

# Metabolic Support

England & Wales · Charity number 1089588

## Details

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Other names	CHILDREN LIVING WITH INHERITED METABOLIC DISEASES, METABOLIC SUPPORT UK, Metabolic Support, CLIMB, THE NATIONAL INFORMATION CENTRE FOR METABOLIC DISEASES
Status	Registered
Legal form	Charitable company
Company number	<a href="#">04267454</a>
Registered	2001-11-30
Register	<a href="#">View on the Charity Commission register</a>

## Contact

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Phone	01244207581
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Website	<a href="http://www.metabolicsupportuk.org">www.metabolicsupportuk.org</a>

## Activities

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**Objects:** A) THE RELIEF OF CHILDREN, YOUNG ADULTS, FAMILY MEMBERS AND CARERS AFFECTED BY METABOLIC DISEASES IN PARTICULAR BY MEANS OF: I) PROVIDING, FOR THE SAME GROUP, AN INFORMATION, ADVICE, AND SUPPORT SERVICE.II) PUTTING, THE SAME GROUP, INTO CONTACT WITH EACH OTHER FOR THEIR MUTUAL BENEFIT, HELP AND SUPPORT.III) THE PROVISION FOR GRANTS AND ALLOWANCES, FOR THE SAME GROUP, AND IN ADDITION TO HOSPITALS, HOMES OR INSTITUTIONS, AS SHALL FROM TIME TO TIME BE DETERMINED, FOR THE PURPOSES OF MEDICAL TREATMENT, CARE AND RELIEF FROM SUFFERING.B) THE RELIEF OF ADULTS WHO ARE AFFECTED BY METABOLIC DISEASES BY THE PROVISION OF SUPPORT AND SERVICES WHICH ARE NOT OTHERWISE PROVIDED BY ANY OTHER METABOLIC DISEASE GROUP IN ENGLAND AS THE TRUSTEES THINK FIT.C)THE EDUCATION OF HEALTH CARE PROFESSIONALS, OTHER PROFESSIONALS AND THE GENERAL PUBLIC ABOUT METABOLIC DISEASES.D)TO PROVIDE MEDICAL RESEARCH INTO METABOLIC DISEASE AND THEIR DIAGNOSIS.

**Activities:** Provide Metabolic disease information, support and services to our service users that meet their immediate specific need, to undertake educational services, lobby on their behalf and research disease specific information to satisfy medium term needs and to support world class research into metabolic diseases to meet the long term needs. We operate worldwide.

## Classification

- **How:** Makes Grants To Individuals, Makes Grants To Organisations, Provides Services, Provides Advocacy/advice/information, Sponsors Or Undertakes Research, Acts As An Umbrella Or Resource Body
- **What:** General Charitable Purposes, Education/training, The Advancement Of Health Or Saving Of Lives, Disability
- **Who:** Children/young People, Elderly/old People, People With Disabilities, Other Charities Or Voluntary Bodies, Other Defined Groups, The General Public/mankind

## Geography

- Northern Ireland
- Scotland
- Throughout England And Wales

## Finances

Period end	Income	Expenditure	Assets	Employees
2025-03-31	£482,462	£406,160	-	-
2024-03-31	£228,017	£374,423	-	-
2023-03-31	£272,424	£287,052	-	-
2022-03-31	£254,275	£227,263	-	-
2021-03-31	£489,462	£400,318	-	-

## Trustees

Name	Role	Appointed
Adrien Felix Lemoine		2023-08-04
Carl Lander		2020-09-02
Dr Reena Sharma		2024-04-18
Paul Astley Cox		2023-08-04
Rosie Lindup		2023-08-04
Scott Mason		2024-08-09



**Metabolic Support**

England & Wales - Charity number 1089588

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# Accounts

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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

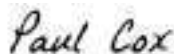
129 Deansgate

Manchester

M3 3WR

The trustees' report was approved by the Board of Trustees on December 19<sup>th</sup> 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.

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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

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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

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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

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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

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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.

**663**

**TOTAL  
ENQUIRIES**

**152**

**INTERNATIONAL  
ENQUIRIES**

**38**

**COUNTRIES  
REACHED**

**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**

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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

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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.

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## ADVOCACY ACHIEVEMENTS 2023-2024

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### 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 Kankanarachchi, 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 Kankanarachchi 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 is 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 AWMSG) 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

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## 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

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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.



18<sup>th</sup> December 2025

**Stephanie Baker BA(Hons) ACA**  
**Xeinadin North West Limited**

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

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# METABOLIC SUPPORT UK

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

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

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

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# METABOLIC SUPPORT UK

## BALANCE SHEET AS AT 31 MARCH 2025

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

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# METABOLIC SUPPORT UK

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

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### 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.

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# METABOLIC SUPPORT UK

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

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### 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.

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# METABOLIC SUPPORT UK

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

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### 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 £
<b>Fundraising and publicity</b>		
Other fundraising costs	8,614	2,436

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# 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 £
<b>Direct costs</b>		
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>
<b>Share of support and governance costs (see note 6)</b>		
Support	3,065	3,395
Governance	7,297	4,900
	<u>397,546</u>	<u>371,987</u>
<b>Analysis by fund</b>		
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>
<b>Analysed between:</b>		
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
	£	£
<b>Governance costs comprise:</b>		
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>
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### 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
Total	<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	1	-

# 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 £
<b>Amounts falling due within one year:</b>		
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	2,352	210
Other creditors	1,611	4,551
Accruals and deferred income	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	<u>462,875</u>	<u>482,462</u>	<u>(406,160)</u>	<u>539,177</u>
<b>Previous year:</b>	<b>At 1 April 2023 £</b>	<b>Incoming resources £</b>	<b>Resources expended £</b>	<b>At 31 March 2024 £</b>
General funds	<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***

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### **14 Related party transactions**

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

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**Metabolic Support**

England & Wales - Charity number 1089588

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# Accounts

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**METABOLIC SUPPORT UK IS A CHARITY REGISTERED IN ENGLAND AND WALES (1089588)  
IN SCOTLAND (SC044634) AND A COMPANY LIMITED BY GUARANTEE (04267454).**



# **METABOLIC SUPPORT UK**

**ANNUAL REPORT AND  
UNAUDITED FINANCIAL  
STATEMENTS FOR THE  
YEAR ENDED 31 MARCH  
2024**

**METABOLIC  
SUPPORT UK**

Your rare condition.  
Our common fight.

# **METABOLIC SUPPORT UK**

## **LEGAL AND ADMINISTRATIVE INFORMATION**

### **TRUSTEES**

Miss R E Lindup (Appointed 4 August 2023)

Mr P A Cox (Appointed 4 August 2023)

Mrs M D Williams (Appointed 4 August 2023)

Mr A F Lemoine (Appointed 4 August 2023)

Dr R E Pugh MBChB FRCP

Mr P J Roper MIET CEng BSC Hons Dr R Vara

Mr C Lander

Dr R Sharma (Appointed 18 April 2024)

### **CHARITY NUMBER (ENGLAND AND WALES)**

1089588

### **CHARITY NUMBER (SCOTLAND)**

SC446344

### **COMPANY NUMBER**

04267454

### **REGISTERED OFFICE**

Centurion House

129 Deansgate

Manchester

M3 3WR

**METABOLIC**  
**SUPPORT UK**

Your rare condition.  
Our common fight.

# **METABOLIC SUPPORT UK**

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## **CONTENTS**

### **TRUSTEES REPORT**

Pages 1-16

### **INDEPENDENT EXAMINERS REPORT**

Pages 17-18

### **STATEMENT OF FINANCIAL ACTIVITIES**

Page 19

### **BALANCE SHEET**

Page 20

### **NOTES TO THE FINANCIAL STATEMENTS**

Pages 21-26

**METABOLIC  
SUPPORT UK**

Your rare condition.  
Our common fight.

## TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) FOR THE YEAR ENDED 31 MARCH 2024 (CONTINUED)

### THE TRUSTEES PRESENT THEIR ANNUAL REPORT AND FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2024.

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)".

### 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 over 500 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.

### PUBLIC BENEFIT

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

### ORGANISATIONAL DEVELOPMENT

This was a year of growth and change for our organisation. We committed to increasing our staff support offering through the recruitment of a new role, Head of Insight and Advocacy, to establish a professional and experienced team member to increase the quality of our internal and external insight provision. This proved immediately effective; we have been praised by both commercial partners and NICE on the quality of our treatment access consultation submissions and our patient advocacy has improved as a result.

## TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) FOR THE YEAR ENDED 31 MARCH 2024 (CONTINUED)

We have increased our consultant model, working with external consultants to add value to our work and to ensure our team benefit from expertise of those who work elsewhere in the sector, including a life science consultant and administrative support. The board of MSUK was also refreshed, with us saying goodbye to our Chair, Elin Haf Davies, and introducing a new Co-chair model designed to increase power sharing and lived experience on the board. Our new Co-chairs, Paul Cox and Carl Lander, bring a combination of lived experience, professional expertise of rare disease networks and organisational management.

### ACHIEVEMENTS AND PERFORMANCE

This year was pivotal for MSUK; a year in which we deepened our commitment to meaningful patient engagement in the rare disease sector through commissioning pioneering research into quality of life and embedding the learnings from this research into our practice and services. Our key focus always includes hearing directly from our community to inform and support our work. Building on our usual engagement methods to centre our community, our research project Thoughts into Action, aimed to identify what quality of life is as determined by our IMD Community using a research methodology that allowed them to speak on their own terms. Representing over 30 different IMDs, 57 people took part including both adults and children living with IMDs, parents and/or caregivers. The report was launched at an event in Westminster hosted by Liz Truss MP and attended by stakeholders from across the rare disease landscape.



### MP LIZ TRUSS HOSTING OUR THOUGHTS INTO ACTION LAUNCH AT WESTMINSTER

Our annual community conference was attended by families from across the UK, healthcare professionals and commercial partners. Sessions included information on clinical trials, clinical research, finances and support and a roundtable on hyperammonaemia.

Our Metabolic Advisory Council (MAC) entered its second year and continues to grow; members have this year contributed their expertise directly into many insight projects and provide in-person representations at scientific meetings on behalf of MSUK. Our phone line rings and emails ping everyday with an increasing number of enquiries from newly diagnosed families and long-term supporters and contacts as we deepen existing relationships and forge new ones.

## TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) FOR THE YEAR ENDED 31 MARCH 2024 (CONTINUED)

### STRATEGY IMPLEMENTATION

We want 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 with these conditions to enjoy a better quality of life.

Our commitment to our community is to make sure that their voices are heard across all levels of decision-making and policy implementation. We work collaboratively and transparently as we strive to achieve our objectives, ensuring the best outcomes for those affected by IMDs.

In order to achieve this, we developed our long-term strategic pillars based on our evidence and insight of the needs of those we support. These four pillars are:

1. Individual support
2. Building communities
3. Empowerment
4. Advocacy

### 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**.



**HELEN MORRIS,  
SUPPORT &  
ADVICE  
MANAGER**

## TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) FOR THE YEAR ENDED 31 MARCH 2024 (CONTINUED)

### WHO HAS CONTACTED US AND WHAT SUPPORT DID WE PROVIDE?

In 2023-24 we received a total of 496 enquiries, a 25% increase from the previous year. This dramatic rise in numbers of people reaching out to us for support which can be attributed to improved signposted and accessibility to our information. The majority of these were via email (43%), Website (28%), Phone (20%), Social Media (7%), and meetings, clinics, letter, texts, and video calls making up the remaining 1.8%.

Enquiries received were in relation to 125 different IMDs, with Medium Chain acyl CoA Dehydrogenase Deficiency (MCADD), Hypophosphatasia (HPP), Klippel Feil Syndrome, Ornithine transcarbamylase deficiency (OTC), and Maple syrup urine disease (MSUD) being the most popular. Across the groups, however, our highest number of enquiries fell within the amino acid disorders group which encompasses the urea cycle disorders and organic acid disorders. Our most popular themes of enquiry were peer support, disorder information, treatment and management, and seeking diagnosis – the latter being from those who either did not have a diagnosis but either they or their healthcare provider believed they may have an IMD, this includes those undergoing confirmatory testing for a suspected IMD.

We received 96 international enquires (19% of total) from 38 countries. Most (25%) were seeking information about how to access treatments or potential new therapies (8%), and/or to seek specialist care (10%). Enquirers also wanted to understand more about the treatment and management of their condition (17%) or seek others living with the condition (14%) to reduce a sense of isolation. 30% of international enquiries were from low-and middle-income countries (LMICs) and over half of these enquiries (62%) were relating to accessing treatments or services or seeking clinical trials. 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.

To support these families, we used our international connections via memberships such as the SSIEM to gain a better understanding of how we can best support those who have restricted access to healthcare services. In 38% of cases, there were international disorder-specific organisations or rare disorder groups situated within the country who we worked with to offer support and signposting.

### INDIVIDUAL SUPPORT ACHIEVEMENTS 2023-2024

#### INITIATION OF CLINIC VISITS

The return of in-person events post-covid and the return of many of our community attending in-person clinic appointments presented us with the opportunity to expand our face-to-face support. We began discussions and planning with IMD teams to attend metabolic clinics to improve visibility of MSUK, thereby improving access to support. We attended our first general metabolic and MCADD clinics at Great Ormond Street Hospital, London which was a huge success. It allowed metabolic teams to directly signpost families to a person in-clinic to discover more about the support available or to discuss the nature of their clinic visit. Such discussions included transition, being informed of a suspected diagnosis, and travelling abroad.



## TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) FOR THE YEAR ENDED 31 MARCH 2024 (CONTINUED)

### IMPROVED CONNECTIVITY - IMPROVED SUPPORT

Our community and team benefitted from improved connectivity with our professional network. This included attendance at the BIMDG 2023 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, and expanded our contacts to gain a better understanding of IMD services in Scotland. Our clinic attendance provided a unique opportunity to talk candidly with metabolic teams about 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 redesigned leaflets and posters for clinic/healthcare settings to improve awareness and signposting and support from adult IMD consultants lending their advice to assist in responding to increasing enquiries around private testing and appointments.

