

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

METABOLIC SUPPORT UK

Annual report and unaudited financial statements for the year ended 31 March 2025



METABOLIC SUPPORT UK

LEGAL AND ADMINISTRATIVE INFORMATION

TRUSTEES

Miss R E Lindup (Appointed 4 August 2023)
Mr P A Cox (Appointed 4 August 2023)
Mr A F Lemoine (Appointed 4 August 2023)
Dr R E Pugh (Appointed 9 August 2001)
Mr P J Roper (Appointed 9 September 2003)
Mr C Lander (Appointed 2 September 2020)
Dr R Sharma (Appointed 18 April 2024)
Dr R Vara (Appointed 27 March 2019)
Mr Scott Mason (Appointed 9 August 2024)

CHARITY NUMBER (ENGLAND AND WALES)

1089588

CHARITY NUMBER (SCOTLAND)

SCO44634

COMPANY NUMBER


04267454

REGISTERED OFFICE

Centurion House
129 Deansgate
Manchester
M3 3WR

The trustees' report was approved by the Board of Trustees on December 19th 2025.

Mr P A Cox, Co-chair of trustees



My C Lancer, Co-chair of trustees



THE TRUSTEES PRESENT THEIR ANNUAL REPORT AND FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2025.

The financial statements have been prepared in accordance with the accounting policies set out in note 1 to the financial statements and comply with the charity's governing document, the Companies Act 2006, the Charities and Trustee Investment (Scotland) Act 2005, the Charities Accounts (Scotland) Regulations 2006, FRS 102 "The Financial Reporting Standard applicable in the UK and Republic of Ireland" and the Charities SORP "Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)".

PUBLIC BENEFIT

The trustees have paid due regard to guidance issued by the Charity Commission in deciding what activities the charity should undertake.

OBJECTIVES AND ACTIVITIES: INTRODUCTION TO MSUK

Metabolic Support UK is an umbrella patient organisation founded in 1981, supporting and advocating for people living with Inherited Metabolic Disorders (IMDs) and their communities. We support over **40,000 people** living with one of **nearly 2000 IMDs** in the UK and a large international community. IMDs are rare, lifelong genetic disorders caused by an enzyme deficiency affecting the metabolic pathway which, if undiagnosed or untreated, can cause irreversible complications, or sadly even death.

Metabolic Support UK delivers a wide range of support and advocacy services to address unmet needs for all IMD communities but with a focus on those for whom there is no established patient organisation. Using qualitative and quantitative data generated via diverse methodologies, our small and dedicated team works to proactively identify priority needs. We develop evidence-based outputs and programmes to ensure the maximum impact for individual patients, collective patient communities and the wider IMD community.

Our vision for the future: By 2030, Metabolic Support UK wants to see advances across all care and services for the IMD community. This includes early diagnosis, informed and empowered patients, and access to the treatments and services that are available to support families living with these conditions to enjoy a better quality of life.

Sadly, loss is a part of our community, and we are deeply saddened by the loss of two cherished members of our community, Billy Slater and Clara Canbolat, whose young lives touched all who had the privilege to know them. Their passing is felt profoundly across our charity family, and we hold their loved ones in our hearts as we honour their memory and the light they brought to our community.

ORGANISATIONAL DEVELOPMENT

This was a year of investment and development for MSUK, with a strong focus on investing in our valued team and board. As a small remote team, we need to actively curate and seek opportunities for shared learning and development to better inform our work and strengthen our impact. A key milestone was our Strategy Day on 2 May 2024, which brought together the team and board, alongside targeted training and investment across the team.

We also expanded our consultant model, working with external specialists to add value to our work and to ensure our team benefits from expertise from across the sector, including a life science consultant and administrative support. Our co-chair model has proven valuable over the year, strengthening shared leadership and governance, with lived experience embedded into all that we do. Our Co-chairs, Paul Cox and Carl Lander, bring a powerful combination of lived experience alongside professional expertise in rare disease networks and organisational management.

Central to all of this remains our commitment to engaging with our community, ensuring learning, insight and lived experience continue to shape and strengthen our work.

REVIEW OF APRIL 2024 - MARCH 2025: ACHIEVEMENTS & PERFORMANCE

This year's work shows the reach a small, skilled team can have when it works strategically and stays rooted in lived experience. At the core is individual support; we responded to 663 enquiries, a significant increase on last year, supporting people affected by over 200 inherited metabolic disorders. Support ranged from one-off information to ongoing emotional and practical help around diagnosis, treatment, education, employment, bereavement and relationships. Tracking enquiry trends has helped us strengthen peer support through Metabolic Connect and begin developing an in-house counselling offer.

Our campaigns are leading the way in rare disease; we delivered prevention and awareness impact through Think Ammonia which had a successful first year combining training, translated resources and digital content reaching 100,000+ people, while FOI work highlighted systemic gaps in ammonia testing. Our campaign drives real-world improvement, not just visibility. Despite our small team, we sustained strong policy and system influence. We were strongly represented in national working groups expanding the UK newborn screening panel, represented communities across UK and international screening bodies, and supported improvements overseas, including in Sri Lanka. We also contributed to consultations and advocacy on rare disease policy and wider pressures affecting families.

We also delivered substantial health technology assessment (HTA) work, making sure patient voices shaped decisions about treatment access. We led community engagement and patient group submissions for NICE and SMC assessments for treatments for MoCD type A and ARG1 deficiency, including surveys, consultation responses and committee participation. In Scotland, this helped achieve conditional approval to allow further data collection — a clear example of patient advocacy influencing access pathways. Finally, we continued building connection through our annual conference, our first UCD Day, and strengthened online engagement — creating spaces where people feel informed, supported, and less alone.

MSUK is a small team delivering connected impact: frontline support, public health campaigns, policy influence, treatment access work, and community building, all focused on improving lives for people living with IMDs.

INDIVIDUAL SUPPORT

Our individual support focuses on providing those living with IMDs with emotional and practical support tailored to individual need. Offered via, phone, email, social media or video calls, support is provided by our experienced team and may vary between short one-off enquiries or longer-term support. We build vital support networks and act as advocate in a range of fields including education and employment. Each request needs time; we explore the context surrounding each enquiry to allow us to determine what additional support may be required and to ensure that the enquirer is aware of all support on offer. This may include identifying local support for the family, seeking peer support opportunities, or signposting to external organisations offering dedicated disorder-specific support where available.

Our data allows us to see peaks and trends in the themes of enquiries and to develop resources addressing unmet need. Establishing trusted relationships takes time and we facilitate peer support so those with lived experiences can share these with others who may be approaching or considering these themes. Such conversations may be facilitated via our dedicated IMD peer support programme, **Metabolic Connect**.

WHO HAS CONTACTED US AND WHAT SUPPORT DID WE PROVIDE?

