

Rare diseases magazine – information platform for all stakeholders in rare diseases in Russia

Myasnikova Irina, Volshakova Vera, Pogosyan Nely, Zavialova Elena, Zakharova Ekaterina

Russian association for rare diseases (RARD)

www.rare-diseases.ru, e-mail: vooz@bk.ru

Rare diseases and stakeholders

A group of blind men heard that a strange animal, called an elephant, had been brought to the town, but none of them were aware of its shape and form. Out of curiosity, they said: "We must inspect and know it by touch, of which we are capable". So, they sought it out, and when they found it they groped about it. In the case of the first person, whose hand landed on the trunk, said "This being is like a thick snake". For another one whose hand reached its ear, it seemed like a kind of fan. As for another person, whose hand was upon its leg, said, the elephant is a pillar like a tree-trunk. The blind man who placed his hand upon its side said, "elephant is a wall". Another who felt its tail, described it as a rope. The last felt its tusk, stating the elephant is that which is hard, smooth and like a spear. The wise man calmly explained to them, "All of you are right. The reason every one of you is telling it differently because each one of you touched the different part of the elephant. So, actually the elephant has all those features what you all said."



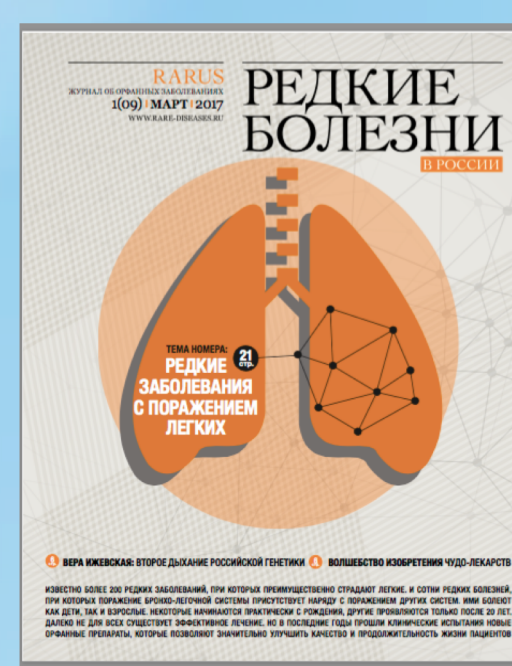
BACKGROUND:

Rare diseases are very diverse in their clinical manifestations, needs, problems faced by patients, doctors, officials and politicians. Like in the parable of the blind men and an elephant different stakeholders see the problem of rare diseases from different sides. And all of them are right.

The main idea of the rare disease magazine - is to unite the interests of all stakeholders on its pages. The main tasks are: help patients find information about their diseases and centers that deal with these conditions and show the problem of rare diseases to doctors, officials, politicians through the eyes of the patient, and the patient - through the eyes of a doctor and an official.

