



SOUTHEASTERN EUROPE INNERMED NETWORKING MEETING

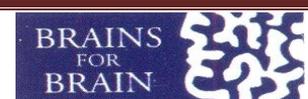
Joint meeting of the “InnerMeD-Information Network” project
partners and collaborating partners and experts from the
Southeastern Europe

Zagreb, Croatia

Hotel „Palace“

May 11th – 13th, 2015

Program





Dear colleagues, collaborators, co-workers, guests and friends,

It is our honour and great pleasure that you are taking part in the “Southeastern Europe InNerMeD Networking Meeting”, thus confirming belonging to the idea of joined efforts as the best way to succeed in coping with the burden of inherited metabolic disease affecting the nervous system. The meeting is a unique opportunity to strengthen and enlarge the “InNerMeD”-network and to intensify our collaboration in the field of inherited neurometabolic disorders with the final aim to help patients and their families suffering from the growing number of inherited neurometabolic diseases.

As you know, “InNerMeD” is an European project and it has been funded by the Executive Agency for Health & Consumers (DG-SANCO) under the Second Programme of Community action in the field of Health, 2008-2013 to be the first European Network on neurometabolic diseases. Since its beginning, it has had the focus to create a network of information targeted on diagnosis and treatment of iNMDs based on the collection and exchange of validated information among scientific community, health professionals, patients, patient associations and all interested stakeholders. In this sense, our joint meeting between project partners and colleagues from Southeastern European countries is a perfect tool to spread idea of the project in this part of Europe.

We are confident that both scientific content and the atmosphere of the meeting will guarantee that all participants will take home pleasant memories and strong motivation to continue working on the “InNerMeD”-project goals in their countries by further spreading of the networking and strengthening of our future collaboration.

We wish you a fruitful participation in the “Southeastern Europe InNerMeD Networking Meeting” and pleasant stay in Zagreb.

On behalf of the InNerMeD project:

Professor Ivo Barić, MD, PhD

(president of the organizing committee)

Professor Maurizio Scarpa, MD, PhD

(project coordinator)





ORGANIZERS

ORGANIZER: "Inherited NeuroMetabolic Diseases Information Network", an European project funded by the Executive Agency for Health & Consumers (DG-SANCO) under the Second Programme of Community action in the field of Health, 2008-2013

CO-ORGANIZER: Section for Metabolic Diseases, Croatian Pediatric Society, Croatian Medical Association

ORGANIZING COMMITTEE

Ivo Barić (president), Maurizio Scarpa (project coordinator), Ljerka Cvitanović-Šojat & Danijela Petković Ramadža (secretaries), Nina Barišić, Ksenija Fumić, Ivan Lehman, Smiljka Vikić-Topić, Lucija Debeljak, Angeles Garcia Corzola, Christine Dali, Franco Bartoloni, Fedele Bonifazi

GENERAL INFORMATION

TIME - May 11th to 13th, 2015

CONGRESS VENUE- Hotel Palace, address: Trg Josipa Jurja Strossmayera 10, 10000, Zagreb, phone: +385-1-4899 600, <http://www.palacehotelzagreb.com>

THE OFFICIAL LANGUAGE OF THE MEETING: English

CONTACTS FOR INFORMATION:

Prof Ivo Barić, tel. +385-1-2388121; fax. +385-1-2376023; e-mail: ibaric@kbc-zagreb.hr

Prof Ksenija Fumić, tel. +385-1-12367244; fax. +385-1-2367395; e-mail: kfumic@kbc-zagreb.hr

Prof Ljerka Cvitanović-Šojat, mob:+385981751431, e-mail:ljerka.cvitanovic-sojat@zg.t-com.hr

Dr Danijela Petković Ramadža, mob: +385959153870, e-mail: dramadza@gmail.com

SPEAKER'S INFORMATION - Presentations are expected to be made in Power Point program and given to the projection staff at least 15 minutes before the session to which presentation is scheduled. If other form of presentation is needed, please, contact the organizers as soon as possible. Speakers are kindly asked to keep strictly with time schedule.

PARTICIPATION VALIDATION: Participation will be credited according to the Croatian Medical Chamber rules on permanent education.

NAME BADGES - Only name badges holders can participate in scientific and social programme.

REGISTRATION AND REGISTRATION FEE - The registration desk for all participants is in the hotel lobby. It will be open on Monday, May 11th from 7 to 8 p.m., on Tuesday, May 12th, from 7.30 a.m. to 6 p.m., and on Wednesday, May 13th, from 8 a.m. to 2 p.m.

There is no registration fee, but registration is necessary for participation. The registration covers the participation in the scientific program, get together dinner, drinks and meals during the meeting, dinner on Tuesday, as well as all printed material.

