

SSIEM Patient Advocacy Session: The Psychosocial Impact of Living with an Inborn Error of Metabolism

Tuesday 29th August 2023, 9am-12pm

Presenters:

Kirsty Hoyle – CEO at Metabolic Support UK

Laura Smith van Carroll – Head of Insight & Advocacy at Metabolic Support UK

Karen Dolins – Research Lead at Maple Syrup Urine Disease (MSUD) Family Support Group

Gulcin Gumus – Research and Policy Project Senior Manager at EURORDIS

Danaé Bartke – Executive Director at HCU Network America

Audience: These sessions are intended for everyone with an interest in the lived experience of people living with inborn errors of metabolism. They are an opportunity to hear stories that give cultural context to the experiences of patients and understand more about the psychosocial impact of living with a rare disease.

Time	Session Topic		The Psychosocial Impact of Living with an Inborn Error of Metabolism
9-10.30am	5 mins	Chair, Kirsty Hoyle	Welcome
	15 mins	Metabolic Support UK	What do patients want? MSUK present early findings from ‘Thoughts into Action’, a research project looking at Quality of Life as defined by patients
	15 mins	MSUD Family Support Group	Present their story of change through community and cross-cultural collaboration
	15 mins	EURORDIS	The wider context: psychosocial impact of living with a rare disease
	10 mins	HCU Network America	Understanding the burden of classical homocystinuria (HCU) from the patient’s perspective: A qualitative study
	30 mins	All	Panel discussion / Q&A
10.30-11am	Refreshment Break		
11-12pm	Patient Community Meet up		Using the concept of ‘Open Space’ this free-flowing session will be an opportunity for all stakeholders with an interest in Inborn Errors of Metabolism to raise issues and fund solutions. A unique opportunity for patients, industry and healthcare professionals to listen and to speak in a shared space.