

# NATIONAL HIGH LEVEL ROUNDTABLE ROMANIA

**Claudia Torje**  
Executive director  
Romanian MS Society

EMSP Winter Conference, 26–27 November 2010

Better access to MS therapies & care in Central and Eastern European countries – strategies for tangible improvement

## Organisation of the national roundtable

---

- ✓ The roundtable was organised by the Romanian Multiple Sclerosis Society and the European Multiple Sclerosis Platform on **13<sup>th</sup> March 2009**;
- ✓ I started organizing the roundtable in **January 2009** when the invitations were sent to the authorities, doctors, members of our society organizations and other major players;
- ✓ To organize the roundtable we have received **support from the EMSP** (of which were covered most of the cost) and the **pharmaceutical companies**;
- ✓ The event was attended by around 40 people.

EMSP Winter Conference, 26–27 November 2010

Better access to MS therapies & care in Central and Eastern European countries – strategies for tangible improvement

Participants of the roundtable :

- ✓ Two representants of the *Minister of Health*;
- ✓ Doctors from wellknown clinics of Romania;
- ✓ Representants of the National Agency for Employment;
- ✓ The Secretary General of EMSP, Mr. Christoph Thalheim;
- ✓ Members of the Romanian Multiple Sclerosis Society board;
- ✓ Members of the executive board;
- ✓ Patients with multiple sclerosis from the member organisations.

EMSP Winter Conference, 26–27 November 2010

Better access to MS therapies & care in Central and Eastern European countries – strategies for tangible improvement



## Message of the national roundtable

---

The main theme of the roundtable was the **results of the European Multiple Sclerosis Barometer**, being presented and discussed by the representants of the governmental organisations, medicine specialists and patients representants.

The main subjects were: Acces to treatment ant therapy; Research in MS; Employment; Empowerment of MS Patients; Costs reimbursement; Exact colection of data; New medicine on the pharmacy market.

EMSP Winter Conference, 26–27 November 2010

Better access to MS therapies & care in Central and Eastern European countries – strategies for tangible improvement

The message focused on the reasons for the **existing inequalities in access to DMDs and rehabilitation**, and the way this relates to EU public health priorities and health competence at EU level, including accessibility and health equity.

We understood the major impact that this will bring to our advocacy initiatives at national level.

Romania was identified as a country in which the quality of services received by people with MS was very low (according to the European MS Barometer). There were made specific recommendations regarding the improvement of the Romanian situation as it appears in the European Barometer.

EMSP Winter Conference, 26–27 November 2010

Better access to MS therapies & care in Central and Eastern European countries – strategies for tangible improvement

The event had the general objective to **find viable and sustainable solutions for raising the level of multiple sclerosis patients quality of life.**

We planned:

- To create a **National Register for multiple sclerosis**, that aims to raise the quality of life and offer more efficient services to the people affected by MS in the country.
- **The facilitation of the patient's National Programme introduction**, that will lower the direct costs.

EMSP Winter Conference, 26–27 November 2010

Better access to MS therapies & care in Central and Eastern European countries – strategies for tangible improvement



- The **implementation of the MS Code of Good Practice in Romania**

through the development of a strategic plan that represents the patients welfare, and which was discussed with the representants of the Minister of Public Healthcare.

- The **need of specialized recovery centers** for MS that has been identified by specialists as being a way to improve the MS patients' quality of life.

EMSP Winter Conference, 26–27 November 2010

Better access to MS therapies & care in Central and Eastern European countries – strategies for tangible improvement

## What we have done so far?

- Talks to achieve a national registry for people with MS have continued and we hope to materialize in the shortest time;
- This year have increased the number of places in the immunomodulatory treatment program;
- Patients in Romania have access to specific treatments, which are available in other European countries;

EMSP Winter Conference, 26–27 November 2010

Better access to MS therapies & care in Central and Eastern European countries – strategies for tangible improvement



- I initiated a **sectoral strategy for people with MS** that we will submit to the Ministry of Labour;
- I developed a **project financed by European structural funds**, aimed at employment of at least 70 people with MS, the change of legislation on employment of persons with disabilities, and changing attitudes of employers and the public towards people with MS.

EMSP Winter Conference, 26–27 November 2010

Better access to MS therapies & care in Central and Eastern European countries – strategies for tangible improvement

### **Expected outcomes (midterm and long-term):**

- The enlarged access to DMD therapies by people with MS.
- Common strategy between Romanian MS society and the Health Ministry.
- Specialized MS rehabilitation centers providing in-patient services to people with MS need to be established as soon as possible.
- The disability support payments system requires a review about the minimum wage and the extent of bureaucracy in administering the system – raising amount of the support payments is imperative.
- Patient organizations need to be actively consulted in all the matters and decision related to MS patients.

EMSP Winter Conference, 26–27 November 2010

Better access to MS therapies & care in Central and Eastern European countries – strategies for tangible improvement

## Follow up of the national roundtable

---

- Following the Romania roundtable, we sent an official letter to the Health Ministry explaining and providing the right information about the services and treatment provided in Romania to patients with MS;
- We were invited to provide more information regarding this issue and to prepare a long term strategy together with the Health Ministry;
- SSMR intends to approach the Labour Ministry in order to develop a common strategy regarding social impact of the MS in the patient's life.

EMSP Winter Conference, 26–27 November 2010

Better access to MS therapies & care in Central and Eastern European countries – strategies for tangible improvement



The roundtable gave us the possibility to speak about major inequality at European level regarding the services provided in the EU countries, and mainly in Romania; it also helped us to have the support of the European bodies and patients organizations in all our lobby and advocacy initiatives;

The roundtable had an additional contribution to strengthening the relationship between our society and national authorities. We were able to show the authorities that our society is a reliable partner that represents the interests of people with multiple sclerosis in Romania.

EMSP Winter Conference, 26–27 November 2010

Better access to MS therapies & care in Central and Eastern European countries – strategies for tangible improvement

In our experience, we recommend to organize a successful round table that:

- ☐ has a clear strategy that you want to implement;
- ☐ invite representants of the public body that can give their contribution in order to have a quality national support in your activities;
- ☐ invite people and influential personalities who can bring their significant contributions to the campaign that you develop.

EMSP Winter Conference, 26–27 November 2010

Better access to MS therapies & care in Central and Eastern European countries – strategies for tangible improvement

## What was difficult:

- To bring to the event leading representatives of the authorities;
- To "pull out" clear promises from authorities;
- To influence the competent authorities, regarding the applicability of the recommendations made by the roundtable specialists.

EMSP Winter Conference, 26–27 November 2010

Better access to MS therapies & care in Central and Eastern European countries – strategies for tangible improvement



# Thank you for your attention!

---

Romania MS Society  
Tel.: +40-359-192-110  
Fax: +40-359-409-715  
[office@smromania.ro](mailto:office@smromania.ro)  
[www.smromania.ro](http://www.smromania.ro)

EMSP Winter Conference, 26–27 November 2010

Better access to MS therapies & care in Central and Eastern European countries – strategies for tangible improvement