



CONFERENCE REPORT

Croatian Association of Multiple Sclerosis Societies National Multiple Sclerosis Day in the Republic of Croatia

On the occasion of National Multiple Sclerosis Day in the Republic of Croatia, which is celebrated every year on September 26, MS Weekend was held from September 30th until October 2nd, 2022 in Biograd na Moru, in the Adria Hotel. Multiple sclerosis sufferers in Croatia celebrate their National Day on September 26. Multiple sclerosis is the most common chronic inflammatory demyelinating disease of the central nervous system, it mostly appears in younger people between the ages of 20 and 50, the cause of the disease is unknown, and women are affected twice as often as men. The MS Weekend was attended by more than 150 people suffering from multiple sclerosis, who are members of 21 basic associations, members of the Croatian Association of Multiple Sclerosis Societies. The MS Weekend program was divided into two parts, the one intended for members suffering from multiple sclerosis and the other for employees of associations suffering from multiple sclerosis. Lectures intended for patients with multiple sclerosis were recorded, and are available on the Association's website and social networks. In addition to the MS Weekend, the celebration of the National Multiple Sclerosis Day was also marked by the MS Week, with recorded content available on the Association's website. As part of MS Week, the following contents were published:

- 26.9.2022. MSTV podcast „New guidelines for the treatment of relapsing-remitting multiple sclerosis“, Prof. Ph.D.Sc. Mario Habek,
<https://www.youtube.com/watch?v=aoKJb8RT9Ok&t=208s>
- 27.9.2022. MSTV podcast „The role of Vitamin D in MS“, Ph.D.Sc. Ivan Adamec,
<https://www.youtube.com/watch?v=wGN5ZaDqS7w&t=11s>
- 28.9.2022. MSTV Podcast „How are children with multiple sclerosis treated in Croatia?“, Prof. Ph.D.Sc. Maša Malenica,
<https://www.youtube.com/watch?v=g9KIV4tDp4A&t=151s>
- 29.9.2022. MSTV podcast „Important factors in the choice of therapy in patients with relapsing-remitting multiple sclerosis“, prim. Ph.D.Sc. Lidiya Dežmalj Grbelja,
<https://www.youtube.com/watch?v=9qr9LdJZl1s&t=211s>
- 2.10.2022. MSTV podcast „Pain and multiple sclerosis“, Ph.D. sc. Iris Zavoreo, exec. prof., <https://www.youtube.com/watch?v=BLS18Rt8Muo&t=555s>

Tea Mirošević Zubonja, MD, specialist neurologist, subspecialist in neuroimmunology, held two lectures, "What is MS fatigue?" and "Frequency of headaches in patients with MS". On the subject of fatigue and multiple sclerosis, she pointed out that the symptoms of fatigue in patients occasionally appear, and with the progression of the disease, they can change in strength and duration. The initial symptoms are most often subjective sensory disturbances, reduction of visual acuity, loss of strength in one or more limbs, double vision, balance disorders and dizziness, urinary and stool control disorders, movement coordination disorders, tremors, slurred speech, appearance of spasticity.

In addition to the above-mentioned symptoms, recently we have noticed less visible, non-motor symptomatology more often, due to which the disease was often "neglected" during diagnosis for several years. Although the non-motor symptoms of multiple sclerosis are an integral part of the overall clinical picture of this autoimmune disease, with a relatively high incidence and prevalence, compared to other neurological diseases, for which we have an increasing number of good drugs, which affect the course of the disease itself (primarily motor diseases), it is interesting that they are not given enough attention, given the fact that their presence significantly affects the quality of life of patients. On the subject of headaches in MS, she pointed out that migraine and multiple sclerosis have a number of symptoms, so if we call MS a disease with a thousand faces, we can also call a migraine a disease with a hundred faces. Migraines and headaches are treated with medication and alternatively, it is recommended to consult a doctor to find out the cause. Migraines and headaches occur frequently in the population of people with multiple sclerosis, but are not mentioned as much.

Professor of psychology and psychotherapist Boris Blažinić held a lecture on "How to increase the feeling of happiness and find inner satisfaction and peace". In his lecture, he pointed out that most people think they need one more thing in order to be successful. The truth is that you will never have everything you need. One more thing won't make a difference. Success is a process, not a goal. In order to be successful, you first need to feel that way. All emotions are like signs on the road, you need to recognize them, appreciate them, interpret them correctly and take appropriate actions. When you realize that fear is your friend and that it begins where knowledge ends, then you will create the preconditions for taking action.

MSc. Vesna Oršulić, MD, specialist in family medicine and gestalt psychotherapist, held the lecture "Are people with multiple sclerosis asexual?", in which she talked about the stereotype of the asexuality of chronic patients, and considered why and how the stereotype arose and offered suggestions for its elimination. Greater knowledge, with less prejudice and greater self-esteem of patients, will lead to greater opportunities for their self-realization in the area of sexuality as well. There is also a greater chance that the patients will allow themselves and admit their sexual needs and desires, and all this will lead to an overall increase in the health of the individual and society as a whole, because different people are integrated into society with all their rights and needs. The views of medics spill over into everyday life as well as into the wider social environment. Better education will influence the development of tolerance not only for the needs common to all people but also for those with different needs from our own. By raising awareness of the existence of a different, often discriminatory approach of healthy professionals towards the patients regarding sexuality, it will surely influence a change in attitudes and behaviour. If we want to stop such an approach, it is preferable to first become aware of what and how we are doing today. We have to start learning how we can do things differently and better because more knowledge makes it easier to change attitudes and raises the threshold of tolerance for everyone with differences, and especially for those with the same needs that all healthy people have.