In 2024-25 we received a total of **663 enquiries**, a 34% increase from the previous year. This dramatic rise in numbers of people reaching out to us for support which can be attributed to improved signposting and accessibility to our information. The majority of these were via email (45%), Website (27%), Phone (22%), Social Media (5%), and meetings, clinics, letter, texts, and video calls making up the remaining 1%.

Enquiries received were in relation to 200 different IMDs, with Medium Chain acyl CoA Dehydrogenase Deficiency (MCADD), Hypophosphatasia (HPP), Ornithine transcarbamylase deficiency (OTC), Maple syrup urine disease (MSUD), and Trimethylaminuria (TMAU) being the most popular. Across the groups, however, our highest number of enquiries fell within the fatty acid oxidation disorders group. Our most popular themes of enquiry were seeking diagnosis, treatment and management, disorder information, and peer support. Those under the 'seeking diagnosis theme' were those who either did not have a diagnosis but either they or their healthcare provider believed they may have an IMD. This also includes those undergoing confirmatory testing for a suspected IMD.

We saw dramatic increases in numbers of enquiries for emotional support, relationships, bereavement, and genetic counselling which has helped to shape our work for the year ahead and has influenced us to begin establishing an in-house counselling service.

INTERNATIONAL ENQUIRIES

We received 152 international enquiries (23% of total) from 38 countries. This was an increase of 58% on last year. Most were seeking information about how to access treatments or potential new therapies (8%) and to seek diagnosis (8%). Enquirers also wanted to understand more about the treatment and management of their condition (7%) or were looking for wider information about a specific IMD (6%). 34% of international enquiries were from low-and middle-income countries (LMICs). 19% of these were relating to accessing treatments, 17% relating to understanding the treatment and management of their IMD and 11% seeking to migrate from their country to access treatment elsewhere. We can attribute this to a lack of access to specialist services and knowledge. Public reimbursement for potential new therapies is not common and there is little opportunity to fund access privately and very poor availability of insurance programmes to assist.



ENQUIRIES IN A NUTSHELL

INDIVIDUAL SUPPORT ACHIEVEMENTS 2024-2025

Clinic Visits

Building on success in early 2024, we expanded our clinic visits to include Birmingham Children's Hospital (25 November), Evelina Children's Hospital (13 May and 29 July), Great Ormond Street Hospital (6 June and 19 September), Leicester Children's Hospital (5 December), Nottingham Children's Hospital (25 September and 13 November), and Salford Royal Hospital (9 October). These visits have strengthened our relationships with the Metabolic clinical teams and ensured families can meet us in a face-to-face setting.

Improved connectivity = improved support

Our community and team benefitted from improved connectivity with our professional network. This included attendance at the BIMDG 2024 annual meeting where we had open discussions around transition programmes and support, paving the way for new resources for families and training support for professionals, we also discussed future clinic visit opportunities, experiences of HCPs in the South West, and had some extremely useful conversations about exercise and IMDs which tied in with our Living Well Movement. Our clinic attendance provided a unique opportunity to talk candidly with metabolic teams about any new ideas, any gaps in information and support resources and determine areas of work where MSUK could meet this need. We also benefitted from support from clinic teams UK-wide in disseminating our leaflets for clinic/healthcare settings to improve awareness and signposting.

In Q4 a news article was published in mainstream media about the potential for many Autism diagnoses to be a result of a form of Cerebral Folate Deficiency which could be treated cheaply and pushed for people to have a specialist test that is unavailable in the UK. Our connections within IMD and neurology teams benefitted us, and we gained their support to draft a statement to manage high enquiries on this topic and to reduce confusion. Further support from specialist metabolic bone disease consultants to assist in responding to enquiries around barriers in referrals being made.

We began to facilitate online video calls for those struggling with financial support forms. We sat with one family for three online sessions to support with the completion of a DLA appeal form talking through the daily impact of the condition and accumulating the information concisely in the form. The combination of both practical support and a listening ear was beneficial for this family as the process can bring up difficult topics and memories. The child's DLA was awarded following the appeal. Similar successes have been had with others applying for or appealing PIP decisions with tailored support and understanding making a vast difference in the collation of evidence.

We continued collaborative efforts in the roll-out of the Inherited White Matter Disease (IWMD) Specialised Service and development of the Patient Registry which improves knowledge of this group of conditions and access to care and specialist advice. The registry and service are both now live.



**MSUK
STATEMENT
ON MTHFR
ENQUIRIES**



Metabolic Connect:

Peer Support continues to be one of the highest trends of enquiry theme with many seeking connection, mutual understanding, lived experiences, and by way of reducing isolation. In 24/25 a further 65 people have joined Metabolic Connect, with this number largely being those who have an IMD that does not have an online community available. The majority we have connected through this service have a diagnosis of Trimethylaminuria (TMAU), an IMD which has no treatment and can lead to isolation and poor mental health.

Peer support for this community is therefore of high importance as is the MSUK wrap around support that reinforces the programme. We use any trends in IMDs coming to us for peer support to identify need for future community building and other resources, as well as identifying gaps in need. The routine phone calls with new sign-ups to the programme, gives clear introductions to the service, the chance to ask any questions, and a direct point of future contact. In addition, it provides an overview of all MSUK support and resources and assists people to access other services or engage with other areas of our work.

BUILDING COMMUNITIES

Living with a rare IMD can feel isolating for both the people living with the condition and their families or caregivers. We continue to work to reduce isolation by helping bring people together to share experiences and seek advice. Anyone affected by an IMD can join our disorder-specific online communities, access one-to-one introductions, or find wider peer-to-peer support. Throughout this support, we remain committed to removing barriers and creating spaces that are inclusive, safe, and accessible for our community.

In the 2024/25 year, we focused on strengthening and expanding our existing disorder-specific groups, now numbering at 56 communities. Membership across these groups grew by 11,859, bringing the total to 53,770 members by the end of March 2025. Taking time to deepen our understanding of these communities continues to provide valuable learning and engagement opportunities, laying a strong foundation for further growth and the development of new groups in the years ahead.

In 2024/2025 we focused our work on building connections with some of the Patient Advisory Groups which we were looking to collaborate with over the next few years, we connected with ARG1d Foundation, who helped with our survey and have become long-term partners, we were also able to facilitate a break-out session for them at our Community Conference in November 2024. We also connected with Lily Foundation - who we spoke to about TK2d. We attend the MitoAction event, Tango2 Family Day, NSPKU conference, Brittle Bone Society Day and Cystinosis UK Conference.



ONLINE ENGAGEMENT

Online spaces remain a lifeline for many in our community, and they continue to be a central focus of our work. Building on last year's progress, we placed greater emphasis on creating content that is relevant, consistent with our brand voice, and offers real value to those who engage with us.

