

EURORDIS

Black Pearl

GALA DINNER

2015



Your Royal Highness, Distinguished Guests, Ladies and Gentlemen

On behalf of Foundation Children with Spinal Muscular Atrophy I am extremely excited and am proud to be honoured by EURORDIS with high level Award - the Award from community of rare patients which have estimated our work. More than ten years has been gone by this significant moment when our work has received such appreciation at the international level. It was impossible without the strong support of my wife, my family, my friends and all around us who are not indifferent to our problem – from ordinary people to doctors and policymakers.

The invaluable support was provided by EURORDIS' staff. I want to express our deep appreciation to them for that. The process of European integration for mutual benefit will be further improved by the co-ordination, EURORDIS and CSMA, building on the tremendous success of the cooperation over the last 8 years.

We sincerely thank all the organizations, representatives of official structures, personally everyone who supports us and gives us confidence in our future, the future of our patients, both in Ukraine and abroad. We hope your friendly shoulders will provide reliable support and in subsequent time become stronger, especially in this difficult time for all of us now.

I would like to thank our patrons Mr. Terkel Andersen and Mr. Yan Le Cam.

I would also like to thank all people from EURORDIS office who have contacted us.

I would like to thank you all for coming this evening to support EURORDIS' initiatives too.

The Foundation has for many years been at the center of efforts to consolidate the interests of patients in Ukraine, representing their needs on the international and national levels, in line with the international community who we will continue taking all possible steps to continue our important work. We are now more powerful than ever that this will happen.

Last year was proving difficult for the entire Ukrainian community of patients with rare diseases. Despite the proximity at the end of 2013 of the adoption of European standards in the field of rare diseases the political situation in Ukraine has caused irreversible and tragic consequences in the country. While the patients needs a care, treatment, the Russian hybrid invasion has led to the fact that we

Have to retire our normal life

Have to hide in bomb shelters and basements

Have to run during outbreaks of rockets

Have to leave our house without confidence that one day you can return. But with hope ...

This requires swift interference and a unity in the international position in order to stop the bloodshed in Ukraine and to preserve the unity and sovereignty of Ukraine and to make sure that the region will not fall into a very serious abyss as well as the whole world. We remain active in the interests of our patients with rare diseases, at the forefront of our information policy, which will return to normal operations with the end of the war in Ukraine. This is of vital importance. We need to ensure that people are free to receive a healthcare in any location where will the best satisfying of their requirements.

In conclusion: This Award marks the promise of us to represent of even greater accomplishments in the days and years ahead. So this is not the end but the beginning of another level. Continue to pursue excellence in all that we do, we are setting lofty goals, persevere through adversity, but, above all, we are sure to leave yourself open to the wonderful, unexpected opportunities that await us.

Always aim high! And we must not fail now!

Thank you.

Слава Україні



EURORDIS

European Organisation for Rare Diseases



Children with Spinal Muscular Atrophy