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. We spoke at Alex TLCs conference to celebrate the success of collaboration between our organisations and the positive outcomes for our joint community. Similar collaborative efforts included working alongside Genetic Alliance and other patient organisations to drive change for future Managed Access Agreements— sharing our learnings and experiences to improve patient group guidance and community support for future early access programmes and participating in a collaborative effort to improve the provision of genomic information and genetic testing information, an area of growing importance for the IMD community.

### INCREASED INTERNATIONAL SUPPORT AND SUPPORT FOR NON-ENGLISH SPEAKING MEMBERS OF OUR COMMUNITY

We also connected with international IMD specialists and other stakeholders to support communities either residing abroad or non-English speaking families in the UK who were struggling to understand their management. This included coordinating a multi-stakeholder approach to assist in accessing medication for an international family during which we expanded our knowledge of different healthcare systems in middle eastern countries. We were able to act on support requests from our clinical networks who were seeking translated information for their patients.

We were able to use our expansive international network to identify specialists to assist in redeveloping or translating advice sheets in Dari and Farsi which allowed the families to clearly understand their child's diet and management plan. Our clinic leaflets were also translated into Punjabi and Urdu. We expanded our connection to international support groups, providing some of these with relevant conversation tools to be used within their own communities and benefitting from these connections to be able to signpost to country-specific or international disorder-specific or rare organisations who were able to assist in the enquiry. We also fully supported an international family to relocate to the UK, assisting in ensuring they had the correct information regarding their visa and health surcharges, assisting in GP registration and urgent referral to a metabolic team for review and treatment, and embedding that family within an online community providing peer support.

## TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) FOR THE YEAR ENDED 31 MARCH 2024 (CONTINUED)



### METABOLIC CONNECT REDEVELOPMENT

We reviewed and rejuvenated our peer support programme, Metabolic Connect, improving our sign-up process and developing more substantial terms and conditions to sit alongside a new FAQ document which provides information on the full process from sign-up to connection and beyond. We also formalised our check-in and review process for those taking part in the service ensuring that those joining the service were clear on the support available throughout. We also introduced the addition of webinars and training resources which aims at providing further information about the programme, it's process and progress, as well as addressing helpful topics such as conversation-starters and managing boundaries and self-care. Since the rejuvenation of the project a further 59 people have joined Metabolic Connect.

### BUILDING COMMUNITIES

Living with a rare IMD can feel isolating for both the people living with the condition and their families or caregivers. We work to reduce isolation by helping to bring people together to share experiences and ask for 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 are keen to remove barriers, creating spaces that are inclusive, safe, and accessible.

In 2023/4 year we focused on learning more about our existing 46 disorder specific groups and their needs, cultivating a growth of over 2600 members across the groups, totalling 41,911 members at the end of March 2024. Taking time to deepen our understanding of our communities affords great learning and engagement opportunities; setting a stable foundation to look to expand the number of groups and communities we support in the coming years.



**BRINGING  
COMMUNITIES  
TOGETHER**

## TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) FOR THE YEAR ENDED 31 MARCH 2024 (CONTINUED)

### ONLINE ENGAGEMENT

Online communities and spaces are vital for many of our communities and are always a focus of our work. Building on last year's success of increasing the regularity and reach of our social media posts, we focused further on the relevance, brand voice, and value-added elements of our posts. Across all social media platforms (Instagram, Facebook, Twitter/X, and LinkedIn), these actions led to an increased engagement rate including reactions, shares, and comments. We delivered 485 public posts, seen by over 224,000 people, and growing our followers by another 14% to 5,470.

Engaging with others through our own posts, resharing others' posts, and joining conversations consistently has demonstrated that we are reliable and approachable. This has resulted in more community members tagging us, sharing posts in direct messages, signposting to us, and reaching out for support through these platforms.

Our social media channels act as springboards for further engagement and interactions beyond the initial engagement. We launched our Think Ammonia! campaign across our socials and within relevant disorder groups. The campaign received a fantastic reception, being widely shared, and celebrated. Importantly, it was also criticised and instigated important and nuanced conversations that were further addressed in dedicated online sessions bringing the MSUK team and UCD community together for shared learning, deepening our connection and relationships. Each point of engagement provides vital insight and helps us better connect with people.

### BUILDING COMMUNITIES ACHIEVEMENTS 2023-2024

- In November 2023 we held our annual community conference attended by over 60 people, bringing together the IMD community for a day of shared learning and vital in-person connection. **"Always nice to connect with others with a lived experience of rare disease in a relaxed setting, but with actual real life tips and knowledge sharing."** - Anonymous Community Member
- We grew both our public, and private, online spaces marking 14% increase in our social media followers and community group members.
- Trialled topic-specific sessions for the fortnightly online Coffee Lounge sessions as part of a continuing review of this long-standing and well-loved support initiative.



**COMMUNITY  
CONFERENCE**

### 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 2023-2024:

#### 1. Metabolic Matters

First launched in January 2022, Metabolic Matters has continued to see growth and development throughout this year. As a platform for sharing our work, the community voice, and the work of organisations we collaborate with, our magazines reached over 1.2 million people worldwide with over 4000 readers. Moving to quarterly productions during this time has allowed for the curation of more in- depth and specialised editions, as well as the introduction of our complementary monthly newsletter, Metabolic Monthly.



#### 2. Metabolic Monthly Newsletter

Introduced in January 2024, our monthly newsletter helps us to share timely updates and opportunities without mailing list. Featuring recurring segments to empower and connect the IMD community, including our Monthly Medicines roundup, a Metabolic Connect call out, and upcoming Clinic Visits, alongside more temporary opportunities, our newsletter aims to empower and connect the IMD community and its many different stakeholders. Throughout the year our mailing list has grown to 1857 people, including people living with, families, and healthcare professionals, to other patient organisations, charities, and companies, and continues to grow.

#### 3. Monthly Medicines Roundup

Introduced in January 2024, alongside our Metabolic Monthly Newsletter, and featured in our latest news at the start of each month, our monthly medicines roundup provides our community with the latest details on medications for inherited metabolic disorders which are being assessed by the health technology assessment bodies across the UK. The roundup shares which treatments have been approved, but also those that are currently being assessed or have been rejected or suspended.

#### 4. Latest News

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 excipients in pharmaceutical products, updates on the UK Government's budgets, Genetic Testing, Benefits 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.

#### 5. Metabolic Clinical Referencing Group (CRG), NHS England

Our CEO, Kirsty Hoyle, represents the voice of our community on the Metabolic CRG, a high profile group of healthcare professionals who are the leading authority on metabolic issues in the UK, providing a direct opportunity to ask questions on behalf of our community.

## TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) FOR THE YEAR ENDED 31 MARCH 2024 (CONTINUED)

### 6. Rare Disease Research Network

Our Head of Insight & Advocacy, Laura Smith van Carroll, was accepted into 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. As a management team member, she supports the running of the organisation through decision-making, setting goals, reviewing and guiding the overall direction of the organisation. Once launched, the project will enable both MSUK and its community members to actively participate in and lead research related to their disorder.

### ADVOCACY

There are many challenges and difficulties faced by those living with a rare metabolic disorder. We work hard to amplify their voices, making sure they are heard, recognised, and equally valued among all stakeholders. There is a lot to learn from our communities and we work to make that happen.

### KEY ADVOCACY ACHIEVEMENTS 2023-2024

#### 1. Think Ammonia

The preparation work for the "Think Ammonia!" campaign was undertaken in 2023; this included the launch of the hyperammonaemia survey which received 34 responses from people representing eight individual disorders. The insight from this work was then further bolstered by the conference hyperammonaemia roundtable, and by the expertise of our "Think Ammonia!" working group which comprises eight senior NHS staff including consultants and laboratory representatives



**OUR TRANSLATED  
THINK AMMONIA  
POSTERS ON  
DISPLAY IN A  
PERUVIAN  
HOSPITAL**

#### 2. 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.



### ADULT RARE BONE DISEASE NETWORK

#### 3. Tyrosinaemia Type One Rollout

Metabolic Support UK are the only patient organisation involved in the working groups tasked with expanding the UK's national screening panel from 9 to 10 conditions. We regularly attend meetings with members of the UK National Screening Committee, the NHS and the UK Health Security Agency. Our role within these meetings is 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.

#### 4. "Cost of Living with an IMD" report

Our 'Cost of Living with an IMD report' was launched in 2023. This report was well received and reached 454,085 people, generating 880 reads with an average read time of 4 minutes. Further increasing its impact, the findings were referenced in the Specialised Healthcare Alliance report on inequalities for rare diseases which was shared with members of the specialised commissioning team at NHS England (NHSE), those with rare disease portfolios at the Department of Health and Social Care (DHSC) and relevant stakeholders at the National Institute of Health and Care Excellence (NICE)

#### 5. Newborn Screening

We represented our communities on both the IMD Screening Advisory Board and the Newborn Bloodspot Group for Wales. In these groups we participate in regular meetings, sharing our thoughts on various documents and also have the opportunity to raise issues with the heads of screening across the four nations during the "service user" section of the meetings.

#### 6. Signing Open Letters

We have acted as signatories on multiple open letters calling for cheaper energy and water bills for our communities who often face financial issues as a result of their condition. One letter advocated against the closure of ticket offices at train stations and in October (2023), the rail passenger watchdogs officially rejected proposals to close hundreds of train ticket offices across the UK.

#### 7. Mental Health Matters

We released an in-depth article on mental health and IMDs, highlighting the issues that our communities face and the statistics around the inequalities that exist at IMD centres.



## TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) FOR THE YEAR ENDED 31 MARCH 2024 (CONTINUED)

### 8. APPG for Rare and Undiagnosed Conditions

We attended APPG meetings chaired by Liz Twist MP. Here we shared insight from our communities about how policy isn't currently reflecting their needs based on our Thoughts into Action report. We also discussed details about our upcoming "Think Ammonia!" campaign.

### 9. Representation at national and international conference

Between April 2023 and March 2024, we attended several national and international conferences. Most notable were Society for the Study of Inborn Errors of Metabolism's (SSIEM) annual conference in September 2023, where we hosted the only patient advocacy session in the program "The psychosocial impact of living with an inborn error of metabolism"; the World Orphan Drug Conference (WODC) in November 2023, where we presented the results of our Thoughts into Action research project; and the British Inherited Metabolic Disorder Group in June 2023, where we presented on a panel.

### 10. Representation on National Forums

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:

- IMD Newborn Screening Advisory Board (Public Health England)
- Inherited White Matter Disorder Group
- Metabolic Clinical Referencing Group (NHS England)
- Newborn Bloodspot Screening for Wales
- Patient Engagement Group (Genetic Alliance)
- Pyruvate Kinase Deficiency Advocacy and Advisory Council
- Rare Disease Framework Forum (gov.uk)
- Rare Bone Disorder Network
- Tyrosinaemia rollout group
- PNPO Research Project
- X-Linked Hypophosphatasia with Kyowa Kirin
- Lysosomal Storage Disease Collaborative
- Genetic Alliance
- Rare QOL



### 11. MSUK Insight Services

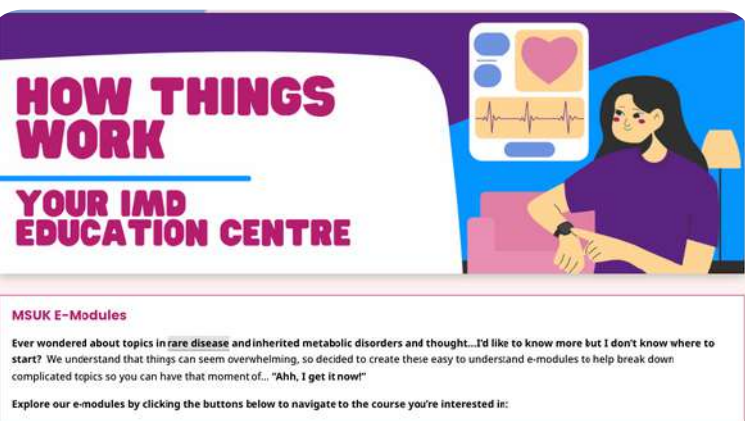
In 2021/22 we launched our ambitions to deepen and expand our insight services, providing best practice patient insight for all stakeholders. As our previous lead for the MSUK Insight Services left at the beginning of 2023 and our new Head of Insight & Advocacy only started in late June 2023, much of 2023/24 focussed on building an insight pipeline with a few also started at the beginning of 2024. Examples of these projects in 2023/24 include:

**HPP landscape review:** A survey of the HPP community to determine what improvements they have observed since asotase alfa (Strensiq) was recommended in England and what improvements they consider to still be possible. This will feed into a roundtable discussion by healthcare professionals to gather their views on the same topic. Finally, a summary report with an overview of the successes and challenges will be generated.

## TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) FOR THE YEAR ENDED 31 MARCH 2024 (CONTINUED)

**Lived experience of nephropathic cystinosis:** A survey, originally developed by the Dutch and Flemish cystinosis patient organisation was translated and revised to include UK-specific topics at the beginning of 2024. The survey will be disseminated among people living with nephropathic cystinosis and analysed to draft a report with findings. The report aims to increase the evidence base on the lived experience of the disorder, as well as enable any future health technology assessment responses.

**IMD Education Centre:** We launched the idea to create an education centre for our IMD community. This saw swift uptake from sponsors, allowing us to scope out three initial e-modules in medicine development, gene therapy and excipients.



### OUR IMD EDUCATION CENTRE

## 12. 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. See below for an overview of our health technology assessment work in 2023-2024:

**Burosumab (Crysvita)**, a treatment for children and adolescents (aged 1 to 17 years) living with X-linked hypophosphataemia, was recommended for use by SMC in January 2024. The same treatment for adults living with X-linked hypophosphataemia was still undergoing NICE technology appraisal at the end of March 2024. MSUK supported XLH UK in their initial patient impact data gathering work (including for other health technology assessment bodies) and provided hands-on support during the NICE consultation period in December 2023.

**Eladocogene exuparvovec (Upstaza)**, a gene therapy for the treatment of children 2-years and older living with L-Amino acid decarboxylase (AADC) deficiency, was successfully recommended for use via the NICE highly specialised technologies assessment process in April 2023 and SMC ultra orphan assessment in September 2023. MSUK collaborated with the AADC Trust to develop a patient survey and represent the patient voice throughout the assessments.

## TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) FOR THE YEAR ENDED 31 MARCH 2024 (CONTINUED)

**Fosdenopterin (Nulibry)**, a treatment of people living with molybdenum cofactor deficiency (MoCD) type A, was still undergoing NICE highly specialised technology appraisal and SMC ultra orphan assessment at the end of March 2024. Between July and August 2023, MSUK gained the patient perspective through conversations with the community and submitted consultation documents to NICE in addition to attending a NICE scoping workshop in September 2023 where we represented the patient voice and provided details of the impact of MoCD type A. MSUK initiated formal data collection methods to support the patient group submission to NICE and SMC in February 2024, with data collection activities still ongoing as of March 2024.

**Mercaptamine bitartrate (Procysbi)**, a treatment for people living with nephropathic cystinosis was not recommended by SMC in November 2023. MSUK collaborated with Cystinosis Foundation UK and Kidney Research UK to gather patient insight through a survey, case studies and put forward a joint submission.

**Pegzilarginase (Loargys)**, an enzyme replacement therapy for the treatment of people living with arginase- 1 deficiency (ARG1d) was still undergoing NICE highly specialised technology appraisal at the end of March 2024. MSUK initiated formal data collection methods to support the patient group submission to NICE in February 2024, with data collection activities still ongoing as of March 2024.

### **We also help further clinical trials for IMDs through:**

Using Ornithine transcarbamylase (OTC) deficiency as a case study, created a magazine edition to explore different type of treatment currently in development. This helps to inform the wider community about these methods grounded in real-life examples, whilst greatly supporting our OTC community to differentiate and understand the different research and clinical trials available to them.

### **In order to support the longer-term development of new IMD treatments we contribute to a number of projects that aim to improve access and accelerate development. An example:**

**Digital Tools for Rare Diseases (DT4RD) project:** This project aims to develop a digital platform for assessing upper limb function remotely and continuously. MSUK represent the PPV throughout the project, having developed the patient engagement strategy, patient-reported experience measures and exit interview discussion guide. Additionally, MSUK reviewed patient-facing materials to ensure appropriateness and provided support during the ethical approval process.

## **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. We joined EasyFundraising to provide our community with an easy and accessible alternative way for the community to support us.

We were delighted to be successful in our National Lottery bid for a grant of £350,000 over three years; an endorsement of our community work and meeting an aim to diversify our funding as set out in our Thoughts into Action report.

## TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) FOR THE YEAR ENDED 31 MARCH 2024 (CONTINUED)

### FUNDRAISING 2023-2024:

#### 1. A+ For Effort...

We were delighted that the students at Wickham School chose MSUK as one of two charities to support during their Charity week. Students and faculty came together to hold bake sales, variety shows, competitions, and game shows. Some even skydived!

#### 2. London Marathon 2023

After the 2022 October London Marathon, the 2023 event returned to an April date seeing a drop in our participants from thirteen the previous year to four. We took the opportunity to focus on building a strong rapport with each runner, improving our processes, and using their experiences to build interest for future events. Each runner surpassed their minimum total, raising a combined total of £6,878.

#### 3. Individual Achievements

Throughout the year over 80 people donated or held individual fundraising events on our behalf. From quizzes, sports tournaments, raffles, dances, climbs, and marathons; including an ultra-marathon. Our community came out in force to help us. Thank you.

#### 4. In Memory and Legacies

We are so grateful to those who have left a donation to us in their will, or have raised funds in memory of a loved one. We are here for our community at all stages of their lives, and their families for as long as they need us.



**BECKI  
GREENE,  
RUNNING  
FOR MSUK**

**The organisations that provided funding towards Metabolic Support's activities in 2023/24 include:**

Alexion, Amicus, Arcturus, Bionical Emas, Cenote, Chiesi, iECURE, Immedica, Jeans for Genes, Kyowa Kirin, Moderna, PTC Bio, Traverso, Ultragenyx

## TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) FOR THE YEAR ENDED 31 MARCH 2024 (CONTINUED)

### FINANCIAL REVIEW

#### Financial Position at Year End

At the year end, Metabolic Support UK's accounts showed a deficit of £146,406 (2023: £14,628) made up of unrestricted funds.

At the year end, Metabolic Support UK's accounts showed a surplus made up of unrestricted funds. Due to the uncertainty of the impact that the cost of living crisis will have on the charity's income generation in 2023/24 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:

- Retaining and supporting the smaller existing staff team to deliver the strategy with the support of freelancers
- Building on the success of the National Lottery win to further attract trusts and foundations funding
- 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 £462,875 - slightly higher than the policy of twelve months running costs (approximately £380,000). However this is a significant decrease from the previous financial year as the board agreed a drawn down of £140,000 from reserves 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 with a pipeline already secured for the next financial year.

At year ending March 2024, 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 three and six month's 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.

## TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) FOR THE YEAR ENDED 31 MARCH 2024 (CONTINUED)

### TRUSTEES

The trustees, who are also the directors for the purpose of company law, and who served during the year and up to the date of signature of the financial statements were:

- Miss R E Lindup (Appointed 4 August 2023)
- Mr P A Cox (Appointed 4 August 2023)
- Mrs M D Williams (Appointed 4 August 2023)
- Mr A F Lemoine (Appointed 4 August 2023)
- Dr R E Pugh MBChB FRCP
- Mr P J Roper MIET CEng BSC Hons Dr R Vara
- Mr C Lander
- Dr R Sharma (Appointed 18 April 2024)

Recruitment and appointment of trustees

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

The trustees' report was approved by the Board of Trustees.

Mr P A Cox  
Co-Chair of  
trustees



Mr C Lander  
Co-Chair of  
trustees



29 January 2025



**PAUL COX &  
CARL LANDER,  
CO-CHAIRS OF  
MSUK**

# METABOLIC SUPPORT UK

Your rare condition.  
Our common fight.

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

### FINANCIAL REVIEW

I report to the trustees on my examination of the financial statements of Metabolic Support UK (the charity) for the year ended 31 March 2024.

### 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

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:

1. 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.
2. The financial statements do not accord with those records; or
3. 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
4. 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).

## INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF METABOLIC SUPPORT UK (CONTINUED)

### FINANCIAL REVIEW (CONTINUED)

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.

### XEINADIN NORTH WEST LIMITED

2 Hilliards Court  
Chester Business Park  
Chester  
Cheshire  
CH4 9QP  
29 January 2025



xeinadin

## STATEMENT OF FINANCIAL ACTIVITIES INCLUDING INCOME AND EXPENDITURE ACCOUNT FOR THE YEAR ENDED 31 MARCH 2024

	Notes	Unrestricted funds 2024 £	Unrestricted funds 2023 £	Restricted funds 2023 £	Total 2023 £
<b>Income from:</b>					
Donations and legacies	2	221,519	248,310	-	248,310
Charitable activities	3	-	24,114	-	24,114
Investments	4	6,498	-	-	-
<b>Total income</b>		<u>228,017</u>	<u>272,424</u>	<u>-</u>	<u>272,424</u>
<b>Expenditure on:</b>					
Raising funds	5	2,436	-	-	-
Charitable activities	6	371,987	287,052	-	287,052
<b>Total expenditure</b>		<u>374,423</u>	<u>287,052</u>	<u>-</u>	<u>287,052</u>
<b>Net expenditure</b>		(146,406)	(14,628)	-	(14,628)
Transfers between funds		-	12,504	(12,504)	-
<b>Net movement in funds</b>	8	(146,406)	(2,124)	(12,504)	(14,628)
<b>Reconciliation of funds:</b>					
Fund balances at 1 April 2023		609,281	611,405	12,504	623,909
<b>Fund balances at 31 March 2024</b>		<u>462,875</u>	<u>609,281</u>	<u>-</u>	<u>609,281</u>

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

## BALANCE SHEET AS AT MARCH 2024

	Notes	2024 £	£	2023 £
<b>Current assets</b> Cash at bank and in hand		496,371		621,093
<b>Creditors: amounts falling due within one year</b>	12	(33,496)		(11,812)
<b>Net current assets</b>			462,875	609,281
<b>The funds of the charity</b>				
Unrestricted funds	13		462,875	609,281
			462,875	609,281

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 2024.

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 29 January 2025

Mr P A Cox  
Co-Chair  
of Trustees

Mr C Lander  
Co-Chair of  
Trustees

Company registration number 04267454 (England and Wales)

### 1. ACCOUNTING POLICIES

#### Charity information

Metabolic Support UK is a private company limited by guarantee incorporated in England and Wales. The registered office is Centurion House, 129 Deansgate, Manchester, M3 3WR

#### 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.

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2024

### ACCOUNTING POLICIES (CONTINUED)

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.

### 1.4. 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 & 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.

#### 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.

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2024

### ACCOUNTING POLICIES (CONTINUED)

#### 1.7. 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 2024 £	Unrestricted funds 2023 £
Donations and gifts	221,519	248,310

#### 3 Income from charitable activities

	Unrestricted funds 2024 £	Unrestricted funds 2023 £
<b>Fundraising</b>		
Sale within charitable activities	-	24,114

#### 4 Income from investments

	Unrestricted funds 2024 £	Unrestricted funds 2023 £
Interest receivable	6,498	-

#### 5 Expenditure on raising funds

	Unrestricted funds 2024 £	Unrestricted funds 2023 £
<b>Fundraising and publicity</b>		
Other fundraising costs	2,436	-

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2024

### 6 Expenditure on charitable activities

	Charitable activities 2024 £	Charitable activities 2023 £
<b>Direct costs</b>		
Staff costs	233,121	216,090
Insurance	1,588	1,505
Printing postage and stationery	869	265
Telephone and IT costs	15,247	14,182
Meetings travel and accomodation	14,416	2,934
Sundries	1,433	6,077
Recruitment fees	6,724	9,070
Bank charges	88	99
Projects	80,822	12,976
Marketing	6,200	6,022
Professional fees	3,184	9,075
	<u>363,692</u>	<u>278,295</u>
<b>Share of support and governance costs (see note 7)</b>		
Support	3,395	5,252
Governance	4,900	3,505
	<u>371,987</u>	<u>287,052</u>
<b>Analysis by fund</b>		
Unrestricted funds	<u>371,987</u>	<u>287,052</u>

### 7 Support costs allocated to activities

	2024 £	2023 £
Human resource fees	3,395	5,252
Governance costs	4,900	3,505
	<u>8,295</u>	<u>8,757</u>
<b>Analysed between:</b>		
Charitable activities	<u>8,295</u>	<u>8,757</u>
<b>Governance costs comprise:</b>	2024 £	2023 £
Audit fees	2,540	2,100
Accountancy fees	2,360	1,405
	<u>4,900</u>	<u>3,505</u>

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2024

<b>8</b>	<b>Net movement in funds</b>	<b>2024</b>	<b>2023</b>
		£	£
	The net movement in funds is stated after charging/(crediting):		
	Fees payable for the independent examination of the charity's financial statements	2,540	2,100
		<u>          </u>	<u>          </u>

### 9 Trustees

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

### 10 Employees

The average monthly number of employees during the year was:

	<b>2024</b>	<b>2023</b>
	<b>Number</b>	<b>Number</b>
Charitable	4	4
Fundraising	1	1
Administration	1	1
	<u>          </u>	<u>          </u>
Total	6	6
	<u>          </u>	<u>          </u>

### Employment costs

	<b>2024</b>	<b>2023</b>
	£	£
Wages and salaries	233,121	216,090
	<u>          </u>	<u>          </u>

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

	<b>2024</b>	<b>2023</b>
	<b>Number</b>	<b>Number</b>
£70,000 to £79,999	1	1
	<u>          </u>	<u>          </u>

### Remuneration of key management personnel

Total remuneration for the key management personnel of the charity was £85,742 (2023: £107,842).

### 11 Taxation

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

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2024

### 12 Creditors: amounts falling due within one year

	2024 £	2023 £
Other taxation and social security	24,885	5,659
Trade creditors Other creditors	210	3,152
Accruals and deferred income	4,551	901
	3,850	2,100
	<u>33,496</u>	<u>11,812</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 2023 £	Incoming resources £	Resources expended £	Transfers £	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>-</u>	<u>462,875</u>
<b>Previous year:</b>					
	At 1 April 2022 £	Incoming resources £	Resources expended £	Transfers £	At 31 March 2023 £
General funds	611,405	272,424	(287,052)	12,504	609,281
	<u>611,405</u>	<u>272,424</u>	<u>(287,052)</u>	<u>12,504</u>	<u>609,281</u>

### 14 Related party transactions

There were no disclosable related party transactions during the year (2023 - none).

**METABOLIC  
SUPPORT UK**

Your rare condition.  
Our common fight.

**Metabolic Support**

England & Wales - Charity number 1089588

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# Accounts

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**Charity registration number 1089588 (England and Wales)**

**Charity registration number SC446344 (Scotland)**

**Company registration number 04267454 (England and Wales)**

**METABOLIC SUPPORT UK**  
**ANNUAL REPORT AND UNAUDITED FINANCIAL STATEMENTS**  
**FOR THE YEAR ENDED 31 MARCH 2023**

# METABOLIC SUPPORT UK

## LEGAL AND ADMINISTRATIVE INFORMATION

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<b>Trustees</b>	Dr R E Pugh MBChB FRCP Mr P J Roper MIET CEng BSC Hons Mr J O'Hara Msc Dr R Vara Dr E H Davies Mr C Lander
<b>Charity number (England and Wales)</b>	1089588
<b>Charity number (Scotland)</b>	SC446344
<b>Company number</b>	04267454
<b>Registered office</b>	Unit 11-12 Gwenfro Technology Park Croesnewydd Road Wrexham LL13 7YP
<b>Independent examiner</b>	McLintocks (NW) Limited 2 Hilliards Court Chester Business Park Chester Cheshire CH4 9PX

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# METABOLIC SUPPORT UK

## CONTENTS

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	<b>Page</b>
Trustees' report	1 - 10
Independent examiner's report	11
Statement of financial activities	12
Balance sheet	13
Notes to the financial statements	14 - 19

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# **METABOLIC SUPPORT UK**

## **TRUSTEES' REPORT (INCLUDING DIRECTOR'S REPORT) FOR THE YEAR ENDED 31 MARCH 2023**

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The trustees present their annual report and financial statements for the year ended 31 March 2023.

