



**All-Russian Public Organization  
of Disabled People with  
Multiple Sclerosis  
/All-Russian MS Society**

# There are 130,000 PwMS in Russia

**70%** families break up after one of the spouses is diagnosed

**29%** patients have not left their homes for over a year

**78%** patients are females under 50

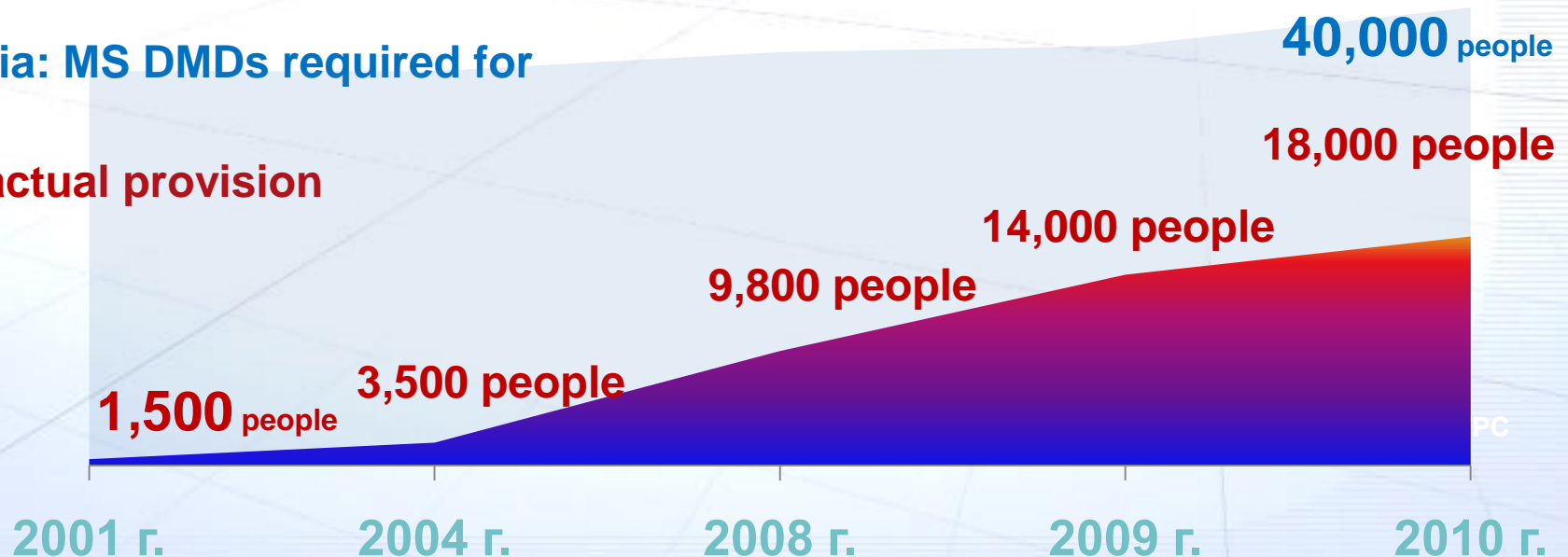
**75%** patients have disabilities

**35%** are young people under 28

**6%** are children aged 10-15

Russia: MS DMDs required for

and actual provision



# Mission

To establish conditions to improve the quality of life of Russian people affected by multiple sclerosis.

# Vision

The All-Russian MS Society is the key public organization among Russian counterparts that represent the interests of people with MS and their family members.

The All-Russian MS Society puts forward, accumulates and guides activities of the general public, government and professional community towards improving the quality of life of people with MS.



# Objectives

1. To improve the quality of medical and social assistance for people affected by MS
2. To ensure the legal safety of people with MS through legislation development and taking measures to control the execution of it with the help of authorities and profile institutions
3. To organize interaction with manufacturing companies in order to promote the production and deliveries of high-effective pharmaceuticals, medical equipment, and rehabilitation facilities
4. To promote training for medical profession in the area of MS
5. To create a positive attitude among general public, raise MS awareness and inform about ways to cope with the problem
6. To activate and consolidate efforts of social partners in fighting MS

# Principles

1. We care for the health and well-being of each person in Russia affected by MS
2. We respect the right of people with multiple sclerosis to make decisions. We do not intervene in the private life of a patient and his/her family without authority
3. We speak out about the real needs of people affected by MS
4. We are a link between the civil society and authorities, between a human and an official. In the capacity of a go-between, we do the monitoring of all social partners' activities with a view to that they meet the norms of human rights
5. We are available to participate in social programmes that contribute to the work of power authorities and social partners in the implementation of rights of people with MS
6. We respect the system of values and the expertise of physicians, business representatives and authority bodies as well as of our other partners
7. We use all possible means to promote healthy lifestyle, make every effort to reveal an example to follow in abiding by social and professional ethical norms
8. We support developments towards improving the quality of medical services and the effectiveness of diagnostic facilities and therapy
9. We contribute to developing the system of healthcare and social medicine