LOGISTICS

PerfectMeetings.hr

Dražena Erceg, Executive Manager, Draskoviceva 66, HR-10000 Zagreb, Croatia; T: +385-1-4827-280; F: +385-1-4832-330, drazena.erceg@perfectmeetings.hr, www.perfectmeetings.hr





SOUTHEASTERN EUROPE INNERMED NETWORKING MEETING

Joint meeting of the "Innermed network" partners and collaborating partners and experts from the Southeastern Europe

PROGRAM

Monday, May 11th, 2015

13.30 - 19.00 InNerMeD - core network partners closed meeting - part I (visit to the Croatian Brain Research Institute)

20.00 - get together dinner in Hotel Palace-

Tuesday, May 12th, 2015.

8.30 - 10.00 Hall „Lenuci“

InNerMeD- core network partners closed meeting - part II

Hall „Strossmayer“

Pre-symposium session - (contributed by the Section for Metabolic Disorders of the Croatian Pediatric Society)

Chairs: Ksenija Fumić, Danijela Petković Ramadža

8.30 *Fran Borovečki (Zagreb, Croatia):* **“Next generation sequencing in diagnosis of neurometabolic disorders“**

9.00 *Danijela Petković Ramadža, Ivo Barić (Zagreb, Croatia):* **„Pompe disease- Diagnostic and treatment challenges“**

9.30 *Ivan Pećin, Diana Muačević-Katanec, Iveta Merčep, Željko Reiner (Zagreb, Croatia):* **„Is Gaucher disease type 1 really a non-neuropathic disease?“**

- coffee break -





Hall „Strossmayer“

10.30 **Welcome and opening:** *Ivo Barić (Zagreb, Croatia), Vlasta Zmazek (Zagreb, Croatian Alliance for Rare Diseases, Eurordis), Maurizio Scarpa (Wiesbaden/ Padova)*

10.45-12.45 INNERMED PARTNERS PRESENTATIONS

Chairs: Maurizio Scarpa, Ivo Barić

10.45 *Maurizio Scarpa (Wiesbaden, Germany / Padova, Italy):* „**The Inherited Neurometabolic Diseases Information Network (InNerMeD-I-Network) - a project to be joined**“

11.15 *Christine Dali, Alan Lund (Copenhagen, Denmark):* „**Lysosome disorders with CNS manifestations**“

11.45 *Ksenija Fumić (Zagreb, Croatia):* „**Laboratory diagnosis and biochemical monitoring of lysosomal disorders**“

12.15 *Maurizio Scarpa (Wiesbaden, Germany / Padova, Italy):* „**New therapies for neurometabolic disorders**“

- lunch -

13.45 -15.25 SOUTHEASTERN EUROPE INNERMED NETWORKING MEETING - presentation of countries - part I (Greece, Slovenia, Albania, Bosnia & Herzegovina, Bulgaria)

Chairs: Angeles Garcia Corzola, David Neubauer

13.45 *Dimitrios Zafeirou (Thessaloniki, Greece):* „**Diagnostic role of MRI in neurometabolic diseases**“

14.05 *David Neubauer, Barbara Gnidovec Stražišar, Mojca Tanšek Žerjav, Urh Grošelj, Barbka Repič Lampret (Ljubljana, Slovenia):* „**Some rare diseases in child neurology**“





14.25 *Artan Haruni, Valentina Tashko (Tirana, Albania):* **“Challenges of diagnosing and managing patients with inherited metabolic disorders in Albania”, “Ketogenic diet in neurometabolic disorders”**

14.45 *Smail Zubčević (Sarajevo, Bosnia and Herzegovina):* **“Neuronal ceroid lipofuscinosis - challenges in diagnostics of neurometabolic diseases in countries with limited resources”**

15.05 *Ivanka Sinigerska, Maria Ivanova, Dobri Dimitrov, Alexej Savov, Ivo Kremensky (Sofia, Bulgaria):* **“The laboratory diagnosis of inherited neurometabolic disorders in Bulgaria”**

15.25 - 15.55 INNERMED WORKSHOP

Angeles Garcia Corzola (Barcelona, Spain): **“Neurometabolic diseases mimicking psychiatric disorders”**

- coffee break -

16.15 - 17.35 SOUTHEASTERN EUROPE INNERMED NETWORKING MEETING-
presentation of countries-part II (Croatia, Cyprus, Czech Republik, Hungary)

Chairs: Jolanta Sykut-Cegielska, Nina Barišić

16.15 *Ivo Barić (Zagreb, Croatia):* **„Inherited disorders of methylation affecting the brain“**

16.35 *Theodoros Georgiou, Paola Nicolaidou, George Tanteles, Anastasia Hadjichristou, Maria Dionysiou, Elli Siana, Georgia Chappa, Violetta Anastasiadou, Anthi Drousiotou (Nicosia, Cyprus):* **„Glutaric aciduria type I in the Cypriot population“**

16.55 *Martin Magner, Jiri Zeman (Prague, Czech Republic):* **„Mitochondrial diseases in children“**

