

AKU INTERNATIONAL PATIENT WORKSHOP 2024

Speaker biographies

JESS BARNES



Jess is a mum to a young son that has AKU and has supported the charity since his diagnosis in 2013. She has been an active fundraiser, appeared in our short films, and last year presented our very successful BBC Radio 4 charity appeal. Jess is the director of her family tech business and also works part-time for a digital agency with a background in sales and marketing. When she is not juggling work and family life Jess enjoys making art, running on the South Downs, and swimming in the sea.

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DEREK CLARKE



Derek Clarke is a Nutricia team chef who also works with Matthew's Friends and The Daisy Garland charities. His career started when he qualified as a Master Baker with Rank Hovis in 1992, and since then he has worked for top London hotels, opened a cake shop in Chester and made countless wedding cakes. Today, his work for Nutricia involves developing new recipes for ketogenic and metabolic diets.

NUTRICIA

JIM FISH



Jim Fish has immersed himself in aquatic pursuits since his youth, beginning with competitive swimming at 13. He continued his aquatic journey through university, excelling in both swimming and water polo while studying kinesiology. His career in medical devices, specializing in bone regeneration and pediatric orthopedic implants, didn't dampen his passion for water-based fitness. Despite recently undergoing five joint replacements in three years, Jim remained dedicated to swimming and golf, utilizing water's therapeutic benefits for healing. He generously shares his expertise, volunteering "Hot Tub Yoga" sessions at local pools and the YMCA. Certified as a swimming and aquatic fitness instructor, Jim advocates for the transformative power of water exercise.



EIMAR HIGGINS

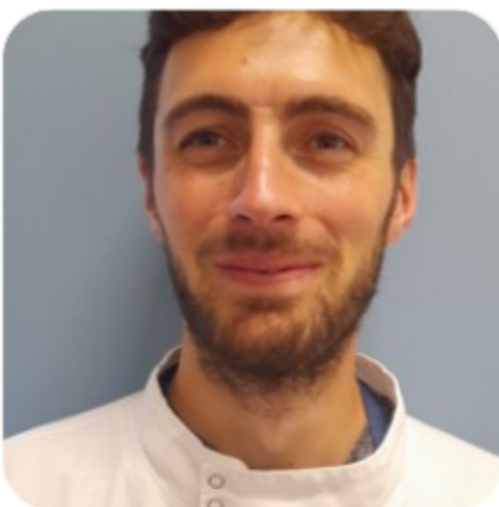
"Eimear is a Metabolic and Ketogenic specialist at Nutricia. She supports NHS Dietetic departments and patients with Nutricia products, services and events. Eimear is a registered Dietitian with 7 years experience working in the NHS and 7 years experience working in the medical nutrition industry. In her current role she supports patients with metabolic conditions and runs educational events and cookery workshops to give patients an opportunity to meet with their peers and expand their knowledge and skills.



JULIETTE HUGHES

Juliette holds an undergraduate master's degree in human anatomy and biology and a PhD in musculoskeletal biology from the University of Liverpool. Her PhD research, under Professors Jim Gallagher, George Bou-Gharios, and Lakshminarayan Ranganath, focused on alkaptonuria in mice. Juliette developed a new AKU mouse model, studied dietary restrictions in nitisinone-treated AKU mice, and examined Hgd expression and liver requirements to prevent AKU. She lectured in Anatomy at Edge Hill University (2021-2023) and now lectures at the University of Liverpool. Her current research explores alkaptonuria and pigmentation, including an extensive examination of an AKU body donor.

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BRENDAN NORMAN

Dr Brendan Norman earned his BSc (Hons) in Psychology from the University of York and his MSc in Clinical Neuroscience from University College London. He completed his PhD at the University of Liverpool in 2020, working with Professors Jim Gallagher and Lakshminarayan Ranganath on alkaptonuria. His expertise in metabolomic techniques and CI/MS workflows has greatly benefitted academic and clinical research. Since his PhD he has expanded his research to include metabolite biomarker discovery in lung and prostate cancers. In 2022, he received a four-year Fellowship from the Alkaptonuria Society to lead research on neutral amino acid metabolism disorders.

