

Program
2nd ALL-RUSSIAN PATIENTS CONGRESS
(2-6 November, 2011, Samara, Russia)

DRAFT

Major Events:

- 2nd All-Russian Patients Congress (3 November)
- Interview of Tatiana Golikova, Minister for Healthcare and Social Development in the Russian Federation, with representatives of patient organizations and media (3 November)
- 3rd All-Russian Congress of the All-Russian Public Organization of Disabled People with Multiple Sclerosis (PwMS RPO - All-Russian Multiple Sclerosis Society) (4th November)
- 1st All-Russian civil conference of patients with orphan diseases (4-5 November)
- All-Russian Scientific and Practical Conference of neurologists ‘Multiple Sclerosis: A Ten-Year Partnership to Serve Patients’ (5-6 November)
- Exhibition ‘We’ll help!’ (3-6 November)

Wednesday, 2nd November 2011

15.00 - ...	Arrival of delegates in Hotel Holiday Inn Samara
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Thursday, 3rd November 2011. Day One

2nd ALL-RUSSIAN PATIENTS CONGRESS

08.00 – 09.30	Breakfast
08.00 — 09.00	<i>Large Banquet Hall</i> Registration of participants of the 2nd All-Russian Patients Congress
09.30 – 10.00	<i>Exhibition Hall (floor 2)</i> Opening of the exhibition ‘ We’ll help!’
9.30 – 11.30	<i>Large Banquet Hall</i> Opening of the 2nd All-Russian Patients Congress <i>Moderator: Yan V. Vlasov</i> - Welcome. <i>The Samara region Administration</i> - Welcome. <i>T.A.Golikova, Minister, Russian Healthcare and Social Development Ministry (HSDM)</i> - Welcome. <i>A.V.Bednova, Deputy, Russian Federation (RF) State Duma (Parliament)</i> - Welcome. <i>G.P.Kotelnikov, Rector, Samara State Medical University</i> - Welcome. <i>G.N.Gridasov, Minister, Samara region Healthcare and Social Development Ministry (HSDM)</i> - Arrangements for rehabilitation of disabled people in Russia: Problems, ways to resolve issues, prospects. <i>S.V.Bondarev, Head of the Agency for state inspection of the quality of rendering social assistance to populations at the Service on Surveillance on Healthcare and Social Development (ROSZDRAVNADZOR) in the RF</i> - Results of the inspection of the pharmaceuticals provision for several groups of citizens and of the upgrading of the healthcare in RF constituent territories. <i>G.A.Petrochenkova, Head, Federal Service on surveillance in healthcare and social development of the RF</i> - About the Role of patients’ societies in the healthcare of Russian citizens. <i>Yan V. Vlasov, co-chair, All-Russian Patients Union</i> - About activities of the Council for advocating rights of patients at the Russian HSDM in 2011. <i>Yuri A. Zhulev, Deputy Chair, Council for advocating rights of patients at the Russian HSDM</i> - ‘Role and significance of the Declaration of Patients’ Rights and the Patients’ Code of Ethics’, <i>A.V.Saverskiy, Chairman, League for advocating patients</i>
11.30 – 12.00	Break at coffee table