17.15 *Eszter Karg, Akos Barath, Peter Monostori, Gabor Racz and Ferenc Papp (Szeged, Hungary):* **„Newborn screening for neurometabolic disorders“**

18.00 Zagreb - guided tour





- 20.30 dinner at the restaurant „Vinodol“ (address: Ulica Nikole Tesle 10, Zagreb)

Wednesday - May 13th, 2015

8.40 -10.20 SOUTHEASTERN EUROPE INNERMED NETWORKING MEETING - presentation of countries - part III (Macedonia, Moldova, Montenegro, Poland, Romania)

Chairs: Beril Talim, Ljerka Cvitanović-Šojat

8.40 *Filip Duma, Vesna Sabolić, Natalija Angelkova, Katerina Vasileva Dimovska, Elena Kochova (Skopje, Macedonia):* "**Neurometabolic diseases in Macedonia - Current diagnostic possibilities**"

Natalija Angelkova, Vesna Sabolić, Elena Sukarova Angelovska, Tanja Zorčec, Elena Kochova, Filip Duma (Skopje, Macedonia): "**Late diagnosis of phenylketonuria - Time for changes**"

9.00 *Natalia Usurelu, Victoria Sacara, Stefan Gatcan (Chisinau, Moldova):* "**The development of neurometabolic field in Moldova**"

Victoria Sacara, Natalia Usurelu, Stanislav Groppa, Maria Duca (Chisinau, Moldova): "**Interaction among folate/homocysteine metabolism genes and endothelial nitric oxide synthase gene polymorphisms in case of Duchenne muscular dystrophy**"

9.20 *Jelena Jovanović, Olja Mandjarelo, Olivera Miljanović (Podgorica, Monte Negro):* „**Diagnostics and treatment of inherited neuro-metabolic diseases in Montenegro: possibilities and limitations**“

9.40 *Joanna Taybert, Jolanta Sykut-Cegielska (Warsaw, Poland):* "**Diagnostics of neurometabolic diseases in Poland - overview**"

Jolanta Sykut-Cegielska, Krystyna Szymanska, Katarzyna Kusnierska, Krzysztof Bankiewicz (Warsaw, Poland): "**AADC deficiency - from diagnosis to therapy**"





10.00 *Catrinel Iliescu (Bucharest, Romania): "Neurometabolic disorders and diagnosis in Romania"*

- coffee break -

10.40 - 11.40 SOUTHEASTERN EUROPE INNERMED NETWORKING MEETING-
presentation of countries - part IV (Serbia, Slovakia, Turkey)

Chairs: Eszter Karg, Smail Zubčević

10.40 *Božica Kecman, Maja Đorđević, Sanja Grković, Adrijan Sarajlija (Belgrade, Serbia): "Neurometabolic disorders in Serbia"*

Sanja Grković, Maja Đorđević, Božica Kecman, Adrijan Sarajlija (Belgrade, Serbia): "Laboratory for inherited metabolic disorders and diagnostic abilities of intermediary metabolism in Serbia"

11.00 *Vladimir Bzduch, Katarina Brennerova, Miriam Kolnikova, Darina Behulova (Bratislava, Slovakia): "Our experience with the treatment of nonketotic hyperglycinemia"*

Katarina Brennerova, Miriam Kolníková, Vladimír Bzdúch (Bratislava, Slovakia): "Synaptic congenital myasthenic syndrome – the cause of recurrent respiratory failure"

11.20 *Beril Talim (Ankara, Turkey): "Congenital muscular dystrophies with brain involvement"*

11.40 Viewpoint from patients & families

Vlasta Zmazek (Croatian Alliance for Rare Diseases, Eurordis): "Innermed and Eurordis"

12.00 -13.00 Unsolved neurometabolic case

Chairs: Christine Dali, Mojca Žerjav-Tanšek

Closing remarks

- lunch and farewell -





POSTERS exhibition will be during the whole meeting in the registration desk area. Poster presentations will take place during coffees brakes.

P.1

Vesna Sabolić (Skopje, Macedonia): “Niemann - Pick type C - case report”

P.2

Ljerka Cvitanović-Šojat, Maša Malenica, Monika Kukuruzović, Tamara Žigman, Kristina Kužnik, Ana Bielen (Zagreb, Croatia): „Mutations of NPC1 gene and the disease course”

P.3

Ivana Kavečan, Jadranka Jovanović Privrodski, Milan Obrenović, Tatjana Redžek Mudrinić, Marija Knežević Pogančev, Aleksandra Stojadinović, Dušan Vuković (Novi Sad, Serbia): „Inherited neurometabolic diseases in the autonomous province of Vojvodina, Republic of Serbia“

P.4

*Sabina Salkanović Delibegović, Nevzeta Mustafić, Amela Numanović (Tuzla, Bosnia and Herzegovina): **Brothers with Menkes disease - clinical presentation and EEG changes - case report***

