METABOLIC SUPPORT
Living well with a rare disease

Metabolic Support is a charity registered in England and Wales (1089588) in Scotland (SCO44634) and a Company Limited by Guarantee (04267454).

OUR NEXT CHAPTER: METABOLIC SUPPORT

OUR HISTORY

Our organisation was founded in the UK after Jennifer Greene was born in 1978 with the rare inherited metabolic disorder (IMD), Cystinosis. Finding little information or support for families affected by metabolic conditions, her parents, Peter and Lesley Greene, established the charity in 1981, originally named the Research Trust for Metabolic Diseases in Children (RTMDC), to provide support, raise awareness and drive research for inherited metabolic disorders. We have always been a small organisation with big impact; our founders were instrumental in the establishment of EURORDIS, the largest patient-driven alliance of rare disease patient organisations in Europe and helped put rare disease more firmly on the radar of the UK healthcare system.

We have over 45 years of history supporting individuals and families affected by inherited metabolic disorders and have grown from a small, family-driven initiative into a nationally and internationally recognised rare disease charity. Over the years, we have expanded our services to support people living with hundreds of rare metabolic conditions worldwide but retained our close connections to our community. We developed core services such as advice and support, building communities, peer support, educational resources and advocacy initiatives, alongside partnerships and policy engagement that have strengthened the voice of the rare disease community. Personal stories from individuals and families are central in driving our work and our impact and we have always been an authentically patient-centric organisation whilst striving for growth. Our name and remit have historically focused on our relevance and strength as a UK-based organisation supporting UK communities and have for the past seven years been called Metabolic Support UK.

THE NEXT STEPS

We have evolved and now offer diverse services, support and advocacy across our impressive range of work. Over the course of a week, we can be found: responding to government policy consultations, hosting community quiz, advocating for social care support, providing sector-leading consultancy with commercial partners and helping connect communities across the globe. Building on this rich, community-built legacy, our work and reach have grown beyond the UK. As our community has expanded internationally, it is important that our name reflects the global nature of the support we provide and research we do, ensuring our doors are open for the 1.43 million people living with IMDs worldwide. That is why this Rare Disease Day 2026 we are proud to share we are changing our name from Metabolic Support UK to Metabolic Support. This is an evidence-driven evolution designed to better reflect what we already do and to help more people find and reach us.

Whilst we remain fully committed to supporting families and healthcare professionals in the UK, our work now also reaches communities, shares resources, and supports collaboration across borders. We can and will help everyone living with an IMD to live well today, tomorrow and beyond. As we grow internationally, we remain committed to ensuring every individual with an IMD has access to the support and resources they need, wherever they live. Our new name, Metabolic Support, reflects this ambition while keeping our UK community at the heart of everything we do

OUR GLOBAL COMMUNITY

Metabolic Support is already working to support our global community:

- **International Enquiries:** From 2024-2025, we received 152 international enquiries from 47 countries, equating to 23% of all enquiries in the year, a 58% increase from 2023-2024
- **Website Insights:** In 2025, 40% of the 90,000 annual website users were from outside of the UK with visitors from 187 countries with top countries ranging from the USA and Canada to India, Turkey and Brazil.
- **Think Ammonia campaign:** Our first international campaign; shared across nine countries with healthcare professional education webinars delivered in: Ukraine, Pakistan, Peru and for over 187 European healthcare professionals with MetabERN. We have co-created the rare disease curriculum in Peru and Pakistan to include hyperammonaemia training,
- **Metabolic Support Sri Lanka (MSSL):** In March 2026, we launch our first international patient group branch.
- **HPP United:** In collaboration with Soft Bones US we are the lead partner in an international cohort of patient groups for people living with HPP
- **ISNS – International Newborn Screening Group:** Collaborating with the CDC, WHO, and global experts to share learnings and improve newborn screening, helping low- and middle-income countries achieve earlier and more accurate diagnoses.
- **EURORDIS – Pan-European Rare Disease Organisation:** Members and co-founders. Three staff completed the EURORDIS Open Academy training, we sit on the Social Policy Action Group.
- **International conferences:** Sharing our insights in person, including a poster at World Orphan Drug Congress (Barcelona) and running sessions at SSIEM (Portugal) and ICIEM (Japan), influencing care and practice globally.