

Prague

26-27<sup>th</sup> November 2010

“Advocacy work in CEE countries”

- individual success stories

*Juliana Ilencikova, PwMS Slovakia*



# We fight for patients' rights in SR

**2002-2006**

We had been gathering information at EMSP and MSIF conferences, foreign MS Societies and at EU Parliament.

**Monika Hebertova** – SMSU secretary at that time asked me to gather information on Rehabilitation Centres worldwide... With the words: **“We need it”**.

**November 2004:**

EMSP Conference in Athens “Recommendation on Rehabilitation Services for PwMS” (Dr. A. Kubek– physiatrist)

Allen O’ Connor, Ireland : **“European Union WILL support your projects but YOU HAVE TO ASK FOR SUPPORT!”**

**Prof. Kesserling, Switzerland: A human being has been created TO WALK,** not to sit in a wheelchair. And wheelchair serves to get from one place to another, not to sit in it all day long.

Rose X., Australia: We will die from cancer or from heart attac, but NOT FROM MS! PwMS must excersize and get rehabilitation.

**At the European Parliament:**



# It happened...

## 4<sup>th</sup> August 2005:

- Ing. Pavol Martin Šaulič
- Angelika's husband with MS living in Sabinov, found an advertisement in Sabinov newspaper about not having been used for 20 years basic school building for rent or sale, Pavol died in June 2010

## 12<sup>th</sup> August 2005:

Appointment with **Ing. Peter Molčan, Mayor of Sabinov City** – my colleague from secondary school, where we both had been teaching before I retired...

## October 2005:

Meeting of SMSU leaders, chairmen of all MS Clubs in Slovakia with Stretnutie predsedov klubov a predsedom SZSM with Ing. Peter Molčan, Mayor of Sabinov City in Kremnica – **unformal agreement on renting or selling building and property to build 1. Social and Rehabilitation Centre for all Slovakian PwMS.**

MILAN SURGOŠ – SMSU Chairman asked me on behalf of SMSU and Slovak PwMS to take care of it as I was a member of an International Committee of PwMS at MSIF and living 20 km from Sabinov

## November 2005:

Appointment with the director of **Regional Development Agency** to work out the Norway Funds application for financial support of Project Documentation. (not affirmed)

## 27<sup>th</sup> November 2005:

MILAN SURGOŠ died...



...but WE HAVE TO GO ON...

**February 2006:**

First appointments with **architects**

**April 2006:**

EMSP Conference in Manchester: “**Fundraising for MS Societies**”

**June 2006:**

Long term rent **application** had been sent to Town of Sabinov

**17<sup>th</sup> August 2006:**

Account for MS rehabcentre had been opened from initial support of **EMSP Conference participants in Manchester**

**19<sup>th</sup> August 2006:**

Fundraising in practice: Open Day of TV Markiza, (7800,-Sk =259 Euro)

**6<sup>th</sup> September 2006:**

Long term rent agreement **ratified**, old school building and property under it



# Fundraising...

At local, regional, national and international levels (1/2)

## Private donors:

- Private Donors from Swiss pharma and Biogen Idec
- Private Donors and MS Clubs from all over Slovakia
- Rimo - catholic. Church Raslavice

## Pharma companies:

- Pharmaceutical firm Richter Gedeon, SR
- Pharmaceutical firm Merck Serono Swiss

## NGOs:

- European Multiple Sclerosis Platform
- Slovakia association of healthy impaired persons, - branch Hermanovce
- Grammar school in Stara Lubovna –“philantropic program”
- Secondary school of Health of Saint Basil the Great in Presov, volunteers
- Secondary school of Trafic in Presov, volunteers

## Events:

- Exposition trades of Prešov, Rožňava, Stará Ľubovňa
- Sport Games MS Club Presov in Sabinov
- “Grease Melting Party in Kokošovce over Štofko´s in the garden“
- Christmas Markets in Prešov
- **MS Walks** in Presov - MS Awareness and Fundraising for Rehab - centre
- **WORLD MS DAY 2009 & 2010 - concerts, Matching Program of “SPP” (SlovakianGass Trust – donated the same ammount as we fundraised (1478,78 + 1478,78 Eur)**





# WORLD MS DAY 2009, 2010



**“International MS Youth Exchange with MS Club Members at MS Walk in Prešov”**

**“Grease Melting Party in Kokošovce over Štofko’s in the garden”**



**“Sport Games in Sabinov”**

# Fundraising...

At local, regional, national and international levels (2/2)

## STATE SUPPORT:

**General Collections:** - under application state permission for fundraising by sending money to account after issuing the announcement in newspapers..., permission used at all fundraising events.