Across all our social media platforms (Instagram, Facebook, X/Twitter, and LinkedIn), these efforts resulted in stronger engagement, reflected in increased reactions, followers, shares, and comments. Our approach goes beyond posting, we actively engage by resharing content, joining conversations, and responding to community members. This consistent presence has strengthened trust and visibility, leading to more people tagging us, signposting to our services, and reaching out for support through these channels.

Social media continues to act as a gateway for deeper engagement. This year, we launched the Think Ammonia! campaign across our platforms and within relevant disorder groups. The campaign sparked widespread discussion—celebrated by many and constructively challenged by others—prompting important conversations. These discussions led to dedicated online sessions that brought the MSUK team and the UCD community together for shared learning, further strengthening relationships and understanding.

Every interaction provides valuable insight, helping us refine our approach and connect more meaningfully with those we support.



BUILDING COMMUNITIES ACHIEVEMENTS 2023-2024

Annual Conference:

In November we hosted our annual Community Conference in Birmingham, we had over 100 people attend, representing a wide range of our community. We had guest speakers, including our staff giving advice on financial support, PIP & DLA. Our community enjoyed coming together and key feedback was 'informative, inspiring, fun, networking, welcoming, awesome'.

MSUK's First UCD Day:

On Saturday 29 June 2024, MSUK hosted its first Urea Cycle Disorder (UCD) Day at the Anomalous Space in London. This inaugural event was created to bring together people living with, and caring for people living with, UCDs for peer connection, shared learning, and community support in a relaxed, informal setting.

Thirty-nine individuals attended, representing 17 families from across the UK and five of the eight recognised UCDs. The group included adults with long-term experience of managing their condition, as well as young children and newly diagnosed families attending a community event for the first time. Although there was no set agenda, discussions were wide-ranging and reflected the community's priorities. Attendees connected over practical aspects of daily management, alongside the emotional impact of diagnosis and ongoing hospital involvement.



Many reported that sharing experiences reduced feelings of isolation and increased confidence about future stages of life. Growing up with a UCD and transitioning into adulthood were prominent themes. Participants highlighted the need for resources to support young people as they gain independence, and for long-term planning where supported living may later be required.

Parents and caregivers discussed varied experiences of transition to adult services, including concerns about losing access to appointments after age 18, fear of letting go of responsibilities they have held for years, and a lack of provision to support families through these changes. Access to treatment and care also generated significant discussion. While families welcomed the advancement of therapies, they also raised ongoing challenges, interest in home ammonia testing, transplant pathways, and MSUK's Think Ammonia! campaign was strongly supported, prompting personal reflections on hyperammonaemia and remembrance of those lost to UCDs.

The event aimed to be inclusive of all in the UCD community with a family-friendly children's activity table running all day and a low-protein lunch and refreshments, provided by DOM Catering. These meals were developed with Chloe Millington, Specialist Dietician at Great Ormond Street Hospital, ensuring dietary needs were met while remaining enjoyable and familiar. To support equitable attendance, MSUK introduced a Travel Assistance scheme to offset travel and accommodation costs. Families reported this support was essential in enabling participation.

An information area offering leaflets and resources from MSUK and partner organisations, including Bloomsbury, iECURE, Immedica, Lucane and Nutricia, was well used and praised by attendees.

Feedback consistently emphasised the value of meeting others in person who understand the realities of living with a rare condition, and of being able to talk openly in a supportive environment. **“Having a rare condition in the family brings up so many questions for us, it was nice to be able to share some our tips and successes and also learn from others”.**



**OUR
UCD
DAY**

EMPOWERMENT

We want to ensure that people living with IMDs are well informed about their choices, at all stages of their life and condition. Our communities should have the means to assert their right to access care or treatment that should be available to them, as well as the ability to provide good self-management.

EMPOWERMENT ACHIEVEMENTS 2024-2025:

Full Website Redesign:

2024 saw the full redesign of the Metabolic Support UK website, a significant step in strengthening how we inform, support, and empower the metabolic community.

The refreshed site offers clearer navigation, improved accessibility, and a more engaging way to explore our services, stories, and resources. As a central point for individuals, families, and professionals, the new design enhances our ability to share vital information and amplify the work of the partners we collaborate with.

This redevelopment also lays strong foundations for continued growth, ensuring the website can evolve in line with the needs of those we serve. Total page views for 2024 reached 57,774, a 136.6% increase from 24,417 in the previous year.



Monthly Medicines Roundups:

Further strengthening the offer of our online presence, we launched our "Monthly Medicines Roundups" that are released on the first of every month, recapping the latest developments in treatments for IMDs over the past month, highlighting MSUK's involvement and sharing ways people can get involved e.g. responding to research needs or engaging in NICE appeal meetings.

Latest News Releases:

Throughout the year, numerous articles have been posted on our latest news section of the website, providing our communities with information on a wide range of topics. This included details about updates on the UK Government's budgets, Treatment Updates, Whole Genome Sequencing and Newborn Screening amongst others. These articles are easy-to-understand and provide details that our communities can utilise to support us in our advocacy activities and to advocate for themselves.

Research Ready Hub & E-Modules

In July 2024, MSUK launched the Research Ready Hub, a dedicated space offering information, resources, and research links. The hub empowers our community to be "research ready" and actively engage in research opportunities. Here, we also share condition specific trials and have shared information on four OTC trials from industry partners. Further building on this, we have utilised the LearnDash LMS to develop in-depth e-modules on topics ranging from medicines development, excipients and metabolic crises.



Generation Study:

Recruitment to the Generation Study began in 2024, aiming to screen 100,000 newborn babies for over 200 genetic conditions (almost half of which are IMDs).

Metabolic Support UK provided significant contribution to this study, publishing articles web pages with guidance on the study, we also reviewed 20 patient information leaflets on request of Genomics England, ran an insight survey to understand our community's views and took part in a parliamentary drop in event alongside Genetic Alliance UK and Genomics England to share our thoughts on the study.



Rare Disease Research Network

In October 2024, our Head of Insight & Advocacy, Laura Smith van Carroll, joined the management team of the newly established Rare Disease Research Network (RDRN). A project aiming to support the rare disease community in building an online network of partnerships and resources to facilitate new patient-centred research opportunities. Throughout 2024, Laura attended several virtual and in-person meetings to support the running of the organisation through decision-making, setting goals, reviewing and guiding the overall direction of the organisation. In November 2024, the RDRN officially launched, enabling PAGs and community members to actively participate in and lead research related to their disorder.

National Clinical Homecare Association (NCHA) Patient Advisory Council

In 2024, Metabolic Support UK joined the National Clinical Homecare Association's Patient Advisory Council, ensuring that the voices and experiences of the IMD community directly inform decision-making at a national level. By participating in discussions on Clinical Homecare standards and policy, we strengthened our ability to advocate for equitable, high-quality services. This role empowers individuals and families by ensuring their concerns are represented at the earliest stages of planning and improvement, helping shape a system that better reflects their real-world needs.