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 (as amended) and "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) (effective 1 January 2019)".

### **Objectives and activities**

The charity's primary aims are to:

- The relief of children, young adults, family members and carers affected by metabolic diseases in particular by means of:
  - i. Providing for the same group, an information, advice and support service.
  - ii. Putting the same group into contact with each other for their mutual benefit, help and support.
  - iii. The provision for grants and allowances for the same group and in addition to hospitals, homes or institutions, as shall from time to time be determined, for the purposes of medical treatment, care and relief from suffering.
- The relief of adults who are affected by metabolic diseases by the provision of support and services which are not otherwise provided by any other metabolic disease group in England, as the trustees think fit.
- The education of Health care professionals, other professionals and the general public about metabolic diseases.
- To provide medical research into metabolic diseases and their diagnosis.

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

# **METABOLIC SUPPORT UK**

## **TRUSTEES' REPORT (INCLUDING DIRECTOR'S REPORT) (CONTINUED)** **FOR THE YEAR ENDED 31 MARCH 2023**

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### **Achievements and performance**

Metabolic Support UK is an umbrella patient advocacy organisation founded in 1981, supporting and advocating for people living with Inherited Metabolic Disorders (IMDs) and their communities.

We support over 20,000 people living with one of over 500 IMDs, across the world. IMD's 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 group. 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.

### **Organisational Development**

A key focus for our community in 2022-2023 was the cost-of-living crisis; an inescapable issue that permeated throughout our communities. We focused on finding out what our community need and providing real-time, accurate information to support them. Our staff team expanded to include a new Community and Communications Coordinator strengthening the links to our community. Building external relationships to increase our networks was vital this year and we took advantage of the increased in-person events to connect at conferences in the UK and abroad. Our insight arm, MSUK Insight, had a successful first year, paving the way to meet our ambition of positioning MSUK as the leading provider of insight in patients living with an inherited metabolic disorder.

### **Achievements and Performance**

This year saw MSUK step firmly into our role as the umbrella support group for all people living with an inherited metabolic disorder. We joined the Disabled Children's Partnership and the Disability Benefits Consortium as a way to start more closely aligning the needs of our rare disease community with wider society. We also planned and delivered work that prioritised educating and empowering our community by removing barriers to accessing treatments, increasing awareness of rare disease policy and responding to community needs such as cost of living crisis. We brought our community together in-person for the first time since 2019 with a fantastic family fun day at Chester Zoo at which many people met others with the same condition as them for the first time. We were involved in six technology appraisals, increasing access to treatments for our diverse community. Our work in Newborn Screening has shown growth over the year, including our impact on the successful approval of an IMD, Tyrosinemia, for addition to the UK Newborn Screening Panel. We have also started our aim to more meaningfully co-produce our work with the launch of our co-production group the Metabolic Advisory Council. Our individual support remained as strong as previous years, with an increase in international enquiries reflecting our growth as the leading international organisation supporting people living with an IMD.

### **Strategic Implementation**

By 2030, we want 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 with these conditions to enjoy a better quality of life.

Our commitment to our community is to make sure that their voices are heard across all levels of decision-making and policy implementation. We work collaboratively and transparently as we strive to achieve our objectives, ensuring the best outcomes for those affected by IMDs.

# METABOLIC SUPPORT UK

## TRUSTEES' REPORT (INCLUDING DIRECTOR'S REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2023

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In order to achieve this, we developed our long-term strategic pillars based on our evidence and insight of the needs of those we support. These four pillars are:

1. Individual Support
2. Building Communities
3. Empowerment
4. Advocacy

### **Individual Support**

Our individual support focuses on providing those living with IMDs with emotional and practical support which is tailored to individual need. Support may be offered via, phone, email, social media or video calls and is provided by our experienced team. The support given may vary between short one-off enquiries or longer term support where we provide scaffolding for the family, building vital support networks, and act as an advocate in a range of fields including education and employment.

Within our individual support, we explore the context surrounding each enquiry to allow us 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 allows us to develop resources to address unmet need and establish conversations 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**.

### **Enquiries**

We received a total of **395 enquiries, a 13.5% increase from last year**. The majority of these were via email (71.6%) with 26.3% of these originating from our website contact form. 18.5% of enquiries were handled by phone, 8.6% by social media, and 1.3% by video call, a newly offered service providing face-to-face support.

Enquiries received were in relation to 96 different IMDs, with Medium Chain acyl CoA Dehydrogenase Deficiency (MCADD), Hypophosphatasia (HPP), Ornithine transcarbamylase deficiency (OTC), and Maple syrup urine disease being the most popular. Our three most popular themes of enquiry were **peer support, access to treatments, and financial support**.

### **Key Support Achievements 2022-2023:**

#### **Managed Access Agreement Support for Hypophosphatasia**

The theme of access to treatments is prominent due to the considerable amount of individual support work completed surrounding the conclusion of the Managed Access Agreement for Asfotase alfa for the treatment of paediatric-onset HPP. This included working alongside the pharmaceutical company, metabolic bone consultants, NICE, and patient support groups to ensure that we carefully addressed the HPP communities worries and concerns and developed supporting information, held focus groups, and provided emotional support during a time of massive uncertainty regarding future access to a life-changing treatment.

#### **Cost of Living Crisis**

The cost of living crisis had a huge impact on the IMD community and this was encapsulated within our Cost of Living Report which derived from conversations in which our community shared their experiences and worries. In order to support those living with IMDs to identify the financial support available to them, we created a series of new resources including, the use of benefits calculators, support completing application forms, and assistance in accessing grant-giving organisations and support with hospital travel.

# METABOLIC SUPPORT UK

## TRUSTEES' REPORT (INCLUDING DIRECTOR'S REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2023

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### Improving connections and signposting

Throughout 2022-2023, work commenced to reconnect with all IMD centres and ensuring that centres had the relevant resources available to signpost those under their care to MSUK for support and advice. We bridged further connections within Scotland to understand the needs of the community in terms of access to services and developed closer relations with disorder-specific patient organisations to support the development of our IMD information pages with improved signposting.

#### • Travel Support

We updated and improved our travel support information and worked closely with travel insurance companies and assessors to ensure that our community understood how applying for and risk assessment within travel insurance quotes works. We felt this was important to ensure travel insurance companies were considering rare disorders as part of their policies and avoid incorrect applications for travel insurance which risk becoming invalid if conditions are not clearly stated or clarified. Our updated list and advice surrounding travel insurance also provides our community with easy steps to ensure they get the best quotes and have the support in place to travel with confidence.

### Building Communities

Living with a rare IMD can feel isolating for both the people living with the condition and their families or caregivers. We work to reduce isolation by helping to bring people together to share experiences and ask for 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 are keen to remove barriers, creating spaces that are inclusive, safe, and accessible.

We aim to expand our communities, supporting harder to reach cohorts and developing a network for each community, provide individual support and resources where needed in a timely manner, and address unmet needs. Identifying and working with Community Ambassadors is vital, ensuring the work we do benefits and supports the community members.

#### Online

Many of our communities rely on online spaces and in 2022/23 we focused on improving our social media engagement with all the IMD community by increasing the regularity and the relevance of our posts. Utilising analytics to gain insight into our activities across our social media channels: Instagram, Facebook, Twitter, and LinkedIn, we have been able to tailor our communications for different audiences. This year we delivered 898 separate pieces of online content, seen by over 400,000 people and increased our followers by 20% to 4,800. Our social media engagement is a key element of our community building; we interact daily with different communities by posting and responding to others' posts. We use our social media to share information but also to ask questions. In September 2022 we asked our Facebook community, 'What are your thoughts on genetic testing, whole genome sequencing and gene therapy'. This sparked an online, open, conversation between group members (patients and caregivers) who shared thoughts such as 'For my family genetic testing gave us answers and choice' and 'Gene therapy would completely change (my daughter's) life'. This valuable, informal insight helps us to better connect with people.

#### Engagement

### Key Community Building Achievements 2022-2023:

1. In November 2022 we held our first in-person event since 2019, a 'Family Fun Day' at Chester Zoo. Attended by over 60 people, this event was an opportunity to connect with our communities and provided a unique opportunity for families to meet each other in person.
- iv. In July 2022 we marked Metabolic Awareness Week by launching a series of online educational materials that provided accessible and relevant information on Rare Disease policy for our communities.
- v. We were directly involved with over 50 online disease specific community groups and developed 4 new disease specific groups across the year.
- vi. Our CEO, Kirsty Hoyle, shared her lived experience as a parent to a child with a rare condition in the rare disease community magazine, Rarity Life. The article was shared with our community and highlighted our values of putting lived experience at the centre of our work
- vii. Coffee and Chat sessions were held fortnightly with the introduction of topic-specific sessions designed to create focused sharing on subjects such as genetic testing and genetic counselling.

# METABOLIC SUPPORT UK

## TRUSTEES' REPORT (INCLUDING DIRECTOR'S REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2023

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### 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.

We aim to provide accessible resources about conditions and new developments, ensuring people are aware of the options available to them. In turn they can make informed decisions ranging from diagnostic tools, treatment options, and care pathways. Facilitating platforms and opportunities for people to share their experiences allows the community to empower each other. Enabling Community Ambassadors in these spaces elevates this, leading people to become more proactive, vocal, and confident. In turn people feel empowered to contribute to development of disorder specific toolkits and frameworks, leading on their condition and self-care.

We aim to provide accessible resources about conditions and new developments, ensuring people are aware of the options available to them. In turn they can make informed decisions ranging from diagnostic tools, treatment options, and care pathways. Facilitating platforms and opportunities for people to share their experiences allows the community to empower each other. Enabling Community Ambassadors in these spaces elevates this, leading people to become more proactive, vocal, and confident. In turn people feel empowered to contribute to development of disorder specific toolkits and frameworks, leading on their condition and self-care.

### Key Advocacy Achievements 2022-2023

1. Our response to the Cost-of-Living Crisis was one of our key areas of work in 2022/23. We surveyed our community on their needs and produced a 'Cost of Living with an IMD report'. This report was well received and reached 453,641 people, generating 815 reads with an average read time of 4 minutes. Further increasing its impact, the findings were referenced in the Specialised Healthcare Alliance report on inequalities for rare diseases which was shared with members of the specialised commissioning team at NHS England (NHSE), those with rare disease portfolios at the Department of Health and Social Care (DHSC) and relevant stakeholders at the National Institute of Health and Care Excellence (NICE).

2. We joined the Disabled Children's Partnership, a coalition of charities who support the needs of disabled children. When we announced we had joined the partnership online one of our community responded "Fabulous news - 2 great charities working together for us 🙏"

3. Newborn Screening was a key focus for us this year:  
- Joining the Newborn Screening Collaborative  
- We were instrumental in the IMD Tyrosinemia being approved for additional to the UK Newborn Screening Panel  
- Providing information to our community on Newborn Screening and seeking insight on their views.

### 4. External Research & Insight

As a trusted umbrella group and signposter, we share information on a number of opportunities for the IMD community for the benefit of patients and all stakeholders. This year we provided information on over 30 external research and insight opportunities from organisations such as Carer's Trust, Health Research Wales, The Patient's Association and Beacon and cooking events with VitaFlo.

### 5. Events, Forums and Partnerships

Our community, and their voices, are at the centre of our work. Throughout the year we continuously sought opportunities to;

- engage with national and international bodies to raise the profile of IMDs.
- utilise our data and evidence to support lobbying for welfare of the wider IMD community
- share our learnings with other patient organisations and stakeholders aiming for a coordinated effort.

In 2022-2023 we focused on increasing our presence at/on external events, forums, groups and committees;

- **Attending relevant professional events allows us to raise the flag for our community and make vital connections with sector colleagues, events included:**  
Cambridge Rare Disease Day  
Integrated Care Systems Roadshow, Manchester  
SSIEM, Germany, the leading international gathering of IMD medical specialists

# METABOLIC SUPPORT UK

## TRUSTEES' REPORT (INCLUDING DIRECTOR'S REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2023

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- **We sit on forums and groups that allow us direct opportunities to influence policy, access to treatments and on-going care:**
  - Rare Disease Framework Forum (gov.uk)
  - Inherited White Matter Disorder Group
  - Metabolic Clinical Referencing Group (NHS England)
  - Mustang Steering Committee
  - Menkes Clinical Trial Steering Committee
  - Pyruvate Kinase Deficiency Advocacy and Advisory Council
  - IMD Newborn Screening Advisory Board (Public Health England)
  - Patient Engagement Group (Genetic Alliance)
- **Our partnerships with academics, healthcare professionals and other patient advocacy organisations provide a unique opportunity to advocate across diverse spaces:**
  - PNPO Research Project
  - X-Linked Hypophosphatasia with Kyowa Kirin
  - Rare Bone Alliance Members
  - Lysosomal Storage Disease Collaborative
  - Genetic Alliance
  - Rare QOL

### 6. 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. This year we delivered a number of insight projects that allowed us to test and refine our offer and service model, something we will focus on with greater import over the next two to three years. Examples of insight projects in 2022/23 include:

AADC Project (report with AADC Trust) - working in partnership with AADC Research Trust, we co-developed an AADC insight report and took part in the NICE appraisal of a gene therapy for people living with AADC. The AADC insight report was finalised in August 2022 and the first patient was treated with the new gene therapy in September 2023.

FGF32 10 (with XLH UK) - working in partnership with XLH UK, we co-designed a FGF23 TIO insight survey to determine the unmet needs of the FGF23 TIO community; we co-wrote a scoping submission and interview guide; subsequently facilitating interviews.

CSID Focus Group - on behalf of one of our partners we organised a focus group with parents/caregivers of people with CSID to gain a deeper understanding of the experiences and challenges people living with CSID experience, focussing on symptoms, the impact of their condition and treatment options. An insight report was generated in August 2022.