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PROFESSOR RANGANATH



Ranga became interested in AKU in 2003, when there was no NHS service available for AKU in the UK. He established an NHS Highly Specialised Services-funded National Alkaptonuria Centre (NAC), of which he is the inaugural director. This provides access to a multidisciplinary team of experts, employing off-label use of nitisinone, as well as other therapies. He has pioneered an assessment of AKU patients, and is the co-ordinator and chief investigator of an EC-funded international research programme involving 3 studies in AKU.

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NICK SIREAU



Nick Sireau, PhD, is the CEO and Chair of Trustees at the AKU Society, which supports people with AKU, a rare genetic disease affecting his children. The AKU Society and Nick won the 2021 Members Award by EURORDIS for their work on developing a new treatment for AKU. Nick co-founded and chairs Beacon, assisting rare disease patient groups. He edited "Rare Diseases: Challenges and Opportunities for Social Entrepreneurs" (2013) and the "Patient Group Handbook" (2016). He also co-founded Orchard OCD, funding OCD research, and Sirgatan Therapeutics, focusing on new OCD treatments. Nick holds degrees from Oxford, Lyon Graduate School of Business, and City University.

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STEVE SMITH



Steve has worked in both the private and public sector as a Personal Development Coach, and also as a Couples Counsellor for Relate. He spent many years as a professional Yacht Skipper and RYA Sailing Instructor, before training as a Mindfulness Teacher.

He is a core teacher trainer for Breathworks, and an 'Living Well' Trainer and Supervisor. He runs both 'Mindfulness for Health' and 'Mindfulness for Stress' programmes and is a qualified Mindfulness in Schools teacher for young people.

Steve's has lived experience of managing an ongoing chronic pain condition, and uses the techniques he teaches on a daily basis to help manage pain and daily life.

RARE MINDS

CLARE SOULSBY



Clare qualified as a dietitian over 30 years ago and have spent most of her career working as a hospital dietitian - working with patients who require artificial nutritional support. She spent several years doing research on nutrition in critically ill patients and gained my PhD at Barts and the London Medical School. Clare has worked as a lecturer on Dietetic undergraduate and postgraduate programmes in Australia (Flinders University of SA) and the UK (University of Chester). She co-wrote the UK guidelines on "Estimating Nutritional Requirements for Adults" leading on protein requirements, which has been very useful for her new role as the dietitian working in AKU. She has been working in AKU for almost 2 years now and says she has enjoyed learning about a new area of nutrition and meeting (and learning from) people living with AKU.

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MARTIN TWYCROSS



Martin trained as an Engineer and gained both his degrees from Oxford Brookes University in 1983 and 1993 respectively. After five years as an Engineering Officer in the British Army, he has held various positions within the ICT sector; working for Dell Computers, British Telecom, Novell, Panasonic and Capita Professional Services.

Martin has worked at Dendrite Clinical Systems for over ten years liaising with MedTech companies, as well as national and international medical societies and patient organisations focusing on Rare Diseases, helping them to design and develop bespoke clinical registries to collect procedural data for outcomes analyses.

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SIAN WILLIAMS



Sian Williams has been teaching Pilates since 1987. She was the co-owner & director of a major West End Pilates studio and teacher training centre from 1997 to 2016. Since then she has divided her time between teaching clients in both 1-1 & group settings, delivering workshops & mentoring Pilates trainees. She is especially interested in, and passionate about, the rehabilitative benefits of Pilates and has worked with many different people with a wide range of diverse abilities & conditions during her 36 years of teaching. Sian first delivered chair based pilates at an AKU workshop in 2019 & she is delighted to be returning this year.