## Preface

- 1992** Establishing the St.-Petersburg public organization 'North-West MS Association'
- 1996** Establishing the Samara regional public organization of disabled people with MS
- 1998** 7 regional public MS organizations activities are at work
- 1999** International MS Conference held in Samara

## Proclamation

- 2001** Congress of representatives of 48 Russian regions proclaimed the All-Russian MS Society
- 2001** The All-Russian MS Society participated in the First All-Russian Civil Forum of NGOs
- 2001** Annual participation in working symposia held by the European MS Platform (EMSP) at the European Union Department for Social Development started
- 2002** Development and incorporation of the first Russian regional target programme to support disabled people with MS in the budget of the Samara oblast

## Expansion into regions

- 2002** Establishing the Polyfunctional Neurocentre for disabled persons with MS in Samara
- 2002** Engaging regional branches in the work of the Public Committees at governors' offices and the health ministries, in the activities of the health committees at the legislative assemblies in 5 regions of the Russian Federation (RF)
- 2003** Development of the discussion and passing of target regional programmes to support disabled people with MS in 12 regions of Russia
- 2003** Conducting investigation of possibilities to adopt Regional Target Programmes to support disabled people with MS in 28 regions of the RF



## Partnership with authorities

- 2003** Permanent cooperation of the All-Russian MS Society with the Healthcare Committee at the State Duma (Parliament) of the Russian Federation launched
- 2004** Conducting the All-Russian Working Conference at the Health Ministry of the RF that tackled issues of medical and social rehabilitation of disabled people with MS
- 2004** Participation in Parliamentary Hearings at the State Duma of the RF, in the forum of the Federation Council, in the meeting of the MS International Federation (MSIF), in Public Hearings on budget development in 13 regions of the RF
- 2005** Engaging in the work of the Committee on healthcare issues at the Public Chamber of the Russian Federation

## Acknowledgment

- 2006** Attracting representatives of the State Duma, the Federation Council, the Public Chamber, the Public Council at the President Administration to the campaign to ensure allocation of funds for the “Programme of 7 nosologies”
- 2006** Signing the agreement on cooperation with the Federal Service on Surveillance in Healthcare and Social Development (RosZdravNadzor). Establishing the Institute of Plenipotentiary Public Experts (PPEs) and the Nursing Service.
- 2008** Entering the EMSP at the European Union Department for Social Development
- 2009** Entering the Multiple Sclerosis International Federation (MSIF)
- 2010** On All-Russian MS Society’s initiative, establishing the All-Russian Patients Union