Insight project with XLH UK looking into the lived experience of people with XLH Working in partnership with Oxalosis and Hyperoxaluria Foundation, we co-designed an insight survey and interview discussion guide. We conducted interviews and published a PH1 insight report in May 2022.

# METABOLIC SUPPORT UK

## TRUSTEES' REPORT (INCLUDING DIRECTOR'S REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2023

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7. Consultations and Submissions  
Involvement in consultations and submissions allows us to ensure our community's voice is heard throughout the entire process that affects them, their treatment, and their wellbeing. See below for an overview of our impact in consultations and submissions in 2022-2023.

8. We work on UK treatment appraisals and have contributed to a number of treatment appraisals (by NICE, SMC or AWMSG) in the UK (NICE shared that our 'insight model is a an example of good practice') and this year contributed to the submissions below:

Pegzilarginase, an enzyme therapy for the treatment of Arginase-1 (ARG1) deficiency which is currently under appraisal. MSUK gained the patient perspective through conversations with the community and submitted consultation documents in addition to attended a scoping workshop in February 2023 where we represented the patient voice and provided detail of the impact of ARG1.

Mercaptamine bitartrate (Procysbi), used in the treatment of Nephropathic Cystinosis was successfully recommended for use in Wales via a AWMSG appraisal in May 2022. MSUK collaborated with Cystinosis Foundation UK to gather patient insight through a survey, case studies and put forward a joint submission.

Lumasiran (Oxlumo), an RNAi gene therapy for the treatment of Primary Hyperoxaluria type 1, was recommended for use via NICE appraisal in March 2023. MSUK collaborated with the Oxalosis and Hyperoxaluria Foundation (OHF) to gain patient perspectives and understand the impact of treatment and produced a patient experience insight report

Eladocagene exuparvovec (Upstaza), a gene therapy for the treatment of L-Amino acid decarboxylase (AADC) deficiency, was successfully recommended for use via a NICE appraisal in April 2023. MSUK collaborated with the AADC Trust to develop a patient survey and represent the patient voice throughout the appraisal.

Asfotase alfa (Strensiq), used for the treatment of paediatric onset hypophosphatasia (HPP) was successfully recommended for use via a NICE appraisal in February 2023. MSUK have been involved since 2014, building the HPP community, successfully fighting for a Managed Access Agreement and supporting the formation of Soft Bones UK charity (led by our patient expert in the NICE process). More recently we carried out multiple evidence gathering engagements with the community including a novel joint Q&A session for patients and caregivers in collaboration with NICE. We also produced an insight report in collaboration with our HPP community to highlight their experience of Strensiq.

Burosumab (Crysvita), used to treat X-linked hypophosphataemia in adults was recommended for use by the SMC in March 2023. (within the ultra-orphan pathway while further evidence on its effectiveness is generated). MSUK collaborated with XLH UK gathering patient impact and on a joint submission.

### **We also help further clinical trials for IMDs through:**

- Providing information to communities to support enrolment and supporting patients on trials Reviewing and developing patient information Educating our community on the clinical trial process through our upcoming 'Get Involved Hub'
- Providing the Patient and Public Voice (PPV) on trials, recent examples include:
- MUSTANG Investigating the role of Miglustat in the management of a patient with Tangier's Disease: a single case experiment (MUSTANG). MSUK sit as an independent member of the trial steering committee overseeing and monitor the trial, safeguarding the interests of the participant.
- HORACE Halting Ornithine transcarbamylase deficiency with Recombinant AAV in children MSUK holds a PPV position on a clinical trial for a new gene therapy AAVLK03hOTC led by UCLH. We review reviewed all patient facing documents ensuring they are friendly for a variety of ages.

# METABOLIC SUPPORT UK

## TRUSTEES' REPORT (INCLUDING DIRECTOR'S REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2023

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In order to support the longer-term development of new IMD treatments we contribute to a number of projects that aim to improve access and accelerate development. An example:

IWMD Registry: MSUK represent the PPV on the core working group (alongside Alex TLC) and implementing the Inherited White Matter Disorders (IWMD) Diagnostic and Management Service and accompanying Registry. The IWMD Registry collates clinical data and also patient and patient representative reported data which will improve understanding of IWMDs and can be used as a verified source of information to assist in the development and approval process of future therapies.

### Fundraising 2022-2023:

1. **A family legacy continues...**  
We were delighted that Beki Greene chose to run for MSUK in the Great Manchester Run. Beki is Jen Greene's sister, whose family founded our charity over forty years ago to raise vital awareness and support at a time when there was no other help. Thank you, Beki!
  
- viii. **London Marathon 2022**  
We had 13 participants for the October 2022 London Marathon. This high-profile event provides a unique opportunity for our supporters to raise vital funds. We are grateful for those that joined Team MSUK and chose to raise funds on our behalf.
  
- ix. **Individual Achievements**  
Throughout the year over 100 people donated or held individual fundraising events on our behalf. From linedancing, selling christmas cards, running marathons and holding an MSUK-themed garden party, our community came out in force to help us. Thank you!
  
- x. Metabolic Support UK's community of fundraisers and donors continued to fundraise via a number of different activities across 2022-23 including remote fundraising. We continue to be grateful for the legacies received from our supporters.

The organisations that provided funding towards Metabolic Support's activities in 2022/23 include:

- Alexion
- Amicus
- Arcturus
- Cenote
- Chiesi
- I-ECure
- Immedica
- Kyowa Kirin
- PTC Bio
- Sanofi
- Ultragenyx

# METABOLIC SUPPORT UK

## TRUSTEES' REPORT (INCLUDING DIRECTOR'S REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2023

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### Financial review

At the year end, Metabolic Support UK's accounts showed a deficit of £14,628 (2022: £27,012) made up of unrestricted funds.

Due to the uncertainty of the impact that the cost of living crisis will have on the charity's income generation in 2022/23 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:

- Stabilising expenditure and focussing on digital service delivery and outputs
- Retaining and supporting the smaller existing staff team to deliver the strategy with the support of freelancers
- Further diversifying income streams to include trusts and foundations

The Board of Trustees of Metabolic Support UK continue monitor the financial health of the charity.

The unrestricted reserves held by the charity is currently £609,281 - higher than the policy of six months running costs (approximately £250,000) due to the historical sale of a property and legacies received. The Board committed to the planned investment of the funds into the development of the charity in the short to medium term, to create future suitability and increase the positive impact on the lives of those who are affected by Inherited Metabolic Disorders now and in the future.

At year ending March 2023, 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.

The trustees has assessed the major risks to which the charity is exposed, and are satisfied that systems are in place to mitigate exposure to the major risks.

### 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.

The trustees, who are also the directors for the purpose of company law, and who served during the year and up to the date of signature of the financial statements were:

Dr R E Pugh MBChB FRCP

Mr P J Roper MIET CEng BSC Hons

Mr J O'Hara Msc

Mr A Johnson

(Resigned 19 July 2022)

Dr R Vara

Dr E H Davies

Mr C Lander

### Recruitment and appointment of new trustees

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

### Induction and training of trustees

New trustees are provided with information about the charity and its work and their role and responsibilities as trustees.

# METABOLIC SUPPORT UK

## TRUSTEES' REPORT (INCLUDING DIRECTOR'S REPORT) (CONTINUED) *FOR THE YEAR ENDED 31 MARCH 2023*

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The trustees' report was approved by the Board of Trustees.

Dr E H Davies  
**Trustee**

23 January 2024

# METABOLIC SUPPORT UK

## INDEPENDENT EXAMINER'S REPORT

### TO THE TRUSTEES OF METABOLIC SUPPORT UK

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I report to the trustees on my examination of the financial statements of Metabolic Support UK (the charity) for the year ended 31 March 2023.

#### **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 Charities and Trustee Investment (Scotland) Act 2005 (the 2005 Act), the Charities Accounts (Scotland) Regulations 2006 (as amended) and the Companies Act 2006 (the 2006 Act). 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 2006 Act 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 2005 Act and section 145 of the Charities Act 2011 (the 2011 Act). In carrying out my examination I have followed the requirements of Regulation 11 of the Charities Accounts (Scotland) Regulations 2006 (as amended) and all the applicable Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act.

#### **Independent examiner's statement**

Since the charity is required by company law to prepare its accounts on an accruals basis and is registered as a charity in Scotland your examiner must be a member of a body listed in Regulation 11(2) of the Charities Accounts (Scotland) Regulations 2006 (as amended). 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:

- 1 accounting records were not kept in respect of the charity as required by section 386 of the 2006 Act and Regulation 4 of the 2006 Accounts Regulations; or
- 2 the financial statements do not accord with those records; or
- 3 the financial statements do not comply with the accounting requirements of Regulation 8 of the Charities Accounts (Scotland) Regulations 2006 (as amended) and do not comply with the accounting requirements of section 396 of the 2006 Act other than any requirement that the accounts give a true and fair view which is not a matter considered as part of an independent examination; or
- 4 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 accounts 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.

Stephanie Baker BA(Hons) ACA  
McLintocks (NW) Limited  
2 Hilliards Court  
Chester Business Park  
Chester  
Cheshire  
CH4 9PX

Dated: 23 January 2024

# METABOLIC SUPPORT UK

## STATEMENT OF FINANCIAL ACTIVITIES INCLUDING INCOME AND EXPENDITURE ACCOUNT

FOR THE YEAR ENDED 31 MARCH 2023

	Notes	Unrestricted funds 2023 £	Restricted funds 2023 £	Total Unrestricted funds 2023 £	Unrestricted funds 2022 £	Restricted funds 2022 £	Total 2022 £
<b>Income from:</b>							
Donations and legacies	2	248,310	-	248,310	227,088	-	227,088
Charitable activities	3	24,114	-	24,114	27,031	-	27,031
Investments	4	-	-	-	156	-	156
<b>Total income</b>		<u>272,424</u>	<u>-</u>	<u>272,424</u>	<u>254,275</u>	<u>-</u>	<u>254,275</u>
<b>Expenditure on:</b>							
Charitable activities	5	287,052	-	287,052	227,263	-	227,263
<b>Net (outgoing)/incoming resources before transfers</b>		<u>(14,628)</u>	<u>-</u>	<u>(14,628)</u>	<u>27,012</u>	<u>-</u>	<u>27,012</u>
Gross transfers between funds		<u>12,504</u>	<u>(12,504)</u>	<u>-</u>	<u>-</u>	<u>-</u>	<u>-</u>
<b>Net (expenditure)/income for the year/ Net movement in funds</b>		<u>(2,124)</u>	<u>(12,504)</u>	<u>(14,628)</u>	<u>27,012</u>	<u>-</u>	<u>27,012</u>
Fund balances at 1 April 2022		<u>611,405</u>	<u>12,504</u>	<u>623,909</u>	<u>584,393</u>	<u>12,504</u>	<u>596,897</u>
<b>Fund balances at 31 March 2023</b>		<u><u>609,281</u></u>	<u><u>-</u></u>	<u><u>609,281</u></u>	<u><u>611,405</u></u>	<u><u>12,504</u></u>	<u><u>623,909</u></u>

The statement of financial activities includes all gains and losses recognised in the year.

All income and expenditure derive from continuing activities.

The statement of financial activities also complies with the requirements for an income and expenditure account under the Companies Act 2006.

# METABOLIC SUPPORT UK

## BALANCE SHEET

AS AT 31 MARCH 2023

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	Notes	2023 £	£	2022 £	£
<b>Current assets</b>					
Cash at bank and in hand		621,093		629,761	
<b>Creditors: amounts falling due within one year</b>	<b>11</b>	<u>(11,812)</u>		<u>(5,852)</u>	
Net current assets			<u>609,281</u>		<u>623,909</u>
<b>Income funds</b>					
Restricted funds	<b>12</b>		-		12,504
Unrestricted funds			<u>609,281</u>		<u>611,405</u>
			<u>609,281</u>		<u>623,909</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 2023.

The director acknowledges her 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 23 January 2024

Dr E H Davies  
Trustee

Company registration number 04267454

# METABOLIC SUPPORT UK

## NOTES TO THE FINANCIAL STATEMENTS

### FOR THE YEAR ENDED 31 MARCH 2023

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#### 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 (as amended) and "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)" (as amended for accounting periods commencing from 1 January 2016). 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 applying FRS 102 Update Bulletin 1 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 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 2023

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### 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 Tangible fixed assets

Tangible fixed assets are initially measured at cost and subsequently measured at cost or valuation, net of depreciation and any impairment losses.

Depreciation is recognised so as to write off the cost or valuation of assets less their residual values over their useful lives on the following bases:

Plant and machinery	33% straight line
Fixtures, fittings & equipment	15% straight line

The gain or loss arising on the disposal of an asset is determined as the difference between the sale proceeds and the carrying value of the asset, and is recognised in the statement of financial activities.

#### 1.7 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.

##### **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 2023

### 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 Donations and legacies

	Unrestricted funds	Unrestricted funds
	2023	2022
	£	£
Donations and gifts	248,310	227,088

### 3 Charitable activities

	Fundraising income	Fundraising income
	2023	2022
	£	£
Sales within charitable activities	24,114	27,031

### 4 Investments

	Total Unrestricted funds	
	2023	2022
	£	£
Interest receivable	-	156

# METABOLIC SUPPORT UK

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2023

### 5 Charitable activities

	Direct charitable activities	Direct charitable activities
	2023	2022
	£	£
Staff costs	216,090	152,468
Rent, rates and cleaning	-	409
Insurance	1,505	1,549
Repairs & maintenance	-	395
Printing, postages and stationery	265	120
Telephone and IT costs	14,182	16,074
Meetings travel & accommodation	2,934	421
Sundries	6,077	1,324
Recruitment fees	9,070	14,645
Bank charges	99	31
Projects	12,976	6,871
Marketing	6,022	49
Professional fees	9,075	24,907
	<u>278,295</u>	<u>219,263</u>
Share of support costs (see note 6)	5,252	4,823
Share of governance costs (see note 6)	3,505	3,177
	<u>287,052</u>	<u>227,263</u>

### 6 Support costs

	Support costs	Governance costs	2023	2022
	£	£	£	£
Human resource fees	5,252	-	5,252	4,823
Independent examination	-	2,100	2,100	2,097
Accountancy	-	1,405	1,405	1,080
	<u>5,252</u>	<u>3,505</u>	<u>8,757</u>	<u>8,000</u>
Analysed between Charitable activities	<u>5,252</u>	<u>3,505</u>	<u>8,757</u>	<u>8,000</u>

### 7 Trustees

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

# METABOLIC SUPPORT UK

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2023

### 8 Employees

The average monthly number of employees during the year was:

	2023 Number	2022 Number
Charitable	4	3
Fundraising	1	-
Administration	1	1
Total	<u>6</u>	<u>4</u>

### Employment costs

	2023 £	2022 £
Wages and salaries	<u>216,090</u>	<u>152,468</u>

Total remuneration for the key management personnel of the charity was £107,842 (2022: £90,462).