Prof. Ph.D.Sc. Edina Šarić, professor at the Faculty of Education and Rehabilitation at the University of Tuzla, held a lecture on "Somatopedia in the rehabilitation of multiple sclerosis". The work procedures of somatopedists in patients with multiple sclerosis who are placed in the clinic are reflected in getting to know the patient's documentation, establishing contact with the patient, evaluating patients, therapeutic assessment from the aspect of somatopedics, determining immediate tasks-goals in somatopedic treatment, detailed planning, and then implementation activities and techniques from the domain of somatopedia, and the final assessment, i.e. conclusion on the results of the educational-rehabilitation program. It is important to note that in the clinical collaboration between a patient with multiple sclerosis and a somatopedist, the somatopedist is a partner who possesses pedagogical, psychological and medical knowledge, as well as the skills to carry out interventions that are coloured by various complementary and supportive therapies, and that in somatopedics every treatment begins and ends with relaxation. During the entire treatment, i.e. the patient's stay at the Clinic, Somatoped provides emotional support to patients and encouraging statements, which significantly affects self-confidence and self-esteem. Also, the patient is encouraged to express his/her emotions, frustrations, sorrows, concerns, joys, but also hopes, while the somatopedist listens and harmonizes with the patient's feelings. During the treatment, the somatopedist is empathetic, open, honest, and provides, among other things, advice on how to deal with everyday life challenges and how the patient can improve social support. For this reason, patients are advised to join associations of patients with multiple sclerosis, which are one of the most important sources of all forms of support for patients, where they certainly feel that "MAN IS THE BEST MEDICINE FOR MAN" and are a place where changes in the consciousness of patients and reaching new levels of what is called "well-being" in Western literature.

Prof. Ph.D.Sc. Edina Šarić also held the Laughter Therapy Workshop - Laugh 4 life by Dina, and M.Sc. Vesna Oršulić, MD, specialist in family medicine and gestalt psychotherapist held the workshop called "How to feel more, when we feel less?".

Maja Liković, mag.act.soc. from the Association of Multiple Sclerosis Societies held a lecture called "New Social Welfare Act - what has changed for people with multiple sclerosis?". In the lecture, she presented the novelties that occurred in the new Social Welfare Act, which affect the rights and status of people with multiple sclerosis.

Helena Smrček held a lecture called "Ease of presentation in the written and verbal segment for persons with disabilities", in which she talked about written presentation in front of a potential employer, about writing a resume and how to present yourself to an employer at a job interview.

The following lectures were held in the part of the MS Weekend dedicated to employees of associations, who are suffering from multiple sclerosis:

- "Incentives for the employment of persons with disabilities", Ana Marinović, spec.oec, vr.d. head of the employment and incentives service of the Institute for Expertise, Professional Rehabilitation and Employment of Persons with Disabilities

- „Professional rehabilitation of persons with disabilities“, Bojana Dražić, prof. soc. pedagogue, Senior professional associate specialist in professional rehabilitation, Central Office - Sector for Professional Rehabilitation - Service for Development, Evaluation and Education, Institute for Expertise, Professional Rehabilitation and Employment of Persons with Disabilities
- "What does the Law on Personal Assistance and the Law on Inclusive Allowance bring to the table?", Marica Mirić, vice-president of SOIH
- Presentation of the National Development Strategy 2030 - importance for associations and people with multiple sclerosis, Dijana Roginić, Executive Director of SDMSH and Tanja Malbaša, Development Associate
- National development strategy - workshop - establishing links between the work of organizations of people suffering from multiple sclerosis and the Knowledge Center, Dijana Roginić, Executive Director of SDMSH and Tanja Malbaša, Development Associate

The lectures that will be presented later, via video, are: "Pregnancy and Multiple Sclerosis" - Prof. Ph.D. Vanja Bašić Kes and "Incontinence in multiple sclerosis", prof. Ph.D. sc. Petar Kes, MD, nephrologist.

About multiple sclerosis

Multiple sclerosis (MS) is a chronic, incurable, inflammatory disease of the central nervous system (CNS), which means that inflammatory damage can affect the cerebrum, cerebellum, brainstem, and spinal cord. MS occurs at any age, but most often between the ages of 18 and 50. The disease has an unknown cause and an unpredictable course. Today's findings and the results of many studies indicate that multiple sclerosis is an autoimmune disease that is caused by environmental factors, but also by the influence of genetic predisposition to MS. It is estimated that almost 7,000 people suffer from multiple sclerosis in Croatia. National Multiple Sclerosis Day is celebrated every year at the end of September and is intended to connect people, groups and organizations in a movement at the international level and participate in events and activities to raise awareness of multiple sclerosis as a global problem. Multiple sclerosis (MS) is the most common inflammatory autoimmune demyelinating disease of the central nervous system (brain and spinal cord). It is predominantly a disease of young people, and in most patients the signs of the disease appear between the ages of 20 and 45, rarely before the age of 15 and after the age of 55. Women get affected twice as often as men.

Dijana Roginić