



LIETUVOS IŠSĖTINĖS SKLEROZĖS SĄJUNGA
LITHUANIAN MULTIPLE SCLEROSIS UNION

National High Level Roundtable

Vilnius

2009 December 3

Aldona Droseikienė - general secretary
PRAGUE, November 26



- ▶ It has become a tradition that the Lithuanian Multiple Sclerosis Union (LMSU) organizes an annual conference at the end of each year at the Seimas (Parliament) and invites patients, politicians, doctors and representatives of the institutions that form the health policy of Lithuania.
- ▶ Reviewing results, sharing good practice and discussing topical questions – such is the purpose of this even.

2009 Roundtable

- ▶ Annual Conference Part I
- ▶ Press Conference Part II
- ▶ Roundtable discussion Part III

Preparatory works

- In July and August we informed various associations, doctors and guests about the conference.
- In October, we sent nominal invitations with the conference programme to the representatives of Governmental institutions politicians, doctors, guests and provided them with specific questions to be answered and discussed during the conference.

Who participated?

❑ **total of 273 people**

- MS patients,
- Their family members,
- Doctors,
- Other representatives of organizations of the disabled,
- Guests from the Estonian and Latvian MS associations,
- Representatives of Governmental institutions,
- Journalists.

Part I Conference

“MS not as widely known as the A (H1N1) flu but much, much worse.”

- ▶ **The reports covered a variety of topics:**
- ▶ MS diagnostics and treatment in Lithuania,
- ▶ European experience,
- ▶ The activity of other organizations in the Baltic States,
- ▶ Vice-Minister of Health also acknowledged our influence on the overall formation of health policy,
- ▶ Dangutė Mikutienė, the Deputy Chairman of the Seimas Committee on Health Affairs, provided assistance by initiating the project "The Journey of a Disease".

Part I Conference

“MS not as widely known as the A (H1N1) flu but much, much worse.”



Vice-Chairman of the EMSP John Golding stated that the availability of the best drugs for the patients both in Lithuania and other Baltic States is poor.



MD Jolanta Kalnina - Latvian MS Center, Latvian Maritime Medicine Center regretted that the attitude towards the patients did not fundamentally change

Part II Press conference

“MS Patients lack not only rehabilitation and pension saving options but drug compensations as well”



Tadas Jačiasuskas (has MS) drew a dual picture of an MS patient

On one hand-

"A man who cannot walk and needs a wheelchair,
finds it difficult to move hands,
is depressed,
constantly forgets everything,
is invalid and even if he can work
he has difficulties in performing daily tasks.

On the other hand-

he can walk, move his hands, is not depressed, has a
job and is capable of doing it properly.

Such state of an MS patient does depend entirely on fate but also on
timely medical assistance and proper medicine. We have a few types
of medicine in Lithuania but ..

many more are available in the rest of Europe".

Resolution

- ▶ During the press conference we asked the Ministry of Health, the National Health Insurance Fund and the State Medicines Control Agency to consider our request which also included the recommendations of doctors as soon as possible.
- ▶ The Government must already start saving money to compensate new and efficient medicine instead of addressing the matter when in the rest of Europe this process is halfway to completion.
- ▶ We stressed that we would continue our demands next year.

Part III Roundtable discussion

“EMPS's sponsors and supporters – overview 2010”

- ▶ It covered the organization's plans and finances for the next year.
- ▶ Participated:
 - ▶ John Golding (then Vice-president of the EMSP)
 - ▶ 10 representatives of 4 pharmaceutical companies
 - ▶ LMSU representatives

Summary

»» Unfortunately, this discussion ended without reaching a unanimous agreement regarding the amount of funds the pharmaceutical companies could donate to help the organization survive financially

Some claimed to have supported the organization as late as in 2008 and that now was the time for other companies to show some generosity based on the market share of compensated drug market.

New events in summer 2010

- ❑ Round table discussion at the Seimas (02.06)
- ❑ Press conference at the Seimas (03.06)
- ❑ Presentation of information materials for the media representatives
- ❑ Day Without MS in Siaurukas train (05/06.06). Invitations to the media representatives for the trip with the LMSU on Siaurukas.
- ❑ Sending of the letters of patient history to the members of the Seimas. More than 70.
- ❑ The information to the media and local communities concerning the organised events, during which 8000 signatures were gathered.

- ▶ Currently, we have already started implementing our plans:
 - ▶ Information, preparation, round table discussion and conclusions during an annual conference on
 - ▶ December 10 at the Parliament.
- ▶ We start looking for money a year before the event. This job is difficult and unpaid.

The latest news from the Ministry

- ▶ These days, we received a reply that due to our number of campaigns and appeals, the Minister issued a decree No.V-976
- ▶ To set up a working group in charge until December 31 to prepare the description of an allocation procedure of the compulsory health insurance funds to review the treatment of MS disease modifying drugs, according to the new stated algorithm.

This decree prompted us to further appeals

- ▶ We presented a letter to the Committee on Health Affairs requesting to increase substantially funds in the compulsory health insurance funds for buying innovative drugs and accumulate reserve.

Recommendations

- ▶ To find the politician who contributes in organizing the roundtable and to mention his role in the nominal invitations to the conference or roundtable discussion.
- ▶ To establish emotional connection with the decision-makers, to inform them of the problem and to involve them in a dialogue.
- ▶ Publicising the problem situations in the media and having direct contact with the media.
- ▶ Publications and Broadcastings.
- ▶ **Our organization has become known only through such events.**

Achieved results

- ▶ I became an expert in the Parliament on Health Committee;
- ▶ I am invited to the Ministry to take part in the meetings in which are discussed the issues of health policy;
- ▶ In the future, I believe that the industry and pharmaceutical companies will realize the importance of our organization and we will not need to beg for funding.

Difficulties

The difficulties we face each year arefinances.

Last year we did not have any problem because have received funding from the EMSP



LMSU was founded in 2000 with the help of the Danish Multiple Sclerosis Society.

Unite 1500 people but represent the interests of almost 4000 affected people.

Co-ordinate the activities of 8 societies in the country's largest cities and district centers.



Place in Europe

- ▶ From 2002 the organization is a member of the European MS Platform.
- ▶ From 2007 we became a member of Euro carer association.
- ▶ From 2010 we got corresponding organization status in the EMSF (increase communication with the MSIF and work towards membership).
- ▶ The Organization also is one of the initiator in the founding of the Baltic MS Alliance

Membership



Projects



National activity

► Projects

- Mobile care
- Employment Projects
- and vocational training

EVENTS

- Day without MS
 - Baltic MS summer camp
 - Autumn seminar-school
- Annual conference





Thank you for the attention