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

	2023 Number	2022 Number
£70,000 to £79,999	<u>1</u>	<u>-</u>

### 9 Taxation

The charity is exempt from tax on income and gains falling within section 505 of the Taxes Act 1988 or section 252 of the Taxation of Chargeable Gains Act 1992 to the extent that these are applied to its charitable objects.

### 10 Tangible fixed assets

	Plant and machinery £	Fixtures, fittings & equipment £	Total £
At 1 April 2022	28,472	9,722	38,194
Disposals	(28,472)	(9,722)	(38,194)
At 1 April 2022	28,472	9,722	38,194
Eliminated in respect of disposals	(28,472)	(9,722)	(38,194)
<b>Carrying amount</b>			
At 31 March 2023	<u>-</u>	<u>-</u>	<u>-</u>
At 31 March 2022	<u>-</u>	<u>-</u>	<u>-</u>

# METABOLIC SUPPORT UK

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2023

### 11 Creditors: amounts falling due within one year

	2023 £	2022 £
Other taxation and social security	5,659	3,555
Trade creditors	3,152	197
Other creditors	901	-
Accruals and deferred income	2,100	2,100
	<u>11,812</u>	<u>5,852</u>

### 12 Restricted funds

During the year £12,504 was transferred from restricted funds to unrestricted funds being a residual unused balance of prior charitable activities.

### 13 Analysis of net assets between funds

	Unrestricted 2023 £	Restricted 2023 £	Total Unrestricted 2023 £	Total Unrestricted 2022 £	Restricted 2022 £	Total 2022 £
Fund balances at 31 March 2023 are represented by:						
Current assets/(liabilities)	609,281	-	609,281	623,909	-	623,909
	<u>609,281</u>	<u>-</u>	<u>609,281</u>	<u>623,909</u>	<u>-</u>	<u>623,909</u>

### 14 Related party transactions

There were no disclosable related party transactions during the year (2022 - none).

**Metabolic Support**

England & Wales - Charity number 1089588

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# Accounts

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**Charity registration number 1089588 (England and Wales)**

**Charity registration number SC446344 (Scotland)**

**Company registration number 04267454 (England and Wales)**

**METABOLIC SUPPORT UK**  
**ANNUAL REPORT AND UNAUDITED FINANCIAL STATEMENTS**  
**FOR THE YEAR ENDED 31 MARCH 2022**

# METABOLIC SUPPORT UK

## LEGAL AND ADMINISTRATIVE INFORMATION

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<b>Trustees</b>	Dr R E Pugh MBChB FRCP Mr P J Roper MIET CEng BSC Hons Mr J O'Hara Msc Mr A Johnson Dr R Vara Dr E H Davies Mr C Lander
<b>Charity number (England and Wales)</b>	1089588
<b>Charity number (Scotland)</b>	SC446344
<b>Company number</b>	04267454
<b>Registered office</b>	Unit 11-12 Gwenfro Technology Park Croesnewydd Road Wrexham LL13 7YP
<b>Independent examiner</b>	McLintocks (NW) Limited 2 Hilliards Court Chester Business Park Chester Cheshire CH4 9PX

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# METABOLIC SUPPORT UK

## CONTENTS

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	<b>Page</b>
Trustees' report	1 - 11
Independent examiner's report	12
Statement of financial activities	13
Balance sheet	14
Notes to the financial statements	15 - 21

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# METABOLIC SUPPORT UK

## TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) FOR THE YEAR ENDED 31 MARCH 2022

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The trustees present their annual report and financial statements for the year ended 31 March 2022.

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 (as amended) and "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) (effective 1 January 2019)".

### Objectives and activities

The charity's primary aims are to:

- The relief of children, young adults, family members and carers affected by metabolic diseases in particular by means of:
  - i. Providing for the same group, an information, advice and support service.
  - ii. Putting the same group into contact with each other for their mutual benefit, help and support.
  - iii. The provision for grants and allowances for the same group and in addition to hospitals, homes or institutions, as shall from time to time be determined, for the purposes of medical treatment, care and relief from suffering.
- The relief of adults who are affected by metabolic diseases by the provision of support and services which are not otherwise provided by any other metabolic disease group in England, as the trustees think fit.
- The education of Health care professionals, other professionals and the general public about metabolic diseases.
- To provide medical research into metabolic diseases and their diagnosis.

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

### Achievements and performance

Metabolic Support UK is an umbrella patient advocacy organisation founded in 1981, supporting and advocating for people living with Inherited Metabolic Disorders (IMDs) and their communities.

We support over 20,000 people living with one of over 500 IMDs, across the world. IMD's 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 group. 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.

# **METABOLIC SUPPORT UK**

## **TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)** **FOR THE YEAR ENDED 31 MARCH 2022**

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### **Organisational Development**

This year our new CEO, Kirsty Hoyle, began in August 2021, building on the existing 2030 strategy to develop a programme of work that is relevant for our communities now and in the future. We broadened our focus with an increase in policy work and developed our insight arm, MSUK Insight, looking for paid opportunities for our communities to contribute to healthcare and treatment development.

### **Achievements and Performance**

This was a year of growth and development for MSUK, against a backdrop of political and social instability. Our communities started to branch out and we saw increased interest in travel and holidays which threw up an issue around travel insurance. We launched a report into travel insurance issues and are now working with leading travel insurers to establish better options for our IMD community. Our international community was affected by the war in Ukraine and we worked with UK stakeholders to establish routes of support for Ukrainians coming to the UK, including publishing our advice leaflet in English and Ukrainian. We hired our first Policy focused member of staff and increased our presence in relevant groups across the rare disease policy space. Our individual support remained as strong as previous years, with an increase in international enquiries reflecting our growth as the leading international organisation supporting people living with a IMD.

### **Strategic Implementation**

By 2030, we want 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 with these conditions to enjoy a better quality of life.

Our commitment to our community is to make sure that their voices are heard across all levels of decision-making and policy implementation. We work collaboratively and transparently as we strive to achieve our objectives, ensuring the best outcomes for those affected by IMDs.

In order to achieve this, we developed our long-term strategic pillars based on our evidence and insight of the needs of those we support. These four pillars are:

1. Individual Support
2. Building Communities
3. Empowerment
4. Advocacy

### **Individual Support**

We recognise that living with a rare IMD can have added financial, practical and emotional burden. As part of our Individual Support stream of work we aim to provide first line emotional and practical support tailored to anyone who wants it via our experienced and qualified support team.

To improve the accessibility of our support we: provide individual and peer support through our helpline and Metabolic Connect services, produce accessible disorder information and resources, and work in collaboration with other organisations. By taking a proactive approach to addressing unmet needs based on data and signposting to other organisations we can ensure relevant and timely support is available.

# METABOLIC SUPPORT UK

## TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2022

### Enquiries

As an international patient organisation, we receive enquiries from across the globe. Whilst most enquiries originated from within the UK, we received enquiries from 32 other unique countries. Across this geographical range we consistently see the same trending themes; evidence of how individually rare IMDs bring collectively common difficulties, issues, and experiences.



We supported a total of 348 enquiries covering 16 unique themes. Some themes were specific to a certain time of year, such as 'COVID-19 Vaccine' which we saw only in Quarter 1, but many were prevalent throughout the year. Queries surrounding 'New Diagnosis' and 'Peer Support' were present in each Quarter, with 'Financial Support' and 'Seeking a Diagnosis' being present from Quarter 2 through to Quarter 4.

### Key Support Achievements 2021-2022:

#### 1. **Disease Explainer Newsletters**

We curated a series of disease area specific newsletters which were sent directly to members of the relevant communities. These provided focused, accessible information on different IMD conditions with relevance. Supporting knowledge and confidence are key to empowering people.

#### 5. **COVID-19 Restrictions Piece**

COVID-19 and the guidelines that came with it were often difficult to navigate. With lockdown restrictions easing we asked our community how they were feeling. Everyone dealt with these changes differently. For some there was a sense of freedom and relief especially around being able to be closer to friends and family. However, many responded with feelings of anxiety and concern, worried about keeping themselves and loved ones safe.

We developed content to offer advice we hoped would help those struggling to take small positive steps with the help of their support networks, such as friends, family, healthcare professionals, patient organisations, and ourselves at MSUK.

#### 6. **Jargon Buster Series**

To support and empower our community we released our Jargon Buster Series to help people understand key terms used in their healthcare. Each video addresses a different term, from 'NICE' and 'MHRA' to 'Trial or Study Steering Committee.'

# METABOLIC SUPPORT UK

## TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2022

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### **MSUK Coffee Lounge**

We continued our virtual coffee lounge. Every other Wednesday all members of our community can join us for an online video chat. It provides a relaxed, confidential space where people can share experiences and seek support from one another. These sessions are continuing to provide value post-pandemic, with a regular cohort of attendees. A number of regulars were able to meet in person for the first time at our Family Fun Day held later in 2022.

### **Building Communities**

Living with a rare IMD can feel isolating for both the people living with the condition and their families or caregivers. We work to reduce isolation by helping to bring people together to share experiences and ask for 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 are keen to remove barriers, creating spaces that are inclusive, safe, and accessible.

We aim to expand our communities, supporting harder to reach cohorts and developing a network for each community, provide individual support and resources where needed in a timely manner, and address unmet needs. Identifying and working with Community Ambassadors is vital, ensuring the work we do benefits and supports the community members.

### Key Community Building Achievements 2021-2022:

#### **1. 40 years of MSUK**

In 2021, MSUK celebrated 40 years of innovation, support, and progress. We took the time to reflect on our story thus far and look toward the future through sharing the voices of our community and a report. It is a story of how one family made a difference for millions of others but also an insight into the rare disease sector more broadly – a sector full of passionate individuals challenging a system that leaves them out.

Moving forward into 2022 and beyond, we will continue to carry the spirit of our founders, delivering knowledge and power directly into the hands of people living with IMDs. Our report looked back on 40 years of change across the rare disease and IMD landscape, celebrating and sharing the progress that has been made, whilst also being critically aware of work that is still needed.

#### **7. Contact Management**

We implemented a new contact record management system which provides full visibility across our different community streams. This system increased our ability to connect our communities by allowing us to make connections across different areas of shared experience including geographic, interest and disease

### **Community Support**

MSUK Communities: In 2022-2022 we supported over 45 Disease specific community groups. We developed 2 new disease specific groups across the year.

### **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.

We aim to provide accessible resources about conditions and new developments, ensuring people are aware of the options available to them. In turn they can make informed decisions ranging from diagnostic tools, treatment options, and care pathways. Facilitating platforms and opportunities for people to share their experiences allows the community to empower each other. Enabling Community Ambassadors in these spaces elevates this, leading people to become more proactive, vocal, and confident. In turn people feel empowered to contribute to development of disorder specific toolkits and frameworks, leading on their condition and self-care.

# METABOLIC SUPPORT UK

## TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2022

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### Key Empowerment Achievements 2021-2022:

#### **1. Metabolic Matters**

Metabolic Matters was developed as a monthly magazine to break down complex information into an engaging format, illuminating a multitude of topics from gene therapies to whole genome sequencing. It works as a platform to highlight not only our own work but also the work of organisations we collaborate with, from Medics 4 Rare Disease to Genetic Alliance UK, and many more.



We released our first issue in January 2022 and by the end of March we saw a total of 655 reads and 1,137 impressions. These numbers include people living with IMDs, their families, clinicians, and pharmaceutical companies.

#### **2. Twitter Takeover with Genetic Alliance UK**

In February 2022 we took over Genetic Alliance UK's Twitter to discuss all things identity, access to emergency care, VLCADD, and more.

#### **3. Rare Thinking Festival**

Metabolic Support UK proudly presented 'Rare Thinking', a three-day festival of ideas, connections, and opportunities for people living with IMDs and their communities. The programme covered 3 main areas:

- Our Common Fight: an exploration of power and identity for people living with IMDs and how this intersects all areas of our lives
- Our Everyday: practical advice on everyday needs from experts helping people to be in control of their lives and an opportunity for lived experiences to contribute to wider learning
- My Rare Condition: an opportunity for selected disorder-specific communities to receive updates on latest developments, connect with others, and help us to shape the rare disease landscape.

These days were curated to empower those affected by IMDs largely through the sharing of information, experience, and co-production. Providing spaces where people could take ownership of their individual situation with increased confidence, feeling heard, valued, and part of a community.

# METABOLIC SUPPORT UK

## TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2022

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### Advocacy

There are many challenges and difficulties faced by those living with a rare metabolic disorder. We work hard to amplify their voices, making sure they are heard, recognised, and equally valued among all stakeholders. There is a lot to learn from our communities and we work to make that happen.

Gaining unique perspective from our communities and working with other organisations we can formulate responses and advocate for solutions to challenges faced in areas such as: research, diagnosis, treatments, services, and care.

Through this pillar of our work, we aim to engage communities in research and drug development processes, generate evidence, collaborate with other organisations and stakeholders, and campaign for change.

### Key Advocacy Achievements 2021-2022

#### 1. The ARDEnt Report

We collaborated with over 30 rare disease organisations to launch the Action for Rare Disease Empowerment (ARDEnt) report entitled 'Making the Unseen Seen: Rare disease and lessons learned from the COVID-19 pandemic'.



This report reveals the impact of the pandemic on every stage of the patient journey, from diagnosis to eventual management. It catalogues the re-assignment of specialists away from rare disease, the fear of infection, the closure of clinics, the fracture of coordination of health and social care, and the delay or termination of clinical studies. Finally, the report makes recommendations intended to bring those living with rare diseases into the light and make their management more robust.