Partnership with Sciensus

In 2024, Sciensus selected Metabolic Support UK as one of their charity partners, strengthening our shared commitment to improving homecare experiences for people with IMDs. Through this partnership, Sciensus shared insights from their patient satisfaction surveys, enabling us to highlight community priorities and influence service improvements.

We also visited their Burton-on-Trent site to present our work and gain a clearer understanding of how medicines are managed and dispatched. This insight helps us empower families with accurate information about their treatment journeys and ensures that lived experience continues to guide homecare service development.

Engagement with Lloyds Pharmacy Clinical Homecare

We met with Lloyds Pharmacy Clinical Homecare to present the work of Metabolic Support UK and explore opportunities for stronger partnership working. Through this engagement, we championed the needs of the IMD community and promoted approaches that give patients greater confidence, clarity and choice in how they receive essential treatments.

Decoding Diagnostics Training

Our team attended Beacon's 'Decoding Diagnostics' training series to expand our understanding of the complexities of genetic testing. Through learning about testing processes, ethical dilemmas and the challenges surrounding private genetic testing, we are now better equipped to empower families to navigate diagnostic pathways with confidence. These insights support our ability to develop clearer, more accessible resources that help community members make informed decisions and self-advocate in clinical environments.

National Society for Phenylketonuria (NSPKU) Annual Conference:

By participating in the NSPKU annual conference, we expanded our understanding of emerging research and innovative projects within the PKU community. The event provided an opportunity to celebrate the work of peer organisations and develop relationships that open new avenues for collaborative support. Strengthening these networks empowers the broader community by ensuring shared learning and coordinated advocacy across metabolic conditions.

BIMDG Nurses Study Day

We presented at the BIMDG Nurses Study Day on the importance of facilitating positive, empowering conversations during transition from paediatric to adult services. By sharing lived experiences and highlighting the challenges young people frequently face, we helped clinicians better understand how to support autonomy, confidence and self-advocacy during this pivotal stage. This work directly contributes to empowering young people with IMDs to take an active role in their own care.

ADVOCACY

Those living with rare metabolic disorders often navigate complex and under-resourced systems. Our role is to make their voices impossible to overlook. By gathering and sharing real lived experiences, we help shape national dialogue, inform policy, and advocate for improvements that lead to better outcomes for patients and families.

Those living with rare metabolic disorders often navigate complex and under-resourced systems. Our role is to make their voices impossible to overlook. By gathering and sharing real lived experiences, we help shape national dialogue, inform policy, and advocate for improvements that lead to better outcomes for patients and families.

ADVOCACY ACHIEVEMENTS 2023-2024

Adult Rare Bone Disease Network

This rare disease collaborative network was established to improve care for adults living with rare bone diseases. As the umbrella organisation for six charities supporting people living with these conditions, we were asked to join the secretariat and to provide significant support to the network. As part of this role, we have developed web pages which act as a homepage for the network. This is used by people living with rare conditions and NHS professionals to submit cases for review by experts in the field. We have also undertaken education of our communities about the network and have so far reached 3000 people.



SPOTLIGHT ON: THINK AMMONIA

In 2024, we launched the Think Ammonia campaign, aiming to improve outcomes for our communities at risk of hyperammonaemia.

In our first year, we have:

- Distributed over 600 posters to hospitals, GPs, metabolic centres and universities, with QR codes linking to guidance that have been scanned over 200 times.
- Shared community videos highlighting lived experience and emphasising the urgency of rapid testing, reaching over 100,000 people.
- Presented at 25 events, including:
 - A high ammonia healthcare professional training event with 333 healthcare professionals,
 - A University of Oxford event for trainee doctors with 60 attendees
 - The MetabERN conference in Budapest with 100 attendees ranging from clinicians to researchers
- Translated our materials into eight languages and shared them across Italy, Sri Lanka, Peru, Pakistan, Afghanistan and Greece with our English posters also shared in the USA and Canada.

We have also sent freedom of information requests to 41 hospitals revealing systemic gaps: on average, one in seven samples were rejected, with some sites rejecting over 50%, and in many hospitals fewer than 1% of patient attendances resulted in testing. Where totals were provided, ammonia tests per site ranged from 64 to over 2,000, averaging 620.

Building on this first year, we are focusing on education, research, and international impact, including providing case studies to the Royal College of Emergency Medicine, delivering webinars and training, researching transplant-related causes of high ammonia, supporting global adoption of materials, and publishing FOI findings to improve outcomes.



**UNIVERSITY
OF OXFORD**



**OUR UCD
DAY**



**TRANSLATED
POSTERS, PERU**

Tyrosinaemia Type One Rollout

Metabolic Support UK were the only patient organisation involved in the working groups tasked with expanding the UK's national screening panel from 9 to 10 conditions. As part of this role, we regularly attended meetings with members of the UK National Screening Committee, the NHS and the UK Health Security Agency. Our role within these meetings was to advocate for our communities to ensure their voice is heard, providing insight on documents, processes and timelines to ensure this rollout is effective and represents what our communities need. We have also engaged our communities and other charities we represent about this work, improving transparency around these complex processes.

Newborn Screening:

We represented our communities on the IMD Screening Advisory Board for England, the Newborn Bloodspot Group for Wales, and the ISNS International Neonatal Screening Group, alongside organisations such as the World Health Organization, the Centers for Disease Control, and the American Society for Haematology. In these roles, we attend regular meetings, review key documentation, and provide insights on newborn screening, ensuring the voices and concerns of our communities are heard and addressed.



Sri Lanka:

Throughout 2024, we supported a leading group of experts in Sri Lanka focused on inherited metabolic disorders, led by Dr Imalke Kankanararachchi, Secretary of the Sri Lanka College of Paediatricians and Head of the country's Newborn Screening Laboratory, and Nuclear Medicine Unit. Alongside this group, we worked collaboratively to drive forward the expansion of newborn screening in the country, supported the development of a rare disease registry and developed translated country specific resources and web pages as part of our Think Ammonia campaign. As a direct result of this campaign, Dr Kankanararachchi arranged for the country's first point-of-care ammonia analyser, which he used to successfully identify hyperammonaemia in a patient, enabling prompt treatment and an improved prognosis.

Policy responses and signing open letters:

We responded to a wide range of policy consultations in 2024, including NICE consultations on new medicines, rare disease policy, and the Change NHS consultation that informed the NHS 10-year plan. Our contribution to the England Rare Disease Action Plan consultation was also recognised by DHSC, which referenced our Thoughts into Action report in the 2025 iteration, acknowledging the importance of focusing on the wider determinants of quality of life as identified through this research. Further to our policy responses, we have also acted as signatories on open letters ranging from a EURORDIS open letter calling for European leaders to develop a European Action Plan for Rare Diseases to letters advocating for reduced energy and water bills for our communities.

