

ALS MND ALLIANCE MEETING ORLANDO FLORIDA 2010

KATHY MITCHELL

EDUCATION-TOUCHING THE FUTURE-
CHANGING QUALITY OF LIFE



OUTREACH GOALS

- * TO INCREASE KNOWLEDGE OF ALS CARE FOR HEALTH CARE PROFESSIONALS
- * COLLABORATE FOR ONGOING ONLINE SUPPORT
- * IDENTIFY GLOBAL RESOURCES OF INTERNATIONAL ALLIANCE

MALTA

- * MEETING WITH PROGRAM COORDINATOR AND NURSING STAFF
- * PRESENTATION TO INTERPROFESSIONAL TEAM OF MALTA HOSPICE MOVEMENT
- * ESTABLISHED TEXT AND ONLINE RESOURCE UNIT FOR MEDICAL STAFF

CYPRUS

- * PRESENTATION TO STAFF OF NEUROLOGY DEPARTMENT IN NICOSIA
- * ESTABLISHED RESOURCES FOR STAFF-TEXTS PRINT CDS
- * MEETING WITH NURSES ON NEURO UNIT RE MODEL OF CARE
- * HOME VISITS TO PATIENTS IN REMOTE AREAS FOR ASSESSMENT AND CARE MANAGEMENT
- * PRESENTATION TO PATIENTS CARE GIVERS AND TEAMS SPONSORED BY MDA OF CYPRUS

ISRAEL

- * REVIEW OF PROGRAMS
- * HOME VISITS-DISCUSSIONS WITH CARE GIVERS
- * MEETING WITH INTER PROFESSIONAL TEAM
- * MEETING WITH DOV LAUTMAN PRESIDENT ALS ISRAEL
- * MEETING WITH PALLIATIVE STAFF IN BEERSHEVA

BELGIUM

- * PRESENTATION AT UNIVERSITY OF LEUVEN ALS RESEARCH SEMINAR
- * VISIT TO ALS LIGA
- * RESEARCH LAB-Dr Wim Robberecht
- * Attended ALS Gala-met Van Rompuy President of EU

the objectives were achieved

- * Health professional education
- * Public awareness
- * Political advocacy

- * Knowledge transfer-interprofessional team
- * Professional collaboration
- * Online resources-social networking
- * Sustainable outreach and global connection

- * Patient autonomy family support

Thanks

- * International Alliance of ALS/MND
- * MDA Cyprus
- * Belgium ALS Liga
- * Algonquin College University of Ottawa

NEWS FROM THE YUGOSLAV MND ASSOCIATION Orlando 2010



On Behalf of Yugoslav MND Association

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First NIPPV Workshop in Serbia



- Yugoslav ALS/MND Association and the Association of health professionals from Clinical Center of Serbia “Sestrinstvo” (Nurses Association) organized first workshop, at the Clinic of Neurology of Clinical Center of Serbia, on 29th January 2010 which purpose was education and training how to use NIPPV in home setting.
- This workshop was organized due to the sponsorship of Canadian government, Canadian Embassy in Belgrade – Canada Fund.

**POD POKROVITELJSTVOM KANADSKE VLADE I AMBASADE KANADE U BEOGRADU
“CANADA FUND” ZA SRBIJU I CRNU GORU**



Government of Canada
Embassy of Canada

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**DRUŠTVO ZA BOLESTI MOTONEURONA
JUGOSLAVIJE**



**UDRUŽENJE MEDICINSKIH SESTARA
–TEHNIČARA KCS „SESTRINSTVO“**



**ORGANIZUJE EDUKACIJU I TRENING SESTARA, BOLESNIKA I ČLANOVA PORODICE ZA NEINVAZIVNU
VENTILACIJU U KUĆNIM USLOVIMA**

Organizatori:

Kanadska Vlada i Kanadska ambasada u Beogradu

Mr. Bruce Steen Savetnik, Šef odeljenja za tehničku saradnju – Zapadni Balkan

Prof. dr Zorica Stević – osnivač Društva za bolesti motoneurona Jugoslavije

Klinika za neurologiju KCS

Klinika za plućne bolesti KCS

Doc. dr Miodrag Vukčević

Društvo za bolesti motoneurona Jugoslavije

Dragan Birtašević – predsednik

Olgica Birtašević

Udruženje medicinskih sestara-tehničara KCS „Sestrinstvo“ Milijana Matijević, Nada Rapajić

Milena Maričić, Radmila Papić

Program of the Workshop

The program contained five parts:

- ① First part contained lectures presented by famous doctors – neurologists, pulmonologists, psychiatrists: concerning importance of application of NIPPV in ALS/MND patients and also when and how to use, as well as how to solve many problems to adapt to NIPPV.
 - ② The second part was education and training of nurses from Serbia how to use NIPPV, cough machine, nasal pressure meter SNIP by special monitors – a doctor specialist and a nurse specialized in treating patients on ventilatory support.
 - ③ The third part consisted of lectures presented by medical health professionals – how to educate/train nurses to recognize what are the first signs of respiratory insufficiency in ALS/MND patients, how to use NIPPV machines in home environment and which are the most frequent problems for the patients and members of their families when using NIPPV machines in home environment.
 - ④ The fourth part of the workshop was about education and training of patients and members of their families in home settings how to use NIPPV – by special monitors – a doctor specialist and a nurse specialized in treating patients on ventilatory support.
 - ⑤ Finally, the aim of the fifth part was to inform us about the quality of the workshop: the participants filled in the evaluation papers.
- We gave the CD with all lectures to all participants.

New Brochure

- All participants also received a new brochure “Dišite sa lakoćom” (Breathe without a problem) – the guidelines for all ALS/MND patients and all other patients with neuromuscular disorders who have a problems with breathing and need NIPPV support
- The brochure was printed in 1000 copies, by the Serbian Muscle Dystrophy Association, with donation of Representatives of the companies which produce NIPPV – “Breas”/TREVIS



Participants

- The participants were the health professionals from the main Clinical Centers in Serbia and patients with ALS as well as members of their families.
- ***The total number of participants was 83 (59 medical health professionals and 24 ALS patients and members of their families).***

Budget Item

Total Budget for one day Workshop was 1,120 € (1,800 \$ CAD), which includes:

- Organization and administration costs
- Food
- Renting the Meeting room
- 3 new Masks for NIPPV and 1 new Respiratory Pressure Meter (Micro RPM®)
- ***All lecturers as well as coordinator will provide their services on voluntary bases!***
- Representatives of the companies which produce NIPPV – “Breas” will provide 2 NIPPV for the use during the workshop and donation of 200 € for the workshop

Conclusion

- *The workshop was very successful and all participants were very satisfied with the knowledge which they obtained.*
- ① **Firstly** we tried to improve and optimize the health system as a whole, thanks to the successful training and education of health professionals from different settings in the various medical centers in Serbia.
- ② **Secondly**, due to practical education all health professionals who were attended to the workshop were qualified for the practical work with patients or members of their families who need NIPPV and also transfer their knowledge to other medical staff in their medical centers in Serbia.
- ③ **Thirdly**, at the same time ALS/MND patients and the members of their families who were attend the workshop were fully informed about the use of the NIPPV .
- *It is extremely important to organize such workshop at least once per year for better knowledge and training of the medical staff and patients about NIPPV, with idea to improve the quality of medical health care and also decrease the expenses of the patients treatment in hospital settings.*

*We wish the best of all luck to all participants of the International
ALS Association with the hope that our cooperation will continue
in more prosperous way!*

HAPPY NEW YEAR !



Thank you