The report focused on three key priority areas;

- Priority 1: helping patients get a final diagnosis faster
- Priority 2: coordination of care
- Priority 3: improved access to specialist care, treatment and drugs

Metabolic Support UK acted as Co-Lead on Theme 2: Coordination of Health and Social Care and facilitated the launch webinar on May 11<sup>th</sup> 2021.

#### 2. Events, Forums and Partnerships

Our community, and their voices, are at the centre of our work. Throughout the year we continuously sought opportunities to;

- engage with national and international bodies to raise the profile of IMDs.
- utilise our data and evidence to support lobbying for welfare of the wider IMD community
- share our learnings with other patient organisations and stakeholders aiming for a coordinated effort.

# METABOLIC SUPPORT UK

## TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2022

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In 2021-2022 we were part of more than 30 events, forums, groups, and committees;

**Attending relevant professional events allows us to raise the flag for our community and make vital connections with sector colleagues:**

- British Paediatric Neurology Association Event, Virtual Stand
- Health Technology Assessment International Conference, Online
- British Inherited Metabolic Disorder Group Conference, Newcastle

**We sit on forums and groups that allow us direct opportunities to influence policy, access to treatments and on-going care:**

- Rare Disease Framework Forum
- Inherited White Matter Disorder Group
- Menkes Clinical Trial Steering Group
- Metabolic Clinical Referencing Group
- Primary Hyperoxaluria Type 1 Discussion Groups and Panels
- Mustang Steering Committee
- Menkes Clinical Trial Steering Committee
- Pyruvate Kinase Deficiency Advocacy and Advisory Council
- IMD Newborn Screening Forum

**Our partnerships with academics, healthcare professionals and other patient advocacy organisations provide a unique opportunity to advocate across diverse spaces:**

- PNPO Research Project
- X-Linked Hypophosphatasia with Kyowa Kirin
- Rare Bone Alliance Members
- Lysosomal Storage Disease collaborative
- Genetic Alliance
- Rare QOL

### **FOCUS ON: Digital Tools for Rare Diseases**

Metabolic Support UK is part of the three-year Digital Tools for Rare Disease project (DT4RD) led by Aparito. This innovative project brings together multinational consortium of leading experts with the aim to develop a digital platform capable of assessing upper limb function remotely. The point between ambulant and non-ambulant is a pivotal juncture in the progression of rare disease which isn't often accounted for in conventional methodology and tools.

Our communities need access to non-invasive tools that allow them to contribute to research without increase to their everyday burden, and we were delighted to be involved from the outset, showing a real commitment to embedding lived experience or rare disease patients in this project.

**We also ensure there are opportunities for our community members to directly advocate:**

In February 2022 we partnered with Genetic Alliance to highlight how IMDs may affect the heart by supporting a member of our community to share their son's story with VLCADD.

CEO Kirsty Hoyle alongside a member of our community spoke at Royal Society of Medicine's event 'Blue Moons are not so rare: Metabolic, Genetics and Uncommon diseases.' The opportunity for one of our families to open such an important event in a supported way is an epitome of our advocacy work.

# METABOLIC SUPPORT UK

## TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2022

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### 3. MSUK Patient Survey 2021

In 2021 we ran a patient survey to gain greater insight into the needs of our IMD community. 97 people responded including people living with IMDs, parents and carers, and family members. Key data from this survey told us that our community face difficulties with misdiagnosis, support following a diagnosis, accessing emergency care at their local A&E department, and accessing care and support.

*"It took several years to find the diagnosis, leading to a delay in treatment and irreparable damage"*

For participants, diagnosis typically took place between the ages of 0-4 with a referral to a specialist in under 3 months. Most said they find their condition easy to manage, with a large majority managing their condition via a combination of diet and medication.

*"There are challenges everyday when living with a metabolic condition"*

*Alongside quantitative data the survey provided an abundance of qualitative data. Whilst this is harder to consolidate, it contributes tremendously to our overall awareness and comprehension of our community; their experiences, difficulties faced, and outstanding areas of support and resources. Together this helps us to centre all our work around the voice, opinions, and experiences of our community.*

*"General fear for the future, fear of the unknown!"*

### 4. Consultations and Submissions

Involvement in consultations and submissions allows us to ensure our community's voice is heard throughout the entire process that affects them, their treatment, and their wellbeing. See below for an overview of our impact in consultations and submissions in 2021-2022:

#### Primary Hyperoxaluria Type 1 (PH1) NICE Consultation

- In collaboration with Oxalosis and Hyperoxaluria Foundation (OHF).
- Carried out interviews and jointly published a report entitled 'The patient perspective of unmet need' in collaboration with RareQOL and OHF.

#### X-Linked Hypophosphataemic Rickets (XLH) NICE Scoping Workshop

- In collaboration with XLH UK

#### Hypophosphatasia (HPP) Managed Access Agreement

- Led on the representation of patient voice during the MAA and provided updates to the community.
- 2021 was the penultimate year of the MAA however we succeed in securing an extension till February 2023 due to COVID-19.

#### Cystinosis Treatments working with Cystinosis Foundation UK

##### - Treatment 1: Cystadrops

- Ongoing collaborative work and recommendation from Clinical Priorities Advisory Group (CPAG) saw NHS England decide to routinely commission Mercaptamine hydrochloride (Cystadrops) for corneal cystine deposits in people aged older than two years.
- Success of this led to the publication of a case study 'Delivering the Patient Voice and Collaborative Working: Cystinosis and the NHS Clinical Priorities Advisory Process' by MSUK and and CFUK.

##### - Treatment 2: Procybi

- Through the SMC, MSYK and CFUK ran a patient survey and worked in collaboration on a joint submission.

# METABOLIC SUPPORT UK

## TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2022

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### Methylmalonic Acidemia (MMA)/Propionic Acidemia (PA) Clinical Trials

- Worked alongside Moderna to provide updates on new clinical trials and reviewing patient-facing information provided by Moderna.
- Facilitated 'Emerging Research, Treatments and Therapies for the MAA and PA Community' focus group session at the Rare Thinking Festival.

### Engagement

In January 2022 we began utilising analytics to gain insight into our activities across social media channels: Instagram, Facebook, Twitter, and LinkedIn. This move coincided with an overhaul of our community engagement and social media branding, with a focus to create both planned and reactive communications to best serve our community.

These changes allow us to move forwards with a data-driven approach to our engagement, allowing us to better assess and reflect on the impact, visibility, and effectiveness of our work.

From January 2021 through to the end of March 2022 we published 414 social media posts, which saw a total of 350 shares, 3,135 likes, and 143,883 impressions (impressions are the number of people of who have seen a post, even if they didn't click, comment, or otherwise engage with the post). The period ended with a combined total of 3,985 followers. Whilst we have no previous data to compare these values against, they provide an exciting base line for future comparison and analysis.

### Fundraising

Metabolic Support UK's community of fundraisers and donors continued to find creative ways to raise funds following the easing of COVID-19 restrictions. Their endeavours are invaluable to our work and as always, we are grateful for their hard work and support.

#### Key fundraising achievements 2021-2022:

#### 1. **MSUK X1 vs Brickfield Rangers**

July saw Christopher, a long-term fundraiser, host an all-star charity football match in aid of Metabolic Support UK. This event brought together local players from teams such as Bellevue FC and national celebrities such as Big Brother contestant Glyn Wise and Sky Sports and BBC Commentator Bryn Law to compete against each other. The day was a huge success, with face painting, food, drinks and many more activities throughout the afternoon.



#### 2. **London Marathon 2021**

We had 15 participants for the October 2021 London Marathon. This high-profile event provides a unique opportunity for our supporters to raise vital funds. We are grateful for those that joined Team MSUK and chose to raise funds on our behalf.

# METABOLIC SUPPORT UK

## TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2022

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### Financial review

At the year end, Metabolic Support UK's accounts showed a surplus of £27,012 (2021: £101,384) made up of unrestricted funds. Last years large surplus was from the sale of a property and legacies received.

The Board of Trustees of Metabolic Support UK continue monitor the financial health of the charity.

The unrestricted reserves held by the charity is currently £623,909 higher than the policy of 6 months running costs (approximately £114,000). The Board committed to the planned investment of the funds into the development of the charity in the short to medium term, to create future suitability and increase the positive impact on the lives of those who are affected by Inherited Metabolic Disorders now and in the future.

The property that formed the charity's headquarters in Crewe was sold in the 2020/21 financial year.

At year ending March 2022, 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.

The trustees has assessed the major risks to which the charity is exposed, and are satisfied that systems are in place to mitigate exposure to the major risks.

### 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.

The trustees, who are also the directors for the purpose of company law, and who served during the year and up to the date of signature of the financial statements were:

Dr R E Pugh MBChB FRCP

Mr P J Roper MIET CEng BSC Hons

Mr J O'Hara Msc

Mr A Johnson

Dr R Vara

Dr E H Davies

Mr B Hopkins

Mr C Lander

(Resigned 18 January 2022)

### Recruitment and appointment of new trustees

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

### Induction and training of trustees

New trustees are provided with information about the charity and its work and their role and responsibilities as trustees.

# METABOLIC SUPPORT UK

## TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) *FOR THE YEAR ENDED 31 MARCH 2022*

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The trustees' report was approved by the Board of Trustees.

Dr E H Davies  
**Trustee**

27 March 2023

# METABOLIC SUPPORT UK

## INDEPENDENT EXAMINER'S REPORT

### TO THE TRUSTEES OF METABOLIC SUPPORT UK

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I report to the trustees on my examination of the financial statements of Metabolic Support UK (the charity) for the year ended 31 March 2022.

#### **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 Charities and Trustee Investment (Scotland) Act 2005 (the 2005 Act), the Charities Accounts (Scotland) Regulations 2006 (as amended) and the Companies Act 2006 (the 2006 Act). 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 2006 Act 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 2005 Act and section 145 of the Charities Act 2011 (the 2011 Act). In carrying out my examination I have followed the requirements of Regulation 11 of the Charities Accounts (Scotland) Regulations 2006 (as amended) and all the applicable Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act.

#### **Independent examiner's statement**

Since the charity is required by company law to prepare its accounts on an accruals basis and is registered as a charity in Scotland your examiner must be a member of a body listed in Regulation 11(2) of the Charities Accounts (Scotland) Regulations 2006 (as amended). 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:

- 1 accounting records were not kept in respect of the charity as required by section 386 of the 2006 Act and Regulation 4 of the 2006 Accounts Regulations; or
- 2 the financial statements do not accord with those records; or
- 3 the financial statements do not comply with the accounting requirements of Regulation 8 of the Charities Accounts (Scotland) Regulations 2006 (as amended) and do not comply with the accounting requirements of section 396 of the 2006 Act other than any requirement that the accounts give a true and fair view which is not a matter considered as part of an independent examination; or
- 4 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 accounts 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.

Michael Caputo FCA  
McLintocks (NW) Limited  
2 Hilliards Court  
Chester Business Park  
Chester  
Cheshire  
CH4 9PX

Dated: 27 March 2023

# METABOLIC SUPPORT UK

## STATEMENT OF FINANCIAL ACTIVITIES INCLUDING INCOME AND EXPENDITURE ACCOUNT

FOR THE YEAR ENDED 31 MARCH 2022

	Notes	Unrestricted funds 2022 £	Restricted funds 2022 £	Total Unrestricted funds 2022 £	Restricted funds 2021 £	Total 2021 £
<b>Income and endowments from:</b>						
Donations and legacies	2	227,088	-	227,088	327,583	327,583
Charitable activities	3	27,031	-	27,031	31,591	31,591
Investments	4	156	-	156	1,404	1,404
Other income	5	-	-	-	128,884	128,884
<b>Total income</b>		<b>254,275</b>	<b>-</b>	<b>254,275</b>	<b>-</b>	<b>489,462</b>
<b>Expenditure on:</b>						
Charitable activities	6	227,263	-	227,263	-	384,784
Other	10	-	-	-	15,534	15,534
<b>Total expenditure</b>		<b>227,263</b>	<b>-</b>	<b>227,263</b>	<b>-</b>	<b>400,318</b>
<b>Net incoming resources</b>		<b>27,012</b>	<b>-</b>	<b>27,012</b>	<b>-</b>	<b>89,144</b>
<b>Other recognised gains and losses</b>						
Revaluation of tangible fixed assets		-	-	-	12,240	12,240
<b>Net movement in funds</b>		<b>27,012</b>	<b>-</b>	<b>27,012</b>	<b>-</b>	<b>101,384</b>
Fund balances at 1 April 2021		584,393	12,504	596,897	12,504	495,513
<b>Fund balances at 31 March 2022</b>		<b>611,405</b>	<b>12,504</b>	<b>623,909</b>	<b>12,504</b>	<b>596,897</b>

The statement of financial activities includes all gains and losses recognised in the year.

All income and expenditure derive from continuing activities.

The statement of financial activities also complies with the requirements for an income and expenditure account under the Companies Act 2006.

# METABOLIC SUPPORT UK

## BALANCE SHEET

AS AT 31 MARCH 2022

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	Notes	2022 £	£	2021 £	£
<b>Current assets</b>					
Cash at bank and in hand		629,761		601,047	
<b>Creditors: amounts falling due within one year</b>	12	<u>(5,852)</u>		<u>(4,150)</u>	
Net current assets			<u>623,909</u>		<u>596,897</u>
<b>Income funds</b>					
Restricted funds			12,504		12,504
Unrestricted funds			<u>611,405</u>		<u>584,393</u>
			<u>623,909</u>		<u>596,897</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 2022.

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 27 March 2023

Dr E H Davies  
Trustee

Company registration number 04267454

# METABOLIC SUPPORT UK

## NOTES TO THE FINANCIAL STATEMENTS

### FOR THE YEAR ENDED 31 MARCH 2022

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#### 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 (as amended) and "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)" (as amended for accounting periods commencing from 1 January 2016). 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 applying FRS 102 Update Bulletin 1 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 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 2022

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#### 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 Tangible fixed assets

Tangible fixed assets are initially measured at cost and subsequently measured at cost or valuation, net of depreciation and any impairment losses.