**Tax:** - **2%** from taxes of physical persons: Tax Departements from Bratislava to Trebišov (34% more than in 2009)

## **Grant Applications:**

### ***For Project Documentation:***

- **NEFO Foundation of Presov Autonomy Region**  
(asked for 16 265 Euros) for partly reconstruction - **APPROVED (280 000 SK = 9 294 Euros)**  
*Disatvantage: we had had to pay for the work by ourselves and only later NEFOF reimbursed 2/3 of the payment*
- **Foundation of Brewery Šariš** - **NOT APPROVED**
- **Norway Funds Application for Project Documentation** - **NOT APPROVED**  
- From 130 applicants we were on 24th place. Only 20 application could be approved.
- **Presov Autonomy Region Funds** - **NOT APPROVED**
- **Fund of Social Developement of Slovak Republic** - **NOT APPROVED**  
- “application relevant only for marginalized inhabitants” /but PwMS are marginalized as well !!!/

### ***For NCSM Building:***

- **Regional Operational Program /April 2010/** - application **CANCELLED** by us for short budget of the fund.  
- If we asked for that short budget, we could not get rest in the future.

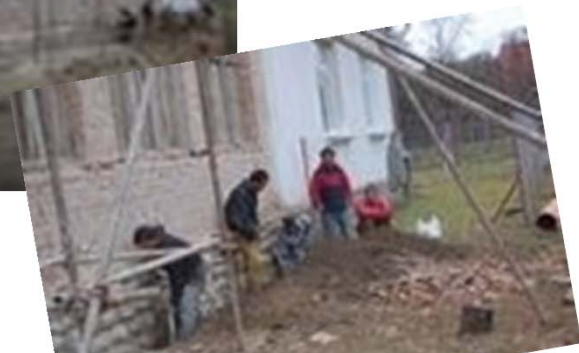
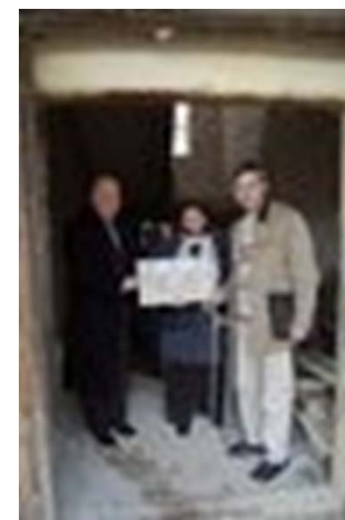
## PARTLY RECONSTRUCTION 2007

NEFO Funds of PRESOV AUTONOMY REGION 188 000 SK = 6 240Eur  
Fundraising of Slovaks 92 000 SK= 3 054 Eur

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TOTAL

280 000 SK = 9294 Eur





# Other Support

## National level:

- Mass Media – Press, Radio, TV
- Town of Sabinov, Community Plan of Social Development
- Town of Prešov, Community Plan of Social Development, state and private organizations and businessmen
- Architects - cut down the price of Project Documentation of 1/3
  - didn't require the whole payment at once
- Volunteers, General Public
- 30 MS Clubs in Slovakia & 8400 PwMS in Slovakia

**Moral Support:**

|                              |   |
|------------------------------|---|
| * Mrs. Iveta Radičová        | - Prime Minister of SR – World MS Day Patronage |
| * Mrs. Beňová, Mr. Mikolášik | - Members of the European Parliament            |
| * Mr. Mihaľ                  | - Minister of Work, Social Work and Family –    |
| * Profesor Traubner          | - President of Slovakian MS Union, neurologist  |