12.00 – 14.00	<p style="text-align: right;"><i>Large Banquet Hall</i></p> <p>The 2nd All-Russian Patients Congress continued Interview of Tatiana Golikova, Minister for Healthcare and Social Development in the Russian Federation, with representatives of patient organizations and media</p> <ul style="list-style-type: none"> - Key-note address. <i>T.A.Golikova, Minister, HSDM</i> - <i>T.A.Golikova answers questions of the Congress participants and attendees</i>
14.00 – 14.45	Lunch: Group 1
15.00 – 15.40	Lunch: Group 2
15.40 – 17.00	<p style="text-align: right;"><i>Large Banquet Hall</i></p> <p>The 2nd All-Russian Patients Congress continued <i>Moderator: Yuri Zhulev</i></p> <p>Statements:</p> <ul style="list-style-type: none"> - ‘Experience of effective advocacy for Russian citizens’ rights – wheelchair users in the Samara region’, <i>Ye.A.Pecherskiy</i> - ‘Problems of onco-hematologic patients in the RF and the patient community involvement in resolving them’, <i>L.F.Matveeva</i> - ‘Experience of citizens’ self-realization in advocating for their constitutional rights with examples of regional patients’ communities’, <i>M.A.Kurapov</i> - ‘Orphan diseases in Russia and ways to resolve issues of patients with orphan diseases’, <i>I.V.Myasnikova</i> - ‘Activities of regional resource centres for NGOs as an important component to develop the civil society in regions’, <i>V.P.Pestrikova</i> - ‘Features in interaction between regional authorities and patient community’, <i>Ye.V.Ustinova</i> - ‘Problems of oncologic patients in regions as the core of the problem of oncologic vulnerability in the RF’, <i>N.P.Dronov</i> <p>Launch of the target list with problems of Congress attendees to submit to the Russian President and Government</p>
17.00 – 17.10	Coffee break
17.10 – 18.30	<p style="text-align: right;"><i>Large Banquet Hall</i></p> <p>The 2nd All-Russian Patients Congress continued <i>Moderator: A.V.Saverskiy</i></p> <ul style="list-style-type: none"> - ‘Institute of the Human Rights Commissioner in the RF and its role in advocating patients’ rights in the example of the Samara region’, <i>I. A.Skupova</i> - ‘Patients’ rights in the system of entitlements for pharmaceutical provision, the future of entitlements for pharmaceutical provision for Russian citizens’, <i>Yu.A.Zhulev</i> - ‘Role of internet technologies in developing the patient community’, <i>O.Yu.Ipatov</i> - ‘Possibilities of Municipal establishments in rendering support to patients residing in the urban area’, <i>P.V.Suchkov</i> - ‘Problems of patients with diabetes in Russia and ways to solve them’, <i>V.A.Peterkova</i> - ‘Arrangement of Negotiation fields for the patient community and authorities of the federal level’, <i>Yan V.Vlasov</i> - ‘Experience of litigation office management to advocate patients rights’, <i>Ye.V.Dokhnova</i> - ‘Ways to optimize the receiving of high-tech medical assistance by citizens of the RF’, <i>Ye.V.Sorokina</i> - ‘Actual problems of the patient community from the viewpoint of ‘the League for advocating patients’, <i>A.V.Saverskiy</i> <p>Close of the target list with problems of Congress attendees to submit to the Russian President and Government Summing-up of the work during Day One of the 2nd All-Russian Patients’ Congress Passing a resolution of paramount problems of the patient community.</p>
18.30 – 19.30	Break at coffee table
20.00	Gala dinner

Friday, 4th November. Day Two.

3rd ALL-RUSSIAN CONGRESS OF THE ALL-RUSSIAN PUBLIC ORGANISATION OF DISABLED PEOPLE WITH MULTIPLE SCLEROSIS (All-Russian MS Society)

