

**Building the Future of Patient Education to Improve Outcomes:  
Integrating behavioral psychology and digital tools to increase dietary  
adherence in people with IEMs**

*A three-part series of online educational events*

## **PART 3: WEBINAR**

The Power of Personalized Education: Improving  
Adherence to Diet and Patient Outcomes in IEMs

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# PART 3: WEBINAR

## The Power of Personalized Education: Improving Adherence to Diet and Patient Outcomes in IEMs

Dr. Alberto Burlina, Prof. Martina Huemer, Dr. Miriam Hufgard-Leitner

### Description:

Join this webinar to learn more about the value of personalized patient education and discover new strategies to help improve adherence among adult patient populations.

### Session learning objectives:

- Review education strategies designed to facilitate communication with teens with IEMs to increase adherence.
- Recognize the impact of personalized educational content in improving outcomes in teens and adults with IEMs.

### Programme:

- ▶ **Welcome**  
*Chair: Alberto Burlina, MD, PhD*
- ▶ **Patient education and patient reported outcomes in children with inborn errors of metabolism and their families**  
*Martina Huemer, MD, Psychologist*
- ▶ **PKU in adults: what we should be doing!**  
*Miriam Hufgard-Leitner, MD, MSc*
- ▶ **Questions and Answers**



Chair and Host

## **DR. ALBERTO BURLINA**

MD, PhD

*Division of Inborn Errors of Metabolism,  
Department of Paediatrics, University Hospital  
of Padova, Padua, Italy and Expanded Neonatal  
Screening Center of North East of Italy*

Alberto Burlina, MD, PhD is Director of the Division of Inborn Errors of Metabolism, Department of Paediatrics, University Hospital of Padova, Padua, Italy. This is also the Expanded Neonatal Screening Center of North East of Italy.

He received his MD in 1979 and was specialized as a Paediatrician in 1983. He is full Professor of Paediatrics. He has published over 250 publications about inborn errors of metabolism with particular interest in laboratory diagnosis including neonatal screening and treatments from diet to organ transplantation.

Since 1980, Dr. Burlina has worked as Metabolic Paediatrician, and now is Director of the Division of Inherited Metabolic Diseases at the University Hospital, Padua. He is involved in the management of patients with metabolic diseases from birth to adulthood and Director of Expanded Newborn Screening Program in the North East of Italy. His focus is on PKU and amino and organic acid disorders.

Dr. Burlina is an Italian Corresponding Member of SSIEM and from 2008 to 2014 he was President of the Italian Society of Inborn Errors of Metabolism. He is active in various European and international advisory boards and working groups on both PKU and other metabolic disorders.



## PROF. MARTINA HUEMER

MD, Psychologist

*Department of Metabolism, University  
Children's Hospital Zürich, Switzerland*

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*Department of Paediatrics,  
Landeskrankenhaus Bregenz, Austria*

Martina Huemer, MD and Psychologist, Professor at the University of Zürich, works as Consultant at the Children's Hospital in Zürich and heads the Specialist Outpatient Clinic for Inborn Errors of Metabolism at University Children's Hospital in Basel, Switzerland, as well as in Vorarlberg, Austria.

She received her degree in Psychology in 1987 and her MD in 1994. After receiving her post-doctoral lecturing qualification for Paediatrics in 2009, she was appointed guest professor at the University of Vienna in 2015 and titular Professor at the University of Zürich in 2016. Her research focuses on the Homocystinurias and on psychological aspects of patient care in inborn errors of metabolism. She is author to more than 80 peer reviewed publications.

Professor Huemer is chair of the European network and registry for homocystinurias and methylation defects (E-HOD) project that was initially supported by the European Union (Health Programme). Beyond the projects within E-HOD she leads several projects, among others:

- Health-related quality of life in intoxication-type metabolic diseases.
- How to explain inborn errors of metabolism to children and families.
- Patient reported outcomes in children with IEM.