Advocating for the IMD community at an international level:

At the World Orphan Drug Congress in Boston, United States of America, in April 2024, we were invited by Sciensus and Worldwide Clinical Trial to speak on the value of patient support programmes and engagement of industry and CROs with PAGs. At the Society for the Study of Inborn Errors of Metabolism's (SSIEM) annual conference, in September 2024, we convened a session on cultural differences of living with an IMD, inviting four PAGs from other countries to share their perspectives and case studies.



SPOTLIGHT ON: LIVING WELL

Living Well (The Campaign):

The campaign is about shifting rare disease thinking from “just healthcare” to real life. Yes, diagnosis and treatment matter, but the report makes the point that people’s quality of life is shaped by loads of other things too — like identity, work, benefits, food and diets, mental health, and big life transitions (school → work, becoming independent). The campaign is pushing for a more joined-up, rights-based approach so people aren’t constantly battling systems just to live a decent everyday life.

Living Well (the Symposium):

The Symposium was the campaign in action. It brought together people with lived experience and professionals from policy, health, law, and advocacy to dig into one big question: what does it actually mean to “live well” with a rare condition? Through keynotes and a panel, it highlighted where things currently fall short (like workplace discrimination, gaps in support, and systems that make people prove they’re ill enough), and it helped turn those experiences into clear messages and practical next steps for future change.



“Living Well isn’t about curing rare diseases. It’s about living fully, irrespective of (diagnosis)”



**ATTENDEES
AT THE
LIVING WELL
SYMPOSIUM**



**TRUSTEE,
CARL
LANDER
SHARING
HIS LIVED
EXPERIENCE**



**GARETH SNELL
MP, DELIVERING
THE OPENING
ADDRESS AT
OUR
SYMPOSIUM**



Representation at national and international conferences:

Between April 2024 and March 2025, we had a stand at several national and international conferences to engage with the community and other stakeholders. Most notably, we were back at the British Inherited Metabolic Disorder Group meeting in June 2024, where we reconnected with HCPs and industry representatives and met numerous new HCPs, industry and CRO representatives. In July 2024, we were invited to the Cystinosis Network Europe bi-annual conference in Manchester, where we launched an insight project into the lived experience of people with cystinosis.

Newly established representation on National Forums

Between April 2024 and March 2025, we established connections with a number of valuable stakeholders in the healthcare space. Most notably, we reached out to medicines and healthcare products regulatory agency (MHRA), All Wales Therapeutics and Toxicology Centre (AWMSG) and the National Institute for health and Care Excellence (NICE). Varying levels of interaction were established, which resulted in joining the MHRA's Patient & Public Community, NICE's Voluntary and Community Sector's Forum and the National Clinical Homecare Association's (NCHA) Patient Advisory Council.

Representation on National Forums and Groups

We sit on forums and groups that allow us direct opportunities to represent people living with or caring for someone with an inherited metabolic disorder, thereby influencing UK policy, access to treatments and on-going care:

- Adult Rare Bone Disorder Network
- Genetic Alliance UK
- IMD Newborn Screening Advisory Board (Public Health England)
- Inherited White Matter Disorder Group
- Metabolic Clinical Referencing Group (NHS England)
- MHRA's Patient & Public Community
- Newborn Bloodspot Screening for Wales
- NCHA Patient Advisory Council
- NICE's Voluntary and Community Sector's Forum
- Patient Engagement Group (Genetic Alliance)
- Rare Disease Framework Forum (gov.uk)
- Tyrosinaemia type 1 rollout group
- PNPO Research Project
- Rare QOL
- Specialised Healthcare Alliance (SHCA)
- X-Linked Hypophosphatasia with Kyowa Kirin

MSUK Insight Services

In 2021/22 we launched our ambitions to deepen and expand our insight services, providing best practice patient insight for all stakeholders. Much of 2023/24 focussed on building an insight pipeline. Throughout 2024/25 we have continued to build on this foundation, progressing the initiatives begun in early 2024 and further strengthening our capacity, reach, and impact across the IMD community. Examples of these projects in 2024/25 include:

Lexicon Review:

In 2024/25, Metabolic Support UK engaged with an industry partner to support its ambition to strengthen people- and patient-centred practice. The company sought an expert review of key terms and their definitions, assessed against three standards: intelligible, appropriate and inclusive. We contributed to this work by drawing on the complementary expertise within our team. Our Individual Advice Lead and Community Lead undertook independent reviews of all terms, each bringing a distinct perspective shaped by their frontline experience in individual support and community engagement. Their feedback was then synthesised by our Head of Insight & Advocacy to ensure a balanced and consensus-driven outcome. The final, consolidated recommendations supported the company in refining its lexicon in a people- and patient-centred fashion.



Lived experience of nephropathic cystinosis:

At the beginning of 2024, a survey, originally developed by the Dutch and Flemish cystinosis patient organisation, was translated and revised to include UK-specific topics. A dissemination plan was developed, together with Cystinosis Foundation UK and Kidney Research UK, including the launch of the survey at the 2024 Cystinosis Network Europe bi-annual conference in Manchester. A total of 39 responses were received, which were analysed and summarised in a poster about "The Impact of Different Cysteamine Formulation on the Lives of People Living with Cystinosis". Results were also used to inform our response to the Clinical Priorities Advisory Group (CPAG) policy proposition on delayed-release mercaptamine bitartrate.

True Faces of Rare

In 2024/25, we began exploratory conversations with Chiesi to address a key gap in the preferences of people living with rare diseases and their communities regarding the use of authentic imagery in disorder-specific materials. To better understand the community's needs, we conducted a survey asking individuals and families affected by rare diseases how important it is to see people affected by their condition in disorder-specific materials, and why.

The response was overwhelmingly clear: authenticity matters. Participants emphasised that accurate, relatable imagery helps foster understanding, reduces stigma, and ensures that lived experiences are represented with dignity. We analysed these insights and published the findings in the Elsevier Rare journal, which was launched shortly before Rare Disease Day 2025, helping to raise broader awareness of the importance of authentic visual representation in rare disease engagement. Subsequently, we initiated discussions to bring these results to a bigger audience, by hosting a dedicated event for True Faces of Rare in 2025.