1st ALL-RUSSIAN CIVIL CONFERENCE OF PATIENTS WITH ORPHAN DISEASES

08.00 – 09.00	Breakfast	
09.00 – 18.00	Exhibition ‘We’ll help!’ in progress	
9.00 – 9.30	Registration of delegates to 3rd PwMS RPO Congress	Registration of participants of the 1st All-Russian Civil conference of patients with orphan diseases
08.00 – 12.00	Departure of participants of the 2nd Congress of the All-Russian Patients’ Union	
9.30 - 11.30	<p><i>Large Banquet Hall</i> 3rd Congress of the PwMS RPO</p> <p>Opening of the 3rd Congress of the PwMS RPO Report on activities over 2006-2011 of the President of the Organization Reports on activities of members of the President Council</p>	<p><i>Samara Hall</i> 1st All-Russian Civil conference of patients with orphan diseases</p> <p><i>Chairmen: I.V.Myasnikova, Yu.A.Zhulev, A.N.Semyachkina, G.N.Salogub</i></p> <p><i>09.30– 10.30 Workshop 1. Orphan diseases in Russia.</i></p> <ul style="list-style-type: none"> - ‘Patients’ Union and rare diseases group – major trends to work on’, <i>I.V.Myasikova</i> - ‘Legal status of rare diseases in the Russian Federation’, <i>Yu.A.Zhulev</i> - ‘Advocating of patients: the EU experience’, Any Helm - ‘Problems with ethics in the area of rare diseases’, <i>V.L.Izhevskaya</i> <p>10.30-10.45 Break</p> <p>10.45-11.30 Workshop 2. High-tech pharmaceuticals to treat rare diseases</p> <ul style="list-style-type: none"> - ‘Differential diagnosing of mucopolysaccharidoses, therapies for the disease of group 1 so far’, <i>A.N.Semyachkina</i> - ‘Gocher’s disease: Diagnosing and treatment’, <i>G.N.Salogub</i> - ‘Pompe's disease in children’, <i>L.M.Kuzenkova</i> - ‘Type 6 mucopolysaccharidosis’, <i>V.I.Larionova</i> - ‘Type 2 mucopolysaccharidosis. Treatment practice in Russia’, <i>L.M.Kuzenkova, T.V.Podkletnova</i>
11.30 - 12.00	Break at coffee table	
12.00 - 13.30	<p><i>Large Banquet Hall</i> 3rd Congress of the PwMS RPO</p> <p>Informational and strategic report on ‘Coherence to treatment for chronic diseases and the patient-doctor relationship’ by <i>A.N.Boiko</i>. Reports on activities of members of the President Council. Continuation.</p>	<p><i>Samara Hall</i> 1st All-Russian civil conference of patients with orphan diseases</p> <p>Workshop 3. Health food in hereditary diseases</p> <ul style="list-style-type: none"> - ‘Pharmaceuticals for rare diseases: from research development to practice’, <i>G.A.Maglov</i> - ‘Neurometabolic diseases in children: diagnosing and treatment’, <i>S.V.Mikhailova</i> - ‘Type 1 hypertyrosinemia’, <i>S.I.Polyakova</i> - ‘X-linked adrenoleukodystrophy’, <i>S.V.Mikhailova</i> - ‘Innovative technology in treating mucoviscidosis’, <i>A.V.Orlov</i> <p><i>Chairmen: S.V.Mikhailova, S.I.Polyakova, M.V.Botalina</i></p>
13.30 - 14.20	Lunch: Group 1	
14.40 - 15.30	Lunch: Group 2	

15.00 – 20.00	Arrival of participants of the All-Russian scientific and practical conference: ‘Multiple Sclerosis: A Ten-Year Partnership to Serve Patients’	
15.30 - 17.45	<p><i>Large Banquet Hall</i></p> <p>3rd Congress of the PwMS RPO</p> <p>Report of the PwMS RPO Board of Directors on the Organization activities over 2006-2011.: Statements by partner organizations.</p>	<p><i>Samara Hall</i></p> <p>1st All-Russian civil conference of patients with orphan diseases</p> <p>Workshop 4. Current methods to treat rare diseases manifesting in adults <i>Chairmen: N.A.Tsareva, A.L.Zubarev, Ye.Yu.Zakharova</i></p> <ul style="list-style-type: none"> - ‘Current approaches to diagnosing and treating pulmonary arterial hypertension’, <i>N.A.Tsareva</i> - ‘Hereditary diseases of metabolism in adults’, <i>Ye.Yu.Zakharova</i> <p>16.15 – 17.15 Satellite symposium of the company ‘Yansen’</p> <ul style="list-style-type: none"> - ‘Essential thrombocytosis’, <i>G.N.Salogub</i> - ‘New methods to treat sarcoma’, <i>A.L.Zubarev</i> <p><i>Discussion.</i> ‘Organizational constructs of NGOs with the example of the all-Russian movement to assist citizens with an orphan pathology’ (Ye.Yu.Zakharova, M.V.Churakov)</p>
17.45 - 18.00	Break at coffee table	
18.00 - 19.30	<p><i>Large Banquet Hall</i></p> <p>3rd Congress of the PwMS RPO</p> <p>Debate Close of the 3rd Congress of the PwMS RPO.</p>	<p><i>Samara Hall</i></p> <p>1st All-Russian civil conference of patients with orphan diseases</p> <p><i>School for NGO</i> <i>Moderator: Yu.A.Zhulev</i></p> <ul style="list-style-type: none"> - ‘Work with authorities’, <i>M.V.Churakov</i> - ‘Patient community under the conditions of changes in the legislation’, <i>A.V.Saversky</i>
20.00	Gala dinner	

Saturday, 5 November 2011. Day Three.

