

# INBORN ERRORS OF METABOLISM: FACTS, DOUBTS AND FUTURE OF NUTRITION THERAPY

IN-PERSON, (VIRTUAL BACK UP) HOTEL KOLOVARE, ZADAR, CROATIA 2-4 JUNE 2022

### **O**VERVIEW

Medical nutrition therapy is an important part of inherited metabolic diseases treatment. Diagnosis and management of these diseases requires a multidisciplinary approach in which dietitians and nutritionists play one of the crucial roles in care of these patients.

### TARGET AUDIENCE

The course is designed preferably for dietetians/nutritionists, but also physicians and other healthcare professionals involved in dietary treatment of inherited metabolic diseases.

## **SCIENTIFIC ORGANISING COMMITTEE**

- Ivo Barić, Zagreb
- Júlio César Rocha, Lisbon
- Valentina Rahelić, Zagreb

## **VENUE**

https://hotel-kolovare.com/

### **LEARNING OBJECTIVES**

After attending this course, participants will have basic knowledge about clinical presentation and dietetic management of inherited metabolic diseases, but will also get information on new trends in this field and an understanding of:

- pathophysiological, biochemical and genetic bases of inborn errors of metabolism;
- nutrition interventions in amino acid and organic acid disorders, urea cycle disorders, hypercholesterolemia, carbohydrate and fatty acid metabolism disorders;
- ketogenic diet and other inherited metabolic disease issues;
- dietary management related to metabolic emergencies;
- importance of proper and regular communications with patients and their families.

### **FEES**

The fees of 250€ include:

- · 2 nights bed and breakfast,
- Lunches, dinners and coffee breaks during the course,
- Speakers' presentations to take away after the course.

Participants are responsible for their own travel arrangements to and from the course.

Fees are only due once candidates have been selected - not refundable.

#### **SELECTION CRITERIA AND REVIEW PROCESS**

Candidates will be selected based on background, experience and the geographical breakdown by the scientific organising committee.

### **REGISTRATION PROCESS AND DEADLINE**

- The registration form should be completed on <u>www.rrd-foundation.org</u> and submitted with your curriculum vitae in English.
- No payment is required at this stage.
- Deadline for registration is the 25th of April 2022.

#### **COVID-19**

Depending on the sanitary situation, local regulations will apply. If required, the course may be converted to a virtual format. Stay updated on local regulations <a href="https://example.com/here">here</a>

#### **CME ACCREDITATION**

An application will be made for local CME accreditation.

CLICK HERE TO
REGISTER

Contact ckellquist@rrd-foundation.org



### **PROGRAMME**

WITH THE SUPPORT OF: REFERRAL CENTRE FOR GENETICS, METABOLIC DISEASES AND NEWBORN SCREENING OF THE MINISTRY OF HEALTH, REPUBLIC OF CROATIA (DEPARTMENT OF PAEDIATRICS, UNIVERSITY HOSPITAL CENTRE ZAGREB); CROATIAN PAEDIATRIC SOCIETY, SECTION FOR METABOLIC DISEASES AND THE CROATIAN SOCIETY OF NUTRITIONISTS AND DIETITIANS

## 2 June

14:00 Start of the course

#### Session I Meet participants

Welcome and introduction

(Ivo Barić, Zagreb, Júlio César Rocha, Lisbon, Valentina Rahelić, Zagreb)

The field of inherited metabolic diseases (Ivo Barić, Zagreb)

Role of dietitians in care of patients with inherited metabolic diseases – round table (Júlio César Rocha, Lisbon and Valentina Rahelić, Zagreb)

#### Session II Low protein diets throughout life cycle – part 1

Phenylketonuria: prototype of inborn errors of metabolism and their treatment (Jiri Zeman, Prague)

Nutrition in phenylketonuria: what is beyond phenylalanine levels? (Júlio César Rocha, Lisbon)

Challenges in nutritional phenylketonuria treatment - interactive session and patients' experience (Charlotte Ellerton, London)

Food replacements - now and beyond (Anita MacDonald, Birmingham)

Dinner at the hotel

Note: Participants are encouraged to prepare case reports which were difficult or illustrative in terms of nutritional management.

### 3 June

#### Session III Low protein diets throughout life cycle – part 2

Overview of organic acidurias (Daniela Karall, Innsbruck)

Nutritional management of organic acidurias (Carmen Rohde, Leipzig)

Clinical spectrum of urea cycle disorders (Ivo Barić, Zagreb)

Nutritional management of urea cycle disorders (Carmen Rohde, Leipzig)

Clinical and biochemical monitoring of metabolic diseases treatable with low protein diets (Jiri Zeman, Prague)

Multidisciplinary approach in treatment of severe ornithine transcarbamylase deficiency - interview with a mother (Moderators: Ivo Barić and Valentina Rahelić, Zagreb)

#### Session IV Carbohydrates and fats

Liver glycogenoses (Danijela Petković, Zagreb)

Nutritional management of glycogenoses (Alice Dianin, Verona)

How restrictive we can be? (Ivo Barić, Valentina Rahelić, Zagreb)

Fatty acid oxidation defects - clinical aspects (Carlo Dionisi Vici, Rome)

Nutritional management of fatty acid oxidation defects - recommendations and open questions (Monika Jörg-Streller, Innsbruck)

Case report (s) (Monika Jörg-Streller, Innsbruck)

Familial Hypercholesterolemia - clinical approach (Albert Wiegman, Amsterdam)

Recommended medical nutrition therapy of hypercholesterolemia (Hülya Gökmen Özel, Ankara)

Unusual patient- Case report

Hypertriglyceridemia - clinical approach (Albert Wiegman, Amsterdam)

Medical nutrition therapy of hypertriglyceridemia (Hülya Gökmen Özel, Ankara)

Dinner with a guided tour of Zadar

#### 4 June

#### Session V Ketogenic diet and special treats

Who needs ketogenic diet? (Daniela Karall, Innsburck)

Ketogenic diet in practice (Nikola Mesarić, Zagreb)

Food supplements in inborn errors of metabolism – do we pay enough attention? (Anita MacDonald, Birmingham)

Pregnancy related challenges in inborn errors of metabolism (Elaine Murphy, London)

#### Debates (each 15 minutes)

- How to prevent tube feeding dependence and aversion to food in inborn errors of metabolism - tricks, tips and facts (Moderators: Danijela Petković Ramadža, Zagreb and Charlotte Ellerton, London)
- Do we need at all a diet for hyperuricemia? (Moderators: Nikola Mesarić, Zagreb and Jiri Zeman, Prague)
- Specific parenteral nutrition for inborn errors of metabolism (Moderators: to be confirmed)

How to educate our patients? (Anita MacDonald, Birmingham)

A family's perspective - (Moderators: Elaine Murphy, London and Julio Cesar Rocha, Lisbon)

#### 13:30 End of the course