

Skyline House 3rd Floor 200 Union Street London SE1 0LX United Kingdom

Tel +44(0) 20 7620 1911 Fax +44(0) 20 7620 1922

www.msif.org info@msif.org

1 December 2009

### Dear Sir/Madam

I am pleased to confirm that during the Multiple Sclerosis International Federation's (MSIF) Board Meeting, held on 2 November 2009 in Chicago, USA, the All-Russian Public Organization of Disabled People with MS (Общероссийская Общественная Организация Инвалидов -Больных Рассеянным Склерозом) was accepted as an MSIF Associate Member.

The All-Russian Public Organization of Disabled People with Multiple Sclerosis, the legally registered address for which is Russia, 123308, Moscow, Zorge Street, 6, bldg 137, was established in 2001. The Organization, through its extensive branch network, reaches out to approximately 85% of the multiple sclerosis (MS) population in the country, serving some 70,000 people with MS, their family members, caregivers and health professionals.

The Organization faces many challenges such as lack of public awareness of the disease; yet its activities underline its commitment to supporting the development of the provision of services and support to people affected by MS in Russia.

The Plenipotentiary Public Expert (PPE) Programme, certified by the Russian Ministry of Health, highlights this commitment. The Programme began in 2006 with the aim of increasing the Organization's access to decision-makers and funding bodies at the regional and district levels. In 2007, the Institute of Plenipotentiary Public Experts was established at the Federal Service on Surveillance in Healthcare and Social Development in the Russian Federation. Through the Institute, 72 PPEs now receive training and guidance in areas such as budget management and lobbying. In 54 districts part of the PPEs' role is to develop and implement regional lists of pwMS entitled to federal support for the cost of treatment.

The Organization has worked with the Samara-based Centre for Social Mechanics and international organisations, such as the US Agency for International Development, in putting together training materials for regional/district-level organisations with information on, for example, how to complete grant applications and how to approach decision-making bodies. By providing these tools, the Organization hopes that the regions/districts will become more self-sufficient. Such tools are used to train regional and district PPEs. In 2008 the Far Eastern, Siberian and

#### Presidents Emeriti

Peter W. Schmidt (USA) Peter A. Schweitzer (USA) James D. Wolfensohn (USA)

# President and Chairman

Sarah Phillips OBE, DL (UK)

#### Treasurer

Robert Hubbard (Australia)

#### Secretary

Weyman T Johnson (USA)

### Founder

Svlvia Lawry (USA)

### **Board Members**

Mario Battaglia (Italy) Pedro Carrascal (Spain) Frits Deiters (Netherlands) Siobhan Gilmour (UK) Ali Hijjawi (Palestinian Authority) Ed Kangas (USA) Peter Kauffeldt (Denmark) Louis Maroun (Canada) Antonella Moretti (Italy) Joyce Nelson (USA) Allen O'Connor (Ireland) Dorothea Pitschnau-Michel (Germany) Chris Polman (Netherlands) Kanya Puspokusumo (Indonesia) Dorinda Roos (Netherlands) Yves Savoie (Canada) Alan Thompson (UK) Steve Umin (USA) Charles van der Straten Waillet (Belgium)

## Honorary Life Board Members

Leon Cligman (France) Alistair M Fraser (Canada) Robin Inchyra (UK) Jürg Kesselring (Switzerland) David L Torrey (Canada)

### Chief Executive

MSIF is an NGO in official relations with the World Health Organization (WHO) Registered Charity 1105321

Urals' PPEs were trained using these tools and in 2009 three-day training courses for PPEs in the Central, North Western, Volga and Southern regions were held.

The Organization is currently working to expand and develop an MS rehabilitation centre network; to ensure that treatment for people with MS is legally regulated and available, at a low cost, to all; to establish a national MS register and ensure all modes of public transport and buildings are accessible. In order to increase government engagement and affect change throughout the country, it is essential that the Organization has the support of the relevant decision makers and funding bodies.

MSIF fully endorses the work of the Organization and would greatly appreciate any support you may be able to extend to President Jan Vlasov; the Director, Dr Alla Grigoryevna Beltyukova and Mr Pavel Zlobin, Vice-President, International Affairs.

Yours sincerely

Peer Baneke Chief Executive