# Structures

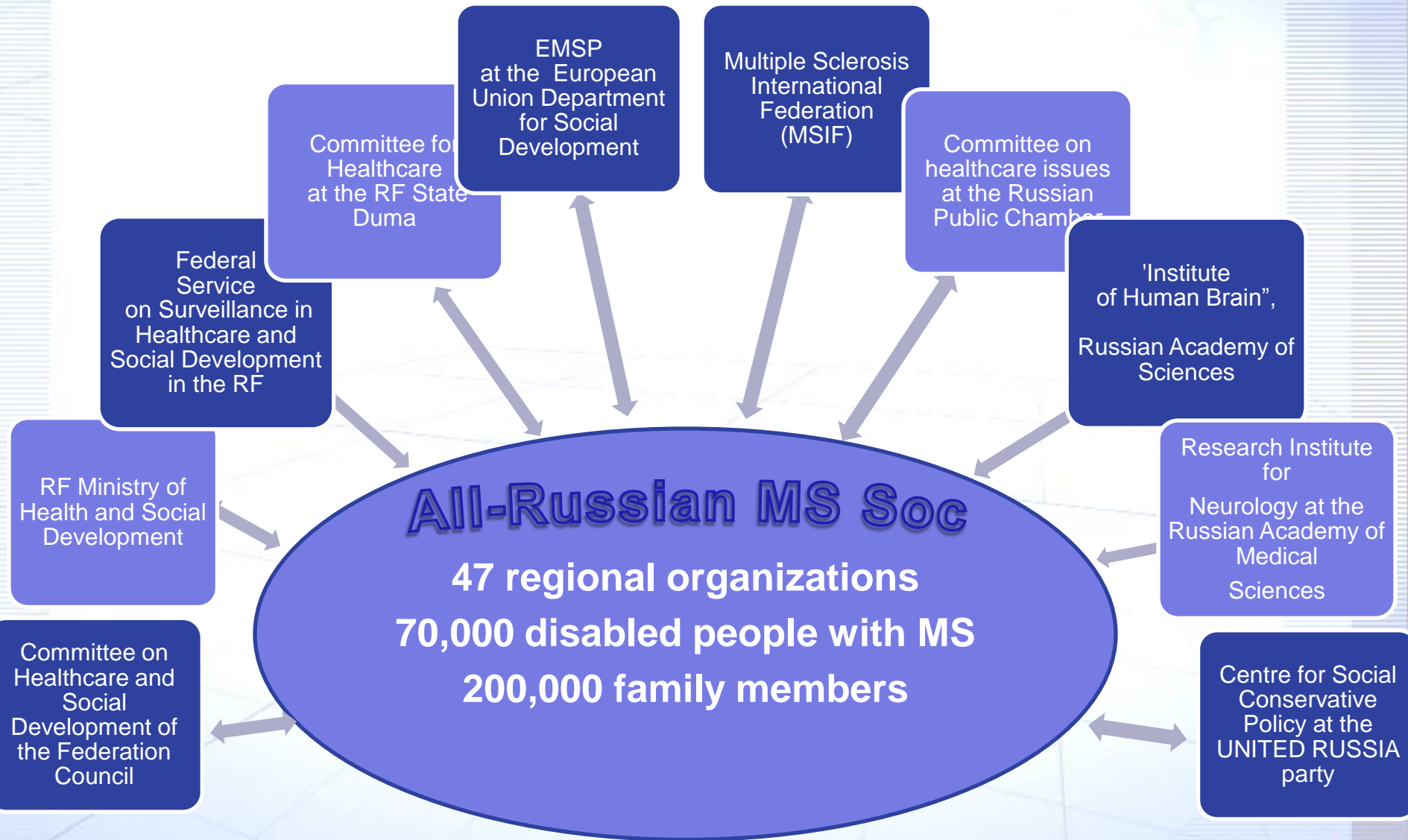




# Collaboration



# Partners



**experience** 350 regional seminars and round-tables  
490 publications in media  
195 public hearings  
44 Applied conferences  
36 grant projects  
23 press-conferences

## **ACHIEVEMENTS**

180 million rubles (5 million euro) was allocated on target regional programmes developed on the initiative of the All-Russian MS Society throughout the RF in 2001-2005.

With the participation of the All-Russian MS Society, the RF Government and State Duma have allocated 99 billion rubles (2.8 billion euro) to treat patients with chronic disabling diseases for the period of 2008-2010.

In 2010, Plenipotentiary Public Experts (PPEs) delegated by the All-Russian MS Society take part in developing regional lists of people with MS and controlling the federal budget financing of the pharmaceutical provision in 75 regions. Nurses work in 55 regions of the RF.



# Grants

1. Co-management of people affected by multiple sclerosis. Involvement of those in social and vocational activities. Management of leisure activities, mutual assistance, employment, making communicative environment, support for the families of people with MS.
2. Assistance in improving the quality of medical and social support.
3. Ensuring advocacy activities for people with MS through legislation development and taking measures to control the execution of it.
4. Contribution to training and retraining of staff on MS issues.
5. Creation of a positive attitude among general public, raising MS awareness and informing about ways to cope with the problem.
6. Activation and consolidation of efforts of social partners in fighting MS.
7. Development in the Third Sector and social participation. Distribution of effective models for NGO activities.

# Grants

## **The Second Eastern European Conference of disabled people with MS from Eastern Europe states.**

Open Society Institute – Samara MS soc..  
USD 60,000.00, Samara, 1998.

A conference with participants from 17 European states, held in Samara, Russia.

## **‘Intrafamilial rehabilitation management for disabled people’.**

USAID – Samara MS Soc..  
USD 20,000.00, Samara, 2000.

Launch of a standing model of working with the families of disabled people.

## **‘Seek health in the saddle. Rehabilitation for disabled people though horse-riding’.**

Ulyanovsk region authority – Ulyanovsk MS society.  
150,000.00 (€4,000.00), Ulyanovsk, 2006.

Material and technical facilities to rehabilitate disabled people with hippotherapy established.

## **‘Setting up the system of public inspection and medical nursing in the Russian Federation’.**

Foundation of Public European Policy, FPEP  
€357,856.00 , Russia, 2007.

Creating the system of GR influence on authorities’ decision-making.

## **‘Public monitoring to control the provision of high-priced pharmaceuticals as a model to present public interests in the area of healthcare and social policy’.**

The Dialogue Programme, IREX, USAID – All-Russian MS Society, Alliance.  
4,700,000.00 rubles (€123,000.00), Russia, 2009.

The Plenipotentiary Public Institute got support.  
The ‘7 Nosologies’ Programme defended and prolonged through 2010.