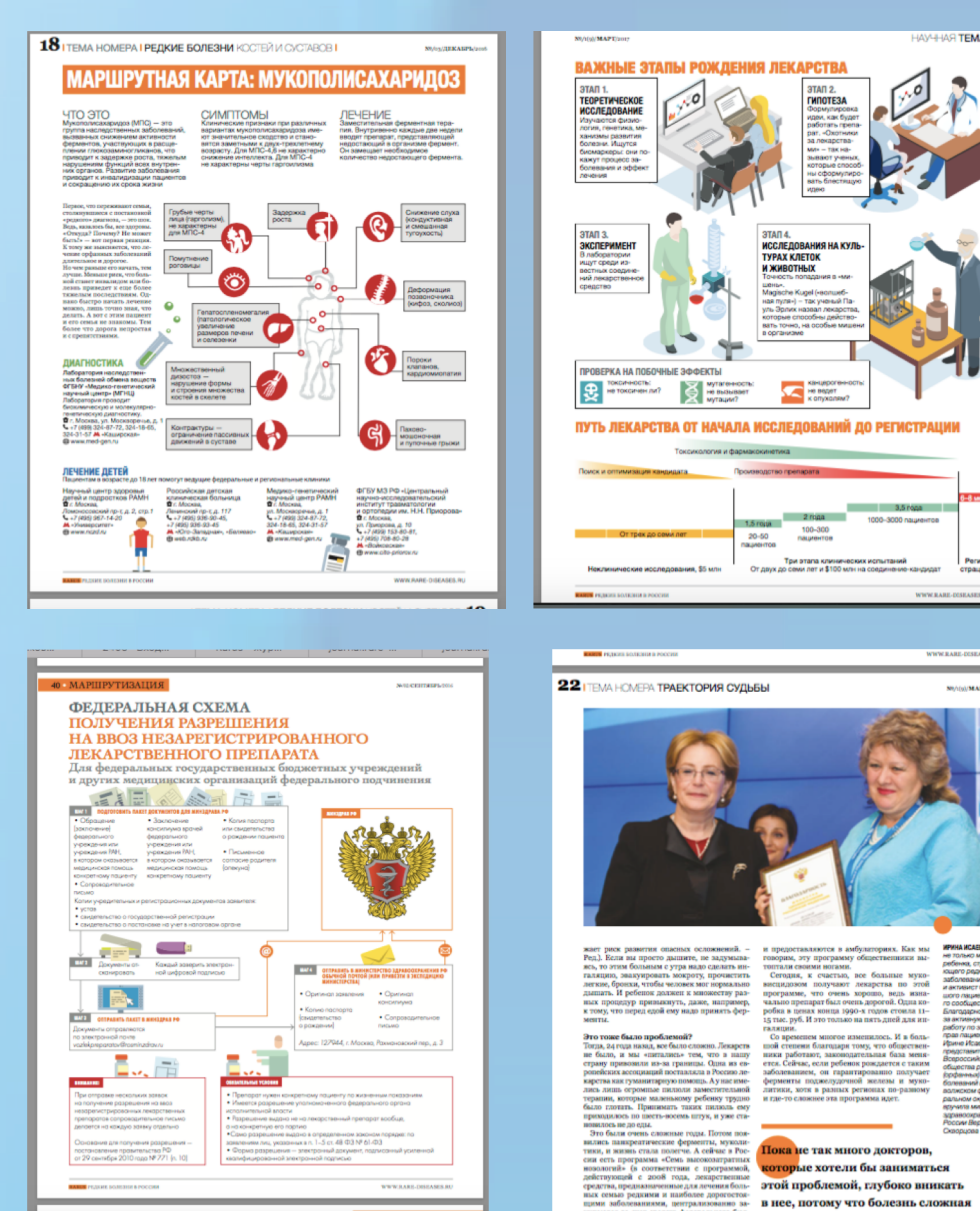
METHODS:

Magazine "RARUS: Rare Diseases in Russia" started in 2012. Russian Association for Rare Diseases (RARD) publishes four issues of the magazine a year. We have different sections in it: news in legislation in Russia and abroad, comments of Russian politicians on the topic of rare diseases, interviews with experts in the field of rare diseases, news from regions, information about some rare diseases, popular scientific articles on various topics, Infographics for patients, step-by-step instructions, patient stories.



RESULTS:

We inform the wide range of public about different aspects of rare diseases in Russia. Thematic issues of the magazine help combine the interests of patients with different rare diseases who are seen by one specialist. RARUS contains information about; specific rare diseases in an accessible form, which is understandable for both the expert and the patients; general topics about legislation in rare diseases; international experience and best practices from the experience of other organizations.



Simple step-by-step instructions with infographics allow one to make information more accessible and visible -not only for patients but also for officials. We develop an infographic to help parents, patients, caregivers and all stakeholders really understand the process of drug development, obtaining disability status, access to social care programs, the process of diagnosis of rare diseases in Russia.

Interviews with leaders in the field of rare diseases set a certain political tone and contribute to the development of understanding of the problem of rare diseases in Russia.

We publish patients stories because these are stories about real life, to which no one can be indifferent.

Doctors can find information about rare diseases and better understand what steps should be taken by patients to get access to treatment.

It is a platform for key stakeholders to speak out their position on rare diseases in Russia.

The magazine is available in electronic form on the website and it is distributed free to patients, to the President office, the Duma (Russian Parliament), the Senate, hospitals, doctor's offices and officials. It is freely disseminated (we send it out, give out during conferences, round table meetings and other events).

CONCLUSIONS:

- It is important to have special magazines on rare diseases for all countries, where one can find information on rare diseases in the country, the peculiarities of legislation and health care organization, social help.
- It is important for networking of all stakeholders
- Infographics is an important tool for explaining complex concepts
- It is important to distribute the special magazines on rare diseases - to all authorities and medical institutions, patients.
- The special magazines on rare diseases should help doctors and officials have to see the problem through the eyes of the patient, and the patients - through the eyes of the doctor and the official.

RARUS: Rare diseases in Russia <http://journal.rare-diseases.ru>

Thematic issues: rare lung diseases, rare muscle diseases, rare disorders of skeleton and etc