Dear Ladies and Gentlemen,

I'm grateful to you for the opportunity to present at this meeting and would like to share the experience of the Russian patient community in bringing up the voice of rare and ultra rare diseases among other healthcare priorities.

Let me quickly go 26 years back to the times when there was no specific rare disease legislation in Russia and rare disease patients had very limited chances to get access to proper diagnostics, specialized medical care and orphan drugs. This was the time when the first patient groups like society for Hemophilia, Gaucher and Cystic fibrosis which I represent and other associations appeared in Russia.

As individual patient organizations we all started with taking care of rare-disease patients, that is consulting them on diagnostics, medical care and teaching them how to live with their conditions through special patient schools. We also started to develop infrastructure, and our first success was neonatal screening program for 5 rare diseases which started back in 2006. This would never be possible without support from the medical community and the Russian Ministry of Health.

As the time went by we understood that the joint efforts could lead to better results and this was how the Russian patients union – an umbrella organization for Russian association of rare diseases and different Russian patient groups – started in 2008.

Our next goal was to secure sustainable funding. Through participation in conferences, meetings within the lower and upper chambers of the Russian parliament, by addressing the Government with letters and in personal meetings, by working with mass media and promoting the initiative on our web sites we were able to deliver this message all the way through. In 2008 the Government approved 5 rare diseases (Hemophilia, Gaucher, Cystic fibrosis, hypophesal nanism and chronic mieloleucemia) to be funded from the federal budget.

Several years later we were happy to be a part of another great success story - namely introduction of Russian rare disease legislation. This was a considerable shift made by the whole Russian society and top level authorities which ensured equal access to medical care to rare disease patients with 24 medical conditions. Those diseases including MPSs, HPA and others are reimbursed on the regional level.

Today we strongly believe that the way the country treats rare disease patients may be characteristic of its healthcare system development. We're happy that the Russian government was able to start addressing this challenge, though there is still room for development.

Now let me have a quick look into the future. I would like to call on rare disease community to develop a UN resolution on rare diseases as it has been done for diabetis and other conditions. Rare disease patients representing a minority of world's population, are still equal part of world's community. For them – access to treatment equals in the majority of cases to keeping their lives. The resolution shall cover all steps starting from addressing high unmet medical needs , specific approach to price assessment and to securing equal access to already available therapies. I strongly believe that a UN resolution will help to leverage the voice of rare disease community and secure rare disease patient rights on equal access to medical care.