ALL-RUSSIAN SCIENTIFIC AND PRACTICAL CONFERENCE: ‘MULTIPLE SCLEROSIS: A TEN-YEAR PARTNERSHIP TO SERVE PATIENTS’

1st ALL-RUSSIAN CIVIL CONFERENCE OF PATIENTS WITH ORPHAN DISEASES

08.00 – 09.00	Breakfast	
09.00 – 18.00	Exhibition ‘We’ll help!’ in progress	
9.00 – 10.00	<i>Large Banquet Hall</i> Registration of participants of the All-Russian scientific and practical conference	
10.00 — 11.30	<i>Large Banquet Hall</i> All-Russian scientific and practical conference: ‘Multiple Sclerosis: A ten-year partnership to serve patients’ Plenary session I Opening remarks by <i>a representative of the Samara region administration</i> . - ‘Multiple Sclerosis: A ten-year partnership to serve patients’, <i>Yan V.Vlasov (Samara)</i> - ‘Current understanding of multiple sclerosis etiology’, <i>A.N.Boiko (Moscow)</i> - ‘Current opportunities for neurovisualisation and treatment of multiple sclerosis’, <i>I.D.Stolyarov, A.M.Petrov, I.G.Nikiforova (Saint-Petersburg)</i> - ‘Multiple sclerosis and pregnancy’, <i>N.A.Malkova, L.A.Babenko (Novosibirsk)</i> - ‘State of the gastrointestinal tract in MS patients and therapy for its disorders’, <i>N.N.Spirin, D.VKiselev (Yaroslavl)</i> - ‘Condition of the cardiovascular system in MS’, <i>N.Yu.Lash, T.K.Djalilova, A.N.Boiko, Ye.I.Gusev (Moscow)</i> - ‘10 year activities of the Samara Centre for diagnosing and treating Multiple Sclerosis’, <i>S.V.Tarasova, T.A.Dolgikh (Samara)</i> <i>Chairmen:</i> <i>A.N.Boiko, Yan V.Vlasov, I.D.Stolyarov, N.A.Malkova</i>	<i>Samara Hall</i> 1st All-Russian civil conference of patients with orphan diseases (Plenary session) - Law ‘About basics of healthcare of citizens of the Russian Federation’, new promises to treat orphan diseases in Russia, <i>Yu.A.Zhulev, co-chair of the All-Russian Patients’ Union</i> - ‘European voluntary organizations of patients with rare diseases to advocate rights of patients in the European Union’, <i>François Houyez. EURORDIS</i> - ‘Practice of interaction between Russian voluntary organizations of patients with rare diseases and international organizations’, <i>I.V.Myasnikova</i> - ‘Rare Diseases Eastern-European Federation as an example of proactive attitudes of the Civil society’, <i>T.Matulka</i> - ‘Rare diseases in the world and in the Russian Federation’, <i>P.V.Novikov, Ye.Yu.Zakharova</i> - ‘Perspectives of the civil society development in the area of advocating rights of citizens who suffer from orphan diseases’, <i>A.V.Saverskiy</i> <i>Chairmen:</i> <i>Yu.A.Zhulev, I.V.Myasnikova, François Houyez, S.A.Mitina</i>
11.30 — 12.00	Break at coffee table	
12.00 — 13.30	<i>Large Banquet Hall</i> All-Russian scientific and practical conference: ‘Multiple Sclerosis: A ten-year partnership to serve patients’ Plenary session II - ‘Clinical research in multiple sclerosis, Quo prodit?’, <i>E.Z.Yakupov (Kazan)</i> - ‘Possibilities for diagnostics and treatment of a neurodegenerative process in multiple sclerosis’, <i>M.F.Davydovskaya, A.N.Boiko, Ye.I.Gusev (Moscow)</i> - ‘Disorders of the neurotrophic control in MS’, <i>F.A.Khabirov, T.I.Khaibullin (Kazan)</i> - ‘Rehabilitation techniques for MS patients used at the rehabilitation centre BEREZA in the Samara region’, <i>I.Ye.Poverennova, A.V.Zakharov (Samara)</i>	<i>Samara Hall</i> 1st All-Russian civil conference of patients with orphan diseases Workshop 5. Advocating rights of patients with orphan diseases. - ‘Results after the work of the working group on rare diseases at the Council for advocating patients rights at the HSDM of the RF’, <i>S.A.Mitina</i> - ‘Palliative care for patients with amyotrophic lateral sclerosis’, <i>L.V.Brylev</i> - ‘Palliative care for patients with rare diseases’, <i>A.A.Sonkina</i> - ‘Resolving problems of high-tech medical assistance for patients with rare diseases’, <i>Ye.A.Sorokina</i>