Health Technology Assessments

Involvement in UK health technology assessments (NICE, SMC and AWMMSG) allows us to ensure that our community's voice is heard throughout the entire process of assessing the appropriateness of including a new medication in the NHS. Below is an overview of our health technology assessment work in 2024/25:

Fosdenopterin (Nulibry):

A treatment for people living with molybdenum cofactor deficiency (MoCD) type A, is being reviewed by NICE under its highly specialised technology pathway and by SMC, under its ultra orphan assessment pathway. MSUK initiated formal data collection alongside the international MoCD community to support the patient group submission to NICE and SMC in February 2024. Collected data was analysed and a patient group submission was developed for both NICE and SMC in Q1 of 2024. Alongside a community representative, we attended the NICE committee meeting and shared the experiences of the community living with MoCD type A, as well as that of carers of both people living with MoCD type A and those that have passed away as a result of the condition. In September 2024, negative draft guidance was published, which we sought to address by surveying both the community and HCPs. Responses were summarised and submitted during the consultation period. As of March 2025, the NICE assessment was still ongoing. In parallel, SMC held its committee meeting, which we also attended, sharing the perspectives of the community. In January 2025, SMC approved the treatment for a limited duration of approximately three years to allow for additional data collection.

Pegzilarginase (Loargys):

An enzyme replacement therapy for the treatment of people living with arginase-1 deficiency (ARG1d) is being reviewed by NICE under its highly specialised technology pathway. We initiated formal data collection alongside the international ARG1d community, and were later joined by the US-based ARG1d foundation to increase the surveys reach. Collected data was analysed and a patient group submission for NICE was developed. Alongside a community representative, we attended the NICE committee meeting and shared the experiences of the community living with ARG1d, as well as that of carers of both people living with ARG1d and those that have passed away as a result of the condition. In September 2024, negative draft guidance was published, which we sought to address by surveying both the community and HCPs. Responses were summarised and submitted during the consultation period. As of March 2025, the NICE assessment was still ongoing.

**TREATMENT
FOR ARG1D:
CALL TO ACTION**



NICE draft guidance does not recommend pegzilarginase for the treatment of ARG1d. Find out more and help us respond to the public consultation.

Triheptanoin (Dojolvi):

The assessment of Triheptanoin (Dojolvi), a treatment for people with one of the six long-chain fatty acid oxidation disorders (LC-FAODs), was initiated by NICE in October 2024. With input from the community we submitted comments to the scoping consultation. The scoping meeting was held in December 2024, which we attended together with a community member to further discuss the scoping document and experiences of those living with an LC-FAOD. In January 2025, we launched formal data collection during the US-based MitoAction virtual Town Hall meeting. As of March 2025, data collection was still ongoing as the NICE process was delayed at the request of the company.

A policy proposition by CPAG for mercaptamine bitartrate (Procysbi), a treatment for people living with nephropathic cystinosis, was disseminated for stakeholder testing in October 2024. Utilising the evidence we collected through the lived experience of nephropathic cystinosis research project, we submitted a response sharing the experiences of the nephropathic cystinosis community. In December 2024, CPAG shared that no funding is currently committed to the policies from previous prioritisation rounds, leaving mercaptamine on hold until funding can be identified.

FUNDRAISING

Metabolic Support UK's community of fundraisers and donors continued to find creative ways to raise funds. From new to returning fundraisers, their endeavours are invaluable to our work and as always, we are grateful for their hard work and support.

As a rare disease charity, everything we do is rooted in our community. From the very beginning, we have fundraised directly alongside the individuals and families we exist to support. Our community-led fundraising efforts reflect the trust, generosity and shared determination of people who understand first-hand the challenges of living with rare and inherited metabolic conditions.

Alongside this, we are grateful to receive vital support through sponsorship and our valued commercial partners. These partnerships enable us to grow sustainably, extend our reach and invest in services that make a meaningful difference to the lives of those affected by metabolic disorders.

We have also strengthened our financial resilience through an increase in paid-for work delivered via our MSUK Insight service. By sharing our expertise, lived experience and data-driven insight, we are able to support research, industry and healthcare while reinvesting this income back into our charitable mission.

None of this would be possible without our incredible donors and regular givers. Your generosity underpins everything we do – from providing practical support and trusted information, to influencing policy and improving care. Every donation, whether one-off or ongoing, plays a vital role. We are deeply grateful to each and every supporter. You truly make a huge difference, and together we are creating lasting impact for the metabolic community.

The organisations that provided funding towards Metabolic Support's activities in 2024/25 include:

- Alexion
- Amicus
- Arcturus
- Aspire
- Chiesi
- iECURE
- Immedica
- Kyowa Kirin
- Moderna
- National Lottery
- Nutricia
- PTC Bio
- RareCare
- Sciensus
- Traverre
- Ultragenyx

FINANCIAL REVIEW

Financial Position at Year End

At the year end, Metabolic Support UK's accounts showed a surplus of unrestricted funds of £76,302 due to an underspend and a successful year of fundraising with reserves maintained from 2023-2024 at £462,875.

Due to the uncertainty of the impact that the cost of living crisis and reduced charitable giving may have on the charity's income generation in 2025/26 and beyond, the priorities for the next financial year will be to preserve as much of the reserves as possible to ensure the future sustainability of the charity by investing in more fundraising capacity through staff recruitment and community engagement and increasing the income stream from paid for services through our insight work. The Board of Trustees of Metabolic Support UK continue to monitor the financial health of the charity.

The unrestricted reserves held by the charity is currently £539,177 - which closely tracks with our reserves policy of nine to twelve months running costs slightly higher than the policy of twelve months running costs (approximately £406,000). The charity benefitted from a generous drawdown of £140,000 reserves in 2023/24 to invest in staff and strategic projects and bring the reserves in line with the policy. This allowed us to build internal capacity to attract new funding streams and our income increased by over 50.

At year ending March 2025, Metabolic Support UK's funds are held in the Co-operative Bank. The charity's assets are considered to be adequate to fulfil our obligations in relation to future financial commitments. As the majority of our assets are liquid, no significant delays or shortfalls are anticipated in realising these assets into cash.

Reserves policy

It is the policy of the charity that unrestricted funds which have not been designated for a specific use should be maintained at a level equivalent to between nine and twelve months' expenditure. The trustees consider that reserves at this level will ensure that, in the event of a significant drop in funding, they will be able to continue the charity's current activities while consideration is given to ways in which additional funds may be raised. This level of reserves has been maintained throughout the year.

Structure, governance and management

The charity is a company limited by guarantee.

That charity is governed by its Memorandum and Articles of Association and the said Memorandum and Articles of Association were amended in January 2014 and the relevant amendments agreed with the Charity Commission for England and Wales and posted with Companies House.

Recruitment and Appointment of Trustees

New trustees are recruited and appointed by the existing trustees as vacancies arise on the Board.

METABOLICSUPPORT UK

INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF METABOLIC SUPPORT UK

I report to the trustees on my examination of the financial statements of Metabolic Support UK (the charity) for the year ended 31 March 2025.

Responsibilities and basis of report

As the trustees of the charity (and also its directors for the purposes of company law), you are responsible for the preparation of the financial statements in accordance with the requirements of the Companies Act 2006, the Charities and Trustee Investment (Scotland) Act 2005 and the Charities Accounts (Scotland) Regulations 2006. You are satisfied that the financial statements of the charity are not required by charity or company law to be audited and have chosen instead to have an independent examination.