She was awarded in 2017 by Nutricia Metabolics Research Fund for her research: 'Clear and understandable health information materials for adolescents with inborn errors of metabolism (IEM) requiring dietary treatment'.



## DR. MIRIAM HUFGARD-LEITNER

MD, MSc

*Clinical Division of Endocrinology and  
Metabolism, Medical University of  
Vienna, Austria*

Miriam Hufgard-Leitner, MD, Msc. is a Medical Specialist for Internal Medicine and Junior Head of Outpatient Clinic for Inherited Metabolic Disorders in Adults at the Department for Endocrinology and Metabolism, University of Vienna, Austria since 2019.

She received her MD in 2010, did a master program in Gender Medicine and specialized as a Medical Specialist in Internal Medicine in 2020. She is working on her PhD that she hopes to complete in 2021.

Dr. Hufgard-Leitner was awarded several times by the Austrian Society for Gender Specific Medicine, and was awarded in 2018 by Nutricia Metabolics Research Fund for her research 'EVAs diet: evaluation of gender-specific PKU management and impact of a structured dietological and educational intervention in adult PKU patients on quality of life, metabolic, neurocognitive and psychological outcome'.

Dr. Hufgard-Leitner is member of several committees of the Medical University of Vienna, among others the committee for Gender and Diversity, the commission for education, and the senate.

# SUMMARY AND KEY TAKEAWAYS FROM PRESENTATION 1

## **Patient education and patient reported outcomes in children with inborn errors of metabolism and their families**

*Martina Huemer, MD, Psychologist*

Inborn errors of metabolism (IEM) are rare diseases. Burdens of the diagnostic process and delay, of the disease itself and of medical treatment and care on patients and families are significant. Patient education is an important component of the empowerment of patients and families to manage the disease successfully and to improve patient reported outcomes such as health-related quality of life and satisfaction with medical care. Patient education materials should be comprehensive to allow fluent processing and, consecutively, improve acceptance of its content. Our group developed individualised patient education materials that combine simple pictures with easy-to-read texts. Since patients prefer online materials, a homepage was created that presents these patient education materials and beyond this, offers advice and information on matters of daily life such as a dietary protocol template, information on what to take when traveling or how to explain the disease to others to gain social support.

**ADAPT to the level of ability of your patient.**

**Interact lively and LISTEN.**

**Patients prefer ONLINE educational materials.**

# SUMMARY AND KEY TAKEAWAYS FROM PRESENTATION 2

## **PKU in adults: what we should be doing!**

*Miriam Hufgard-Leitner, MD, MSc*

Therapy adherence is the key challenge in treating (adult) PKU patients. Despite the importance of this matter, evidence regarding impact factors or results of interventional studies are scarce. Facing the high numbers of lost, to follow up or non-adherent patients, it is urgent to provide data and to work together on best practice models.

In the session, the first steps to provide evidence of (successful) PKU management are presented.

These comprise clear definitions of targets, transparent control mechanisms, overview of patient numbers and interventional study protocols. Based on results, our management approach has to be re-evaluated to improve the therapy outcome of PKU patients.

**Define clear targets/therapy adherence/compliance and influential interventions**

**Involve the patient in development of best practice**

**Provide evidence of interventional studies and gain knowledge about successful ones**

**Share your knowledge and experience!**

# ADDITIONAL RESOURCES

[If you are interested in the full educational series, please explore:](#)

- ▶ **PART 1 PODCAST MINI-SERIES:**  
**CONNECTING THE DOTS: USING BEHAVIORAL AND COGNITIVE PSYCHOLOGY TO SUPPORT TEENS WITH IEMS**  
This podcast series covers topics relating to teenage development, and how to use this knowledge in support of patients with IEMs through the discussion of patient case studies.
- ▶ **PART 2 ROUND TABLE DISCUSSION:**  
**IS SOCIAL MEDIA THE KEY TO PATIENT EDUCATION IN IEMS?**  
Join experts in inborn errors of metabolism and social media for a round table and Q&A on using social media to engage with patients and support better management of their condition.



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