## European and International level:

- Petition Report of Uma Aaltonen, Member of the European Parliament
- European Code of Good Practice, EMSP
- Recommendation on Rehabilitation Services for PwMS“, EMSP 2004
- Principles to Promote Quality of Life of PwMS, MSIF, 2004
- EMSP General Secretary Christoph Thalheim visit in Sabinov, meeting with architects and Mayor (2008)
- Brussels , Belgium (2009) - Architects and Mayor of Sabinov participation + NCSM presentation at EMSP
- Visit of the National MS Centre in Moelsberg, BE,
- Zug, Switzerland (2010, April) - “MS and Mobility“ and NCSM Presentation at Biogen Idec meeting
- Brussels, 2010, June - “European Open Health Forum“, - meeting with N. Bedlington, Mr. Skorvaga
- Brussels, 2010, October, - “Amplifying the voice of PwMS“ – meeting of Novartis, EMSP, RIMS and PwMS

# What have we done so far...

We have used information from EMSP, MSIF and other foreign MS Societies in our streaming to fulfill our dream to build centre for social and rehabilitation services for all Slovakian PwMS.

## August 2008:

- **National Multiple Sclerosis Centre, non profit organisation - specialized centre - REGISTRATION**

## July 2009:

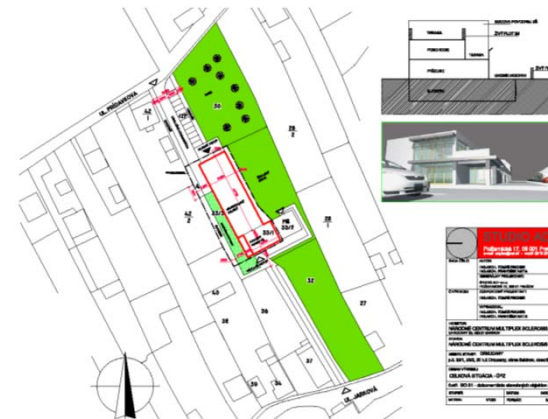
- **Next cca 3700 square meters with an old school for 1 Euro/year for 30 years in Sabinov City, RENT**

## 2009 -2010

- We have fundraised **31 00 Euro** for Project documentation within 2009 -2010.

- **Other Professionals Work on Project Documentation (2009-2010)**

1. Regional Departement of Public Health Appraisal,very good,  
"PD is even better than it should be." - I was told.
2. architectonic - building design/solution
3. stress analysis/statics appraisal
4. fire protection appraisal
5. heating appraisal



**PROJECT DOCUMENTATION IS READY FOR EUROFUNDS APPLICATION**

# Christoph Thalheim – EMSP Secretary General in Sabinov in 2008

Infront of the future administrative part of NCSM with architects and PwMS and with the Mayor of Sabinov City, November 2008



In May 2009, Architects and Mayor of Sabinov attended the EMSP Conference in Brussels