Having satisfied myself that the financial statements of the charity are not required to be audited under Part 16 of the Companies Act 2006 and are eligible for independent examination, I report in respect of my examination of the charity's financial statements carried out under section 44(1)(c) of the Charities and Trustee Investment (Scotland) Act 2005 and section 145 of the Charities Act 2011. In carrying out my examination I have followed the requirements of Regulation 11 of the Charities Accounts (Scotland) Regulations 2006 and the Directions given by the Charity Commission under section 145(5)(b) of the Charities Act 2011.

Independent examiner's statement

Since the charity has prepared its financial statements on an accruals basis and is also registered in Scotland, or the charity's gross income exceeded £250,000, the independent examiner must be a member of a body listed in Regulation 11(2) of the Charities Accounts (Scotland) Regulations 2006 and section 145 of the Charities Act 2011. I confirm that I am qualified to undertake the examination because I am a member of ICAEW, which is one of the listed bodies.

I have completed my examination. I confirm that no matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

Accounting records were not kept in respect of the charity as required by section 44(1)(a) of the Charities and Trustee Investment (Scotland) Act 2005, Regulation 4 of the Charities Accounts (Scotland) Regulations 2006 and section 386 of the Companies Act 2006.

The financial statements do not accord with those records; or the financial statements do not comply with the accounting requirements of Regulation 8 of the Charities Accounts (Scotland) Regulations 2006 and the accounting requirements of section 396 of the Companies Act 2006 other than any requirement that the financial statements give a true and fair view, which is not a matter considered as part of an independent examination; or the financial statements have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities applicable to charities preparing their financial statements in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102).

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the financial statements to be reached.



18th December 2025

Stephanie Baker BA(Hons) ACA
Xeinadin North West Limited

The Foundation
Herons Way Chester
Business Park Chester
Cheshire CH4 9GB

METABOLIC SUPPORT UK

STATEMENT OF FINANCIAL ACTIVITIES INCLUDING INCOME AND EXPENDITURE ACCOUNT FOR THE YEAR ENDED 31 MARCH 2025

	Notes	Unrestricted funds 2025 £	Unrestricted funds 2024 £
Income from:			
Donations and legacies	2	474,643	221,519
Investments	3	7,819	6,498
		<hr/>	<hr/>
Total income		482,462	228,017
		<hr/>	<hr/>
Expenditure on:			
Raising funds	4	8,614	2,436
Charitable activities	5	397,546	371,987
		<hr/>	<hr/>
Total expenditure		406,160	374,423
		<hr/>	<hr/>
Net income/(expenditure) and movement in funds		76,302	(146,406)
Reconciliation of funds:			
Fund balances at 1 April 2024		462,875	609,281
		<hr/>	<hr/>
Fund balances at 31 March 2025		539,177	462,875
		<hr/>	<hr/>

The statement of financial activities includes all gains and losses recognised in the year. All income and expenditure derive from continuing activities.

METABOLIC SUPPORT UK

BALANCE SHEET AS AT 31 MARCH 2025

	Notes	2025 £	£	2024 £	£
Current assets					
Debtors	11	7,941		-	
Cash at bank and in hand		537,509		496,371	
		<u>545,450</u>		<u>496,371</u>	
Creditors: amounts falling due within one year	12	(6,273)		(33,496)	
		<u></u>		<u></u>	
Net current assets			539,177		462,875
			<u></u>		<u></u>
The funds of the charity					
Unrestricted funds	13		539,177		462,875
			<u>539,177</u>		<u>462,875</u>
			<u></u>		<u></u>

The company is entitled to the exemption from the audit requirement contained in section 477 of the Companies Act 2006, for the year ended 31 March 2025.

The directors acknowledge their responsibilities for complying with the requirements of the Companies Act 2006 with respect to accounting records and the preparation of financial statements.

The members have not required the company to obtain an audit of its financial statements for the year in question in accordance with section 476.

These financial statements have been prepared in accordance with the provisions applicable to companies subject to the small companies regime.

The financial statements were approved by the trustees on 19th December 2025

Paul Cox

Mr P A Cox
Trustee

Carl Lander

Mr C Lander
Trustee

Company registration number 04267454 (England and Wales)

METABOLIC SUPPORT UK

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2025

1 Accounting policies

Charity information

Metabolic Support UK is a private company limited by guarantee incorporated in England and Wales. The registered office is Unit 11-12 Gwenfro, Technology Park, Croesnewydd Road, Wrexham, LL13 7YP.

1.1 Accounting convention

The financial statements have been prepared in accordance with the charity's governing document, the Companies Act 2006, the Charities and Trustee Investment (Scotland) Act 2005, the Charities Accounts (Scotland) Regulations 2006, FRS 102 "The Financial Reporting Standard applicable in the UK and Republic of Ireland" and the Charities SORP "Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)". The charity is a Public Benefit Entity as defined by FRS 102.

The charity has taken advantage of the provisions in the SORP for charities not to prepare a statement of cash flows.

The financial statements are prepared in sterling, which is the functional currency of the charity. Monetary amounts in these financial statements are rounded to the nearest £.

The financial statements have been prepared under the historical cost convention. The principal accounting policies adopted are set out below.

1.2 Going concern

At the time of approving the financial statements, the trustees have a reasonable expectation that the charity has adequate resources to continue in operational existence for the foreseeable future. Thus the trustees continue to adopt the going concern basis of accounting in preparing the financial statements.

1.3 Charitable funds

Unrestricted funds are available for use at the discretion of the trustees in furtherance of their charitable objectives.

Restricted funds are subject to specific conditions by donors or grantors as to how they may be used. The purposes and uses of the restricted funds are set out in the notes to the financial statements.

1.4 Income

Income is recognised when the charity is legally entitled to it after any performance conditions have been met, the amounts can be measured reliably, and it is probable that income will be received.

Cash donations are recognised on receipt. Other donations are recognised once the charity has been notified of the donation, unless performance conditions require deferral of the amount. Income tax recoverable in relation to donations received under Gift Aid or deeds of covenant is recognised at the time of the donation.

Legacies are recognised on receipt or otherwise if the charity has been notified of an impending distribution, the amount is known, and receipt is expected. If the amount is not known, the legacy is treated as a contingent asset.

METABOLIC SUPPORT UK

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2025

1 Accounting policies

(Continued)

1.5 Expenditure

Expenditure is recognised once there is a legal or constructive obligation to transfer economic benefit to a third party, it is probable that a transfer of economic benefits will be required in settlement, and the amount of the obligation can be measured reliably. Expenditure is classified by activity. The costs of each activity are made up of the total of direct costs and shared costs, including support costs involved in undertaking each activity. Direct costs attributable to a single activity are allocated directly to that activity. Shared costs which contribute to more than one activity and support costs which are not attributable to a single activity are apportioned between those activities on a basis consistent with the use of resources. Central staff costs are allocated on the basis of time spent, and depreciation charges are allocated on the portion of the asset's use.