	<p>- ‘Pathology of the thyroid gland in MS and influence on its function of a pathogenetic immunomodulating therapy’, <i>L.V.Petrova, Ye.V.Kostenko, A.N.Boiko (Moscow)</i></p> <p>- ‘Pending issues in the system of providing quality medical assistance’, <i>N.G.Petrova (Saint-Petersburg)</i></p> <p><i>Chairmen:</i> <i>N.N.Spirin, E.Z.Yakupov, F.A.Khabirov, N.G.Petrova</i></p>		<p>- ‘Role of public establishments of patients in updating the healthcare legislation’, <i>N.P.Dronov</i></p> <p>- ‘Arranging for palliative care for children with rare diseases: International and \Russian practices’, <i>M.A.Byalik</i></p> <p>Debate.</p> <p><i>Chairmen:</i> <i>A.V.Saverskiy, Yan V.Vlasov, M.D.Terekhova</i></p>
13.30 — 14.20	Lunch: Group 1		
14.40 — 15.30	Lunch: Group 2		
15.30 — 16.30	<p><i>Auditorium 3</i></p> <p>All-Russian conference: ‘Multiple Sclerosis: A ten-year partnership to serve patients’</p> <p>Workshop 1. Satellite symposium of the pharmaceutical company ‘Teva’</p>	<p><i>Auditorium 4</i></p> <p>All-Russian conference: ‘Multiple Sclerosis: A ten-year partnership to serve patients’</p> <p>Workshop 2. ‘Differential \diagnosing for MS ’, <i>professor N.N.Spirin</i></p>	<p><i>Samara Hall</i></p> <p>1st All-Russian civil conference of patients with orphan diseases</p> <p>Workshop VI. NGO contribution to resolve issues of patents with orphan diseases</p> <p>- Experience of interaction between organizations of patients with rare diseases and legislative and executive authorities, <i>M.D.Terekhova</i></p> <p>- ‘Interdisciplinary and interdepartmental approaches to resolve issues of people with rare genetic diseases in Russia and abroad (by the example of Rett syndrom)’, <i>O.V.Timutsa</i></p> <p>- Charity in rare diseases, <i>P.Ye.Filippova (British charity foundation CAF)</i></p> <p>- Internet resources for people with rare diseases, <i>A.A.Bocharov</i></p> <p>- Comprehensive approach to effectively tackle issues of orphan diseases, <i>Ye.Yu.Zakharova</i></p> <p>Debate.</p> <p><i>Chairmen:</i> <i>I.V.Myasnikova, Yu.A.Zhulev, Ye.Yu.Zakharova</i></p>
16.30 — 17.30	<p><i>Auditorium 3</i></p> <p>Workshop 3. Satellite symposium of the pharmaceutical company ‘Biotech’</p>	<p><i>Auditorium 4</i></p> <p>Workshop 4. ‘MS in children’, <i>O.V.Bykova, I.A.Nankina, T.T.Batysheva</i></p>	
17.30 — 17.50	Break at coffee table		
17.50 — 18.50	<p><i>Auditorium 3</i></p> <p>All-Russian conference: ‘Multiple Sclerosis: A ten-year partnership to serve patients’</p> <p>Workshop 5 Satellite symposium of the pharmaceutical company ‘Genfa’</p>	<p><i>Auditorium 4</i></p> <p>All-Russian conference: ‘Multiple Sclerosis: A ten-year partnership to serve patients’</p> <p>Workshop 6. Nursing service at the PwMS RPO’, <i>M.V.Mikheeva, N.I.Kuznetsova</i></p>	<p><i>Samara Hall</i></p> <p>1st All-Russian civil conference of patients with orphan diseases</p> <p>Conference close Summing-up of the Civil Conference on orphan diseases issues in Russia. Passing the Decree of the Civil Conference. Conference Close.</p>
20.00	Gala dinner		