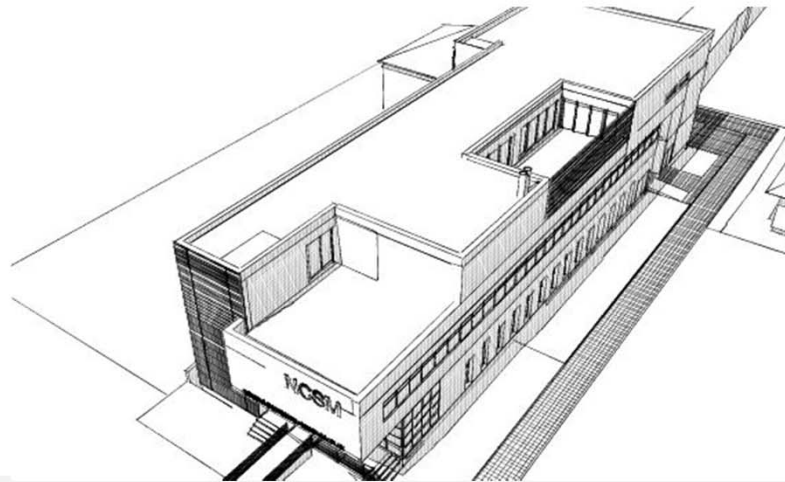
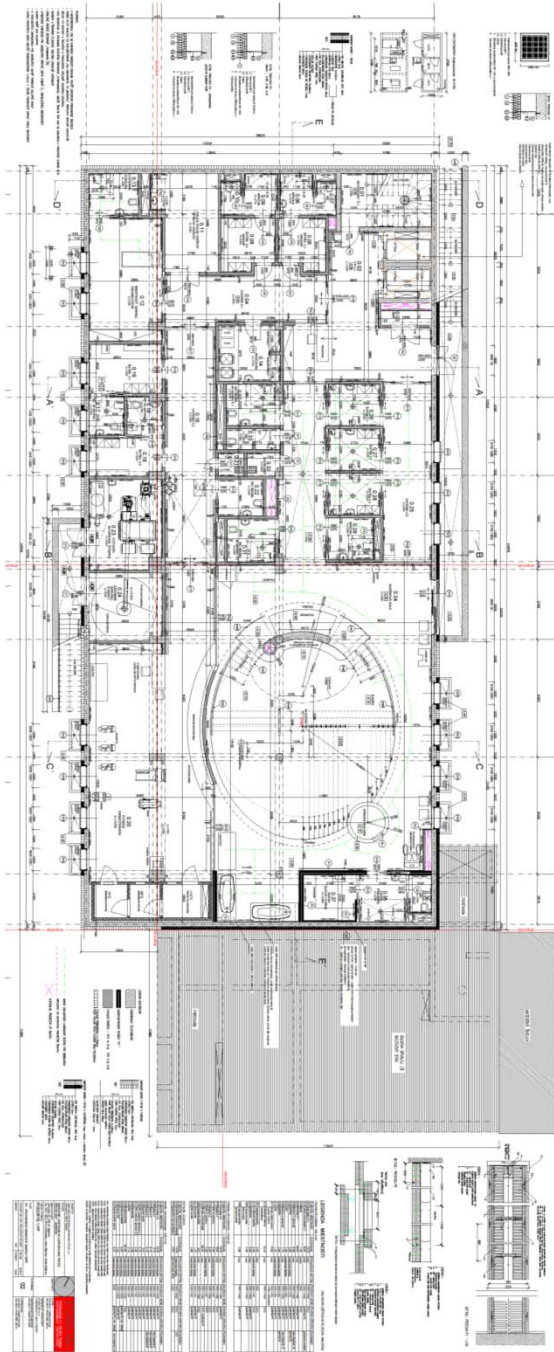
# What else do we need to do...

- **Few approvals of Other Professionals Work on Project Documentation** PD Profesists - work continues
  - Energetic Audit – project evaluation of the building
  - Budget
  - Electricity approval
  - Soil Fund Approval
  - Departement of Trafic Approval
  - Territory Approval
  - Building Permit
- **We still need** cca 1700 Euro for Project Documentation, **FUNDRAISING - CONTINUES**
- **We need 5% (125 000 Eur)** of the required total ammount of 2 500 000 Eur on the NCSM account If we want to apply for Eurofunds. We will ask pharmaceutical firms, banks and other donors for help.

## **New Law from 2008: Par. 448 Chapter on Social Services, art. 36 on specialised centres on MS**

- **Obstacles:** - Ministry of Work, Social Work and Family issues calls for Houses of Social Services, not for “Specialised Centres” (low budget)
  - Ministry of Health SR supports only Health Organizations, not social... ??? (Open Health Forum EUP, Brussels 2010 : “Social things and Health shouldn´t be considered as two separated things”)
- **We need further support of STRONG persons and organizations:** Nicola Bedlington (EUP), EMSP, Pharma Firms, Slovakian Ambassadors in EUP, Members of Slovakian Parliament, Ministeries ...
- **We look for Partner MS Organiztions** from PL, U, HU, RO from around the border ( International Project)
- **We want to establish a non profit MS Foundation** to help us to build NCSM and to support PwMS.