1.6 Cash and cash equivalents

Cash and cash equivalents include cash in hand, deposits held at call with banks, other short-term liquid investments with original maturities of three months or less, and bank overdrafts. Bank overdrafts are shown within borrowings in current liabilities.

1.7 Financial instruments

The charity has elected to apply the provisions of Section 11 'Basic Financial Instruments' and Section 12 'Other Financial Instruments Issues' of FRS 102 to all of its financial instruments. Financial instruments are recognised in the charity's balance sheet when the charity becomes party to the contractual provisions of the instrument. Financial assets and liabilities are offset, with the net amounts presented in the financial statements, when there is a legally enforceable right to set off the recognised amounts and there is an intention to settle on a net basis or to realise the asset and settle the liability simultaneously.

Basic financial assets

Basic financial assets, which include debtors and cash and bank balances, are initially measured at transaction price including transaction costs and are subsequently carried at amortised cost using the effective interest method unless the arrangement constitutes a financing transaction, where the transaction is measured at the present value of the future receipts discounted at a market rate of interest. Financial assets classified as receivable within one year are not amortised.

Basic financial liabilities

Basic financial liabilities, including creditors and bank loans are initially recognised at transaction price unless the arrangement constitutes a financing transaction, where the debt instrument is measured at the present value of the future payments discounted at a market rate of interest. Financial liabilities classified as payable within one year are not amortised.

Debt instruments are subsequently carried at amortised cost, using the effective interest rate method.

Trade creditors are obligations to pay for goods or services that have been acquired in the ordinary course of operations from suppliers. Amounts payable are classified as current liabilities if payment is due within one year or less. If not, they are presented as non-current liabilities. Trade creditors are recognised initially at transaction price and subsequently measured at amortised cost using the effective interest method.

Derecognition of financial liabilities

Financial liabilities are derecognised when the charity's contractual obligations expire or are discharged or cancelled.

METABOLIC SUPPORT UK

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2025

1 Accounting policies

(Continued)

1.8 Employee benefits

The cost of any unused holiday entitlement is recognised in the period in which the employee's services are received. Termination benefits are recognised immediately as an expense when the charity is demonstrably committed to terminate the employment of an employee or to provide termination benefits.

2 Income from donations and legacies

	Unrestricted funds 2025 £	Unrestricted funds 2024 £
Donations and gifts	474,643	221,519

3 Income from investments

	Unrestricted funds 2025 £	Unrestricted funds 2024 £
Interest receivable	7,819	6,498

4 Expenditure on raising funds

	Unrestricted funds 2025 £	Unrestricted funds 2024 £
Fundraising and publicity		
Other fundraising costs	8,614	2,436

METABOLIC SUPPORT UK

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2025

5 Expenditure on charitable activities

	Charitable activities 2025 £	Charitable activities 2024 £
Direct costs		
Staff costs	273,899	233,121
Insurance	1,697	1,588
Printing postage and stationery	1,435	869
Telephone and IT costs	14,505	15,247
Meetings travel and accomodation	16,509	14,416
Sundries	1,208	1,433
Recruitment fees	3,282	6,724
Bank charges	61	88
Projects	38,082	80,822
Marketing	3,224	6,200
Professional fees	31,954	3,184
Other charitable expenditure	1,328	-
	<u>387,184</u>	<u>363,692</u>
Share of support and governance costs (see note 6)		
Support	3,065	3,395
Governance	7,297	4,900
	<u>397,546</u>	<u>371,987</u>
Analysis by fund		
Unrestricted funds	<u>397,546</u>	<u>371,987</u>

6 Support costs allocated to activities

	2025 £	2024 £
Human resource fees	3,065	3,395
Governance costs	7,297	4,900
	<u>10,362</u>	<u>8,295</u>
Analysed between:		
Charitable activities	<u>10,362</u>	<u>8,295</u>

METABOLIC SUPPORT UK

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2025

6 Support costs allocated to activities

(Continued)

	2025 £	2024 £
Governance costs comprise:		
Audit fees	2,100	2,540
Accountancy fees	5,197	2,360
	<u>7,297</u>	<u>4,900</u>

7 Net movement in funds

2025
£

2024
£

The net movement in funds is stated after charging/(crediting):

Fees payable for the independent examination of the charity's financial statements	<u>2,100</u>	<u>2,540</u>
--	--------------	--------------

8 Trustees

None of the trustees (or any persons connected with them) received any remuneration or benefits from the charity during the year.

9 Employees

The average monthly number of employees during the year was:

	2025 Number	2024 Number
Charitable	4	4
Fundraising	1	1
Administration	1	1
	<u>6</u>	<u>6</u>

Employment costs

2025
£

2024
£

Wages and salaries	<u>273,899</u>	<u>233,121</u>
--------------------	----------------	----------------

The number of employees whose annual remuneration was more than £60,000 is as follows:

	2025 Number	2024 Number
£70,001 - £80,000	-	1
£80,001 - £90,000	<u>1</u>	<u>-</u>

METABOLIC SUPPORT UK

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2025

9 Employees (Continued)

Remuneration of key management personnel

Total remuneration for the key management personnel of the charity was £100,986 (2024: £85,742).

10 Taxation

The charity is exempt from taxation on its activities because all its income is applied for charitable purposes.

11 Debtors

	2025 £	2024 £
Amounts falling due within one year:		
Trade debtors	7,761	-
Other debtors	180	-
	<u>7,941</u>	<u>-</u>

12 Creditors: amounts falling due within one year

	2025 £	2024 £
Other taxation and social security	-	24,885
Trade creditors Other creditors	2,352	210
Accruals and deferred income	1,611	4,551
	2,310	3,850
	<u>6,273</u>	<u>33,496</u>

13 Unrestricted funds

The unrestricted funds of the charity comprise the unexpended balances of donations and grants which are not subject to specific conditions by donors and grantors as to how they may be used. These include designated funds which have been set aside out of unrestricted funds by the trustees for specific purposes.

	At 1 April 2024 £	Incoming resources £	Resources expended £	At 31 March 2025 £
General funds	462,875	482,462	(406,160)	539,177
	<u>462,875</u>	<u>482,462</u>	<u>(406,160)</u>	<u>539,177</u>
Previous year:	At 1 April 2023 £	Incoming resources £	Resources expended £	At 31 March 2024 £
General funds	609,281	228,017	(374,423)	462,875
	<u>609,281</u>	<u>228,017</u>	<u>(374,423)</u>	<u>462,875</u>

METABOLIC SUPPORT UK

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) ***FOR THE YEAR ENDED 31 MARCH 2025***

14 Related party transactions

There were no disclosable related party transactions during the year (2024 - none).
