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> Rare Disease Day in Ukraine

Associations in Ukraine have participated in Rare Disease Day since 2008, using the occasion to launch publicity campaigns in major cities, holding conferences to progress Ukraine's National Plan on rare diseases, as well as to air a television show based on rare diseases on national television and use the internet as a tool to reach greater numbers of people.

The Ukrainian Rare Disease Day campaign, which began in 2008 and is organised each year by the Charitable Foundation "Children with SMA" has assumed a new form by becoming a National Alliance – NGO Rare Diseases of Ukraine – since 2014.

You can also get involved! Write to us at rarediseaseday@eurordis.org.



[OFFICIAL VIDEO](#)



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> Events in Ukraine

 Lviv, Ukraine, 10 Feb 2015 - 28 Feb 2015

City Lights





Kyiv, Chernivci, Kharkiv, Ukraine, 19 Dec 2014 - 30 Dec 2014

Talk Show: "Concern Everyone" - SMA story



Kyiv, Ukraine, 26 Feb 2015

All-Ukrainian Congress of Orphan patients



Kyiv, Ukraine, 10 Feb 2015 - 28 Feb 2015

Photography exhibition "Orphan, but not rightless" in the lobby of the Parliament building



Kyiv, the Cabinet of the Ministers of Ukraine, Ukraine, 26 Feb 2015

Public demonstration and installation "Orphan, but not rightless"

Lviv, Ukraine, Ukraine, 01 Feb 2015 - 28 Feb 2015

Activities in Lviv Region



> National Alliance representing Ukraine



NGO "RARE DISEASES OF UKRAINE"



Kyiv, Kharkiv - <http://www.csma.org.ua> - +380503640673

>> Contact

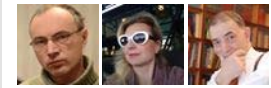
NGO "Rare Diseases of Ukraine" was founded just a few months ago; however, its recognition was a huge step by all patients organisations with rare diseases in Ukraine in the common effort to create an "umbrella" organisation.

The main tasks of the organisation are to: protect and promote of the full rights and interests of people suffering from orphan (rare) diseases, promote the maintenance of high professional standards of medical care, find scientific and practical solutions to contemporary challenges in the areas of rare (orphan) diseases, and provide assistance to meet medical and organisational needs of professionals in the fields of rare (orphan) diseases and their patients.

We welcome partnerships and collaboration to sponsor charitable projects and everyone who is not indifferent to the problems of people with rare diseases in Ukraine! We invite all patients with rare diseases to communicate with all rare diseases civic and charitable organisations in Ukraine! Visit our page to communicate and share ideas!

Запрошуємо до партнерства та співпраці, до спонсорських та благодійних проєктів всіх бажаючих та не байдужих до проблем людей з

Day. 58,659 people like Rare Disease Day.



Tweets Follow

Rare Disease Day @rare diseaseday 28 Feb

Today is #RareDisease Day 2015! Find out what's happening all around the world! ow.ly/JkDRw #RareDiseaseDay2015 #RDD2015

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Rare Disease Day

Підписатися +1

+ 948

орфаними хворобами в Україні!
Запрошуємо до спілкування всіх пацієнтів з рідкими хворобами, всі громадські та благодійні організації по рідкісним хворобам в Україні!
Ласкаво просимо на нашу сторінку до спілкування та обміну думками!
ГО "Асоціація пацієнтів на легеневу гіпертензію в Україні"
<http://pha.org.ua/>
Спінальна м'язова атрофія представлена в Україні,
<http://www.csma.org.ua/>
Фенілкетонурия в Україні <https://www.facebook.com/ukrpkuorg>
Громадське об'єднання сімей України, що виховують дітей хворих на мукополісахаридоз <http://vk.com/mpsinukraine>
Бульозний епідермоліз в Україні. <http://www.debra-ukraine.org/>

> Friends of Rare Disease Day in Ukraine

> [What is a Friend of Rare Disease Day and how can you become one?](#)



 **Charitable Foundation "Children with Spinal Muscular Atrophy"**

 **Charitable Foundation of "Sister Dalila"**

 **PHA Ukraine**

 **Ukrainian public organization "Ukrainian association helping patients with cystic fibrosis"**

 **Genzyme, a Sanofi Company**

RARE DISEASE DAY IS ORGANISED BY

OFFICIAL PARTNERS





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