Water Physiotherapy – basement,  
ARCHITECTONICAL STUDY



# Rehabilitation centre (NCSM) description

according to “EUROPEAN RECOMMENDATIONS on REHABILITATION SERVICES for PwMS” EMSP, 2004:

## Accessibility:

- all the complex fully accessible - parking area for NCSM clients, building complex with 3 lifts, lifting system,
- 30 beds in accessible rooms, each with accessible toilette / bathroom.

- Daily Stationary for PwMS and others ... 10 clients/month
  - Respite Care Centre ... 15 clients/week
  - Rehabilitation Treatment ... 10 clients/month
  - House of Social Services for lonely PwMS - Long Term Residents Rooms, 5 clients
- = **3740 persons per year = cca 50 %** from the total number of PwMS in Slovakia (8400).

**Basement:** hydrotherapy, physiotherapy: fitness/kinesitherapy, cryochamber, local cryotherapy , exercise room and “FRR” bathroom, multi – leveled spill pool with massage banch, infrasauna, steam/dry sauna, massage, hydromassage bath tub,

- frass heating plant, store room, wheelchairs repairment, maintenance area, etc.

**Groundfloor: Foyer:** entrance, information desk, examine rooms for “Multidisciplinary team”, space for physiotherapy, electrotherapy, massage. Buffet for the clients and their quests , creative workshops.

*CREATIVE WORKSHOPS:* Internet cafe, Ergotherapy, Art Therapy, Music Therapyetc.,

**First floor:** bed/lodging part of the object for 30 clients, training “mobile” kitchen / social room.

**Second floor:** social part with dining room, kitchen for the clients and administration.

**New Technologies:** “FRR” bathroom, frass heating plant, solar heating in the future,

# Future 1/2

## **Financing:**

- Ministry of Health,
- Ministry of Work, Social Work and Family,
- Health Insurance Companies,
- Social Insurance Company,
- Towns and Villages Association of Slovakia
- Presov Autonomy Region,
- Department Work, Social Work and Family,
- Grants,
- Donors,
- Clients / PwMS

## **Decentralisation** of the MS Centre:

- the clients will not be excluded from the society,
- an opened walking path saved for walkers – inhabitants of the city,
- after project finishing it will be “a little city” with not bordered area of the NCSM.

## **Next lodging capacity:**

- by building the pensions, renting houses or flat units within the local place, among local houses.

# Future 2/2

## OTHER THERAPIES:

- **Training Park** with Paths for Clients using wheelchair /like in Meolsberg, Belgium/
  - with “Come Through Piece” for Adults
  - with Swing for Adults
  - with Our Garden
- **Hypotherapy**
- **Canistherapy**
- **Protected working place** for PwMS and other healthy impaired persons
- **Kindergarden** - Co – operation (connecting building)
- **Education** of PwMS, Family Members, Employers, General Public, ...INFORMATION CENTRE
  - **Reconditioning stays** for groups of PwMS
  - **Co – operation with students** of Physiotherapy from Faculty of Health in Presov and other student
  - **International Volunteers Programs**
  - **International MS Youth Exchanges**
  - **International Project** – participants /clients from other countries
- **Research**
  - Membership in RIMS
  - Co – operation with Pharmaceutical Firms
  - Co – operation with EMSP, MSIF



# Advices

*"I cannot do everything, but still I can do something" Helen Keller*

*"The biggest sin is sitting on your ass" Rose Kennedy*

1. **DREAM** - *You will get back what you transmit.*
2. **STRONG WILL / HEAR HEAD** - *If there is no way this way, think about ANOTHER WAY.*
3. **HELPFULL FRIENDS / SURROUNDING** - *One can do very little, but TOGETHER WE CAN DO A LOT!*

**LEARN, LISTEN, READ AND WATCH**

**DO NOT HESITATE / ASK FOR SUPPORT**

**DO IT !!!**

**NEVER GIVE UP 😊 !!!**

WE KEEP GOING ON.....

**THANK YOU**

[www.ncsm.szm.com](http://www.ncsm.szm.com)