Sunday, 6 November 2011. Day Four.

ALL-RUSSIAN SCIENTIFIC AND PRACTICAL CONFERENCE: ‘MULTIPLE SCLEROSIS: A TEN-YEAR PARTNERSHIP TO SERVE PATIENTS’

08.00 – 09.00	Breakfast
08.00 - 12.00	Participants leave hotel rooms
09.00– 10.30	<p><i>Auditorium 1</i></p> <p>All-Russian scientific and practical conference: ‘Multiple Sclerosis: A ten-year partnership to serve patients’</p> <p>Plenary session III</p> <ul style="list-style-type: none"> - ‘Immunological “problems” of diagnosing and the current therapy for multiple sclerosis’, <i>A.M.Petrov, M.V.Votintseva, Ye.V.Ivashkova, I.D.Stolyarov (Saint-Petersburg)</i> - ‘Improving possibilities for symptomatic MS treatment’, <i>T.Ye.Schmidt (Moscow)</i> - ‘Clinical and genetic aspects of tailored therapy for multiple sclerosis’, <i>V.M.Alferova (Tomsk)</i> - ‘Expertise for an intractable loss of working ability in multiple sclerosis’, <i>K.Z.Bakhtiyarov, R.V.Magzhanov, Z.B.Gumerova (Ufa)</i> - ‘Syndrome of pathological fatigue in MS: medicamental and non-medicamental strategies of therapy’, <i>D.S.Kasatkin, N.N.Spirin (Yaroslavl)</i> - ‘Results of the research on the quality of life of people with multiple sclerosis in the Samara region’, <i>A.M.Milovanova (Samara)</i> <p><i>Chairmen: A.N.Boiko, Yan V.Vlasov, K.Z.Bakhtiyarova, N.N.Spirin</i></p>
10.30 — 11.00	Break at coffee table
11.00 – 12.30	<p><i>Auditorium 1</i></p> <p>Plenary session IV</p> <ul style="list-style-type: none"> - ‘Comprehensive approach to rehabilitation of people with multiple sclerosis’, <i>F.A.Khabirov, T.I.Khaibullin, N.I.Babicheva (Kazan)</i> - ‘Non-medicamental methods to rehabilitate people with multiple sclerosis’, <i>Yu.V.Klimova, N.F.Popova</i> - ‘Neurovisualised assessment for the restoration of mobility disorders in relapsing-remitting MS’, <i>S.N.Kulikova, V.V.Bryukhov, M.V.Krotenkova, A.N.Peresedova, I.A.Zavalishin</i> - ‘Multiple Sclerosis: Medical literacy of patients and level of training among physicians’, <i>S.V.Kotov</i> - ‘Internet communications in the adaptation of patients with MS in daily life’, <i>O.Yu.Ipatov (Samara)</i> <p><i>Chairmen: T.Ye.Schmidt, I.Ye.Poverennova, V.M.Alferova, S.V.Kotov</i></p>
12.30 — 12.45	Break at coffee table
12.45— 14.00	<p><i>Auditorium 1</i></p> <p>Plenary session V</p> <p>ROCTRIMS session</p> <p>Event close</p> <p>Summing-up of the event</p> <p>Statements by representatives of the medical, patient and scientific communities</p> <p>Outlining major trends for ongoing development of the system to render medical and social assistance to patients with multiple sclerosis</p> <p><i>Chairmen: A.N.Boiko, Yan V.Vlasov, I.Ye.Poverennova, I.D.Stolyarov</i></p>
14.00 – 16.00	Lunch