenda forward we need a strong political commitment. It is therefore time to bring the discussion on universal health coverage to New York to gain the highest level of political attention. At the same time, this will not be possible without the private sector and the civil society, and your knowledge and expertise, to make this collective effort a success.

8. With that said, I would like to inform you that the President of the General Assembly will organise an interactive multi-stakeholder hearing on 29 April here in New York. This will be a great opportunity for you to raise your voice and concerns to all Member States. The inputs received will be taken into account in the development of the draft political declaration, in accordance with GA resolution 73/131 involving the scope and modalities of the High-level Meeting on UHC.

9. In addition, as you may already know, Japan, a true champion and leader on UHC, has created the Group of Friends of UHC, now consisting of over 40 countries with one common goal. The Group of Friends will be another important platform to push this important agenda forward.

10. Before I conclude, let me assure you that, as Co-facilitators for the UHC process, both Ambassador Katalin Annamária Bogyay of Hungary and myself are committed to facilitate all Member States of the United Nations to arrive at a deliverable and action-oriented outcome through a transparent, open, and inclusive negotiation process.

11. I wish you all a successful event and I thank you.