Depreciation is recognised so as to write off the cost or valuation of assets less their residual values over their useful lives on the following bases:

Plant and machinery	33% straight line
Fixtures, fittings & equipment	15% straight line

The gain or loss arising on the disposal of an asset is determined as the difference between the sale proceeds and the carrying value of the asset, and is recognised in the statement of financial activities.

##### 1.7 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.

##### **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 2022

### 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 Donations and legacies

	<b>Unrestricted funds</b>	Unrestricted funds
	<b>2022</b>	2021
	£	£
Donations and gifts	227,088	327,583

### 3 Charitable activities

	<b>Fundraising income</b>	Fundraising income
	<b>2022</b>	2021
	£	£
Sales within charitable activities	27,031	31,591

### 4 Investments

	<b>Unrestricted funds</b>	Unrestricted funds
	<b>2022</b>	2021
	£	£
Interest receivable	156	1,404

# METABOLIC SUPPORT UK

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2022

### 5 Other income

	Total	Unrestricted funds
	2022	2021
	£	£
Other income	-	8,467
Coronavirus job retention scheme	-	27,607
National Lottery Coronavirus grant	-	92,810
	<u>-</u>	<u>128,884</u>

### 6 Charitable activities

	Direct charitable activities	Direct charitable activities
	2022	2021
	£	£
Staff costs	152,468	259,354
Depreciation and impairment	-	7,518
Rent, rates and cleaning	409	22,629
Insurance	1,549	1,632
Light & heat	-	3,791
Repairs & maintenance	395	2,045
Printing, postages and stationery	120	729
Telephone and IT costs	16,074	27,887
Meetings travel & accommodation	421	-
Sundries	1,324	2,943
Recruitment fees	14,645	10,000
Bank charges	31	1,047
Projects	6,871	24,266
Equipment hire	-	6,066
Marketing	49	1,458
Professional fees	24,907	5,992
	<u>219,263</u>	<u>377,357</u>
Share of support costs (see note 7)	4,823	3,444
Share of governance costs (see note 7)	3,177	3,983
	<u>227,263</u>	<u>384,784</u>

# METABOLIC SUPPORT UK

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2022

### 7 Support costs

	Support costs	Governance costs	2022	2021
	£	£	£	£
Human resource fees	4,823	-	4,823	3,444
Independent examination	-	2,097	2,097	2,100
Accountancy	-	1,080	1,080	1,883
	<u>4,823</u>	<u>3,177</u>	<u>8,000</u>	<u>7,427</u>
Analysed between Charitable activities	<u>4,823</u>	<u>3,177</u>	<u>8,000</u>	<u>7,427</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: 4

	2022 Number	2021 Number
Charitable	3	5
Fundraising	-	2
Administration	1	1
Total	<u>4</u>	<u>8</u>

### Employment costs

	2022 £	2021 £
Wages and salaries	<u>152,468</u>	<u>259,354</u>

Total remuneration for the key management personnel of the charity was £90,462 (2021: £88,677).

There were no employees whose annual remuneration was more than £60,000.

# METABOLIC SUPPORT UK

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2022

### 10 Other

	<b>Total</b>	Unrestricted
	<b>£</b>	funds
	<b>2022</b>	2021
Net loss on disposal of tangible fixed assets	-	15,534
	<u>-</u>	<u>15,534</u>
	<u>-</u>	<u>15,534</u>

### 11 Tangible fixed assets

	Plant and machinery	Fixtures, fittings & equipment	Total
	£	£	£
<b>Cost</b>			
At 1 April 2021	28,472	9,722	38,194
	<u>28,472</u>	<u>9,722</u>	<u>38,194</u>
At 31 March 2022	28,472	9,722	38,194
	<u>28,472</u>	<u>9,722</u>	<u>38,194</u>
<b>Depreciation and impairment</b>			
At 1 April 2021	28,472	9,722	38,194
	<u>28,472</u>	<u>9,722</u>	<u>38,194</u>
At 31 March 2022	28,472	9,722	38,194
	<u>28,472</u>	<u>9,722</u>	<u>38,194</u>

### 12 Creditors: amounts falling due within one year

	<b>2022</b>	<b>2021</b>
	£	£
Other taxation and social security	3,555	2,051
Trade creditors	197	-
Accruals and deferred income	2,100	2,099
	<u>5,852</u>	<u>4,150</u>
	<u>5,852</u>	<u>4,150</u>

### 13 Analysis of net assets between funds

	Unrestricted	Restricted	Total	Unrestricted	Restricted	Total
	2022	2022	2022	2021	2021	2021
	£	£	£	£	£	£
Fund balances at 31 March 2022 are represented by:						
Current assets/(liabilities)	623,909	-	623,909	584,393	12,504	596,897
	<u>623,909</u>	<u>-</u>	<u>623,909</u>	<u>584,393</u>	<u>12,504</u>	<u>596,897</u>
	<u>623,909</u>	<u>-</u>	<u>623,909</u>	<u>584,393</u>	<u>12,504</u>	<u>596,897</u>

# **METABOLIC SUPPORT UK**

## **NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)** ***FOR THE YEAR ENDED 31 MARCH 2022***

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### **14 Related party transactions**

There were no disclosable related party transactions during the year (2021 - none).

**Metabolic Support**

England & Wales - Charity number 1089588

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# Accounts

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Charity Registration No. 1089588 (England and Wales)

Charity Registration No. SC446344 (Scotland)

Company Registration No. 04267454 (England and Wales)

**METABOLIC SUPPORT UK**  
**ANNUAL REPORT AND UNAUDITED FINANCIAL STATEMENTS**  
**FOR THE YEAR ENDED 31 MARCH 2021**

# METABOLIC SUPPORT UK

## LEGAL AND ADMINISTRATIVE INFORMATION

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**Trustees**

Dr R E Pugh MBChB FRCP  
Mr P J Roper MIET CEng BSC Hons  
Mr J O'Hara Msc  
Mr A Johnson  
Dr R Vara  
Dr E H Davies  
Mr B Hopkins  
Mr C Lander

(Appointed 2 September 2020)

**Charity number (England and Wales)** 1089588

**Charity number (Scotland)** SC446344

**Company number** 04267454

**Registered office**

Unit 11-12 Gwenfro  
Technology Park  
Croesnewydd Road  
Wrexham  
LL13 7YP

**Independent examiner**

McLintocks (NW) Limited  
2 Hilliards Court  
Chester Business Park  
Chester  
Cheshire  
CH4 9PX

# METABOLIC SUPPORT UK

## CONTENTS

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	<b>Page</b>
Trustees' report	1 - 6
Independent examiner's report	7
Statement of financial activities	8
Balance sheet	9
Notes to the financial statements	10 - 18

---

# **METABOLIC SUPPORT UK**

## **TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT)**

### **FOR THE YEAR ENDED 31 MARCH 2021**

---

The trustees present their report and financial statements for the year ended 31 March 2021.

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 (as amended) and "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) (effective 1 January 2019)".

#### **Objectives and activities**

The charity's primary aims are to:

- The relief of children, young adults, family members and carers affected by metabolic diseases in particular by means of:
  - i. Providing for the same group, an information, advice and support service.
  - ii. Putting the same group into contact with each other for their mutual benefit, help and support.
  - iii. The provision for grants and allowances for the same group and in addition to hospitals, homes or institutions, as shall from time to time be determined, for the purposes of medical treatment, care and relief from suffering.
- The relief of adults who are affected by metabolic diseases by the provision of support and services which are not otherwise provided by any other metabolic disease group in England, as the trustees think fit.
- The education of Health care professionals, other professionals and the general public about metabolic diseases.
- To provide medical research into metabolic diseases and their diagnosis.

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

#### **Achievements and performance**

Metabolic Support UK is an umbrella patient advocacy organisation founded in 1981, supporting and advocating for people living with Inherited Metabolic Disorders (IMDs) and their caregivers.

There are approximately 30,000 people in the UK today living with one of over 500 IMDs. These 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.

Focusing specifically on the rarest of the IMDs, those which have no other patient organisation or support group, Metabolic Support UK delivers a wide range of support and advocacy services to address unmet needs. Using qualitative and quantitative data generated via various methodologies, our small dedicated team works to proactively identify priority needs and 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.

# **METABOLIC SUPPORT UK**

## **TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)**

### ***FOR THE YEAR ENDED 31 MARCH 2021***

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#### **Covid-19 Response**

During this year our work was heavily influence by the need to respond to the Covid-19 pandemic. We responded with a number of specific projects that included:

- Produced 10 Covid Patient Insight videos, demonstrating the impact the Pandemic has had on patients and families living with Inherited Metabolic Disorders. These will be a powerful tool in advocating for patients on CRG and in informing collaborative awareness raising campaigns and wider policy issues.
- Developed a Covid resource hub on our website which has received over 15,000 visitors to date. The resource hub ensures patients are kept up to date and informed with accessible, factual and reliable information.
- Hosted 3 covid themed webinars and produced 13 self-care when shielding and social distancing videos. These videos provided reassurances and support to our patient community during the national lockdowns.
- Responded to over 600 Covid-19 related enquiries, alleviating the pressure on our Metabolic Centre colleagues in the NHS
- Introduced our popular Virtual Coffee and Chat which run fortnightly and provide a space for our communities to connect and chat online.

Whilst our immediate priority was to respond to the emerging and ever-changing needs and challenges in light of the coronavirus pandemic, it was also important to keep our long term strategic objectives at the forefront of the businesses and services that we create and deliver. We want to ensure that once the pandemic is over, the communities that we support and engage with, remain together and engaged with us. It is our aim that we represent a strong unified patient voice and ensure that patients and families living with rare diseases are not forgotten during and in the aftermath of the pandemic. Therefore we are driving forward with collaborative initiatives with other patient organisations. It is essential that we combine our knowledge and understanding of the impact of Covid-19 on our rare disease patient populations so we can better advocate for the needs of our communities together. With the rare disease framework launch, NICE methods review, review of medicines and other policy items, it is vital that patients have a platform to participate in issues that affect them. To support our communities, we had to upskill our team and provide trusted and up to date support for our community.

#### **Organisational Development**

During this year we went through some personnel changes as a response to the Covid-19 pandemic and to better structure the future of Metabolic Support UK in line with our ten year strategy. Our CEO, Lindsay Weaver resigned during this financial year and the board began external recruitment for a new CEO, with Kirsty Hoyle appointed in August 2021.

# **METABOLIC SUPPORT UK**

## **TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)**

### **FOR THE YEAR ENDED 31 MARCH 2021**

---

#### **Achievements and Performance**

Metabolic Support UK continues to deliver support and advocacy for patient and their families, from point of diagnosis, through all stages of the patient's journey to bereavement and beyond. With over 500 extremely rare conditions, the spectrum of unmet need is wide-ranging and diverse.

Our work this year began with our Covid-19 response. The pandemic affected the whole IMD patient community, many of whom were considered extremely clinically vulnerable and increased demand for the charity's support services. The staff team and Board immediately mobilised to respond to the crisis, supporting staff to work from home, increasing digital presence, and upskilling in the technology required to deliver its projects virtually. In the first two months of 2020-21 we:

- Directly supported 142 patients and their families through our individual enquiries with an average resolution time of 15 hours.
- Sent communications to over 25k people with 64% direct to patients and their families
- Had over 4,000 views on our online Covid-19 resources.

Alongside this immediate response, and against a background of the continuing pandemic and organisational change, we continued to offer our core services – in line with our strategy – throughout 2020/21:

#### **Information, Education and Connecting Patients**

- o First online conference attended by over 100 patients, families, healthcare professionals, industry representatives and other IMD stakeholders.
- o Connected over 50 families worldwide via Metabolic Connect (peer support programme) offering and receiving peer support to reduce isolation and share experiences.
- o Supported over 350 Individual Enquiries through our Information and Advice Line
- o Commenced the building of eight disorder-specific patient communities.
- o Launched our 'Jargon Busters' video series

#### **Awareness Raising and Visibility**

- We were a member of the ARDENT (Action for Rare Disease Empowerment) project working group, evidencing the impact of Covid-19 on the rare disease community with partners such as the Cambridge Rare Disease Network.
- We worked in collaboration with other stakeholders to build our profile and partnerships including our work on the COVID-19 Vaccine webinar in collaboration with the Lysosomal Storage Disorders Patient Collaborative and the British Inherited Metabolic Disease Group.
- Our team represented the charity at a variety of meetings including the Metabolic CRG meetings, IMD Screening Advisory Group meetings, Specialist Healthcare Alliance meetings, and APPG for Access to Medicines and Medical Devices meetings.

#### **Advocacy**

- Metabolic Support UK is recognised as the leading patient advocate group for all Inherited Metabolic Disorders in the UK, and holds stakeholder positions with NICE, the UK Screening Committee and other groups. 2020/21 positions include:
  - IMD Newborn Screening Advisory Committee
  - Metabolic Clinical Referencing Group
- In September 2020 we launched our work with Breaking Down Barriers, sharing our new Patient Insight Series and recruiting a BAME Ambassador and putting in measures to ensure we capture ethnicity and religion of patients in our data to better understand and serve all communities
- We joined the working group for Rare QOL, a social prescribing working group for rare disease communities.
- Supported the development of a new disease-specific patient community organisation, Thrive PKD, with one of our trustees.

# METABOLIC SUPPORT UK

## TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2021

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### Strategic Implementation

2020/21 was the first year of our implementation for our new strategy and ten-year plan, approved by the board in March 2020; a strategy designed to adapt to fast-paced changes in the rare disease landscape, deliver effective and impactful support services to meet increasing demand, and secure the long-term sustainability of the charity. This was put to the test immediately in this year by the Covid-19 pandemic. We structured support for our community under the four key strategic pillars of our strategy during this very difficult year:

Our team provided unrivalled frontline emotional and practical **Individual Support** to patients and caregivers via our experienced and qualified support team.

We focused on **Building Patient Communities** for new rare diseases, expanding opportunities for peer to peer support.

Patients were offered increased opportunity to contribute to the decisions around access to care or treatment through our **Empowerment** work.

Our work gathering data and evidence from our communities during this year has advanced our patient's opportunities for meaningful **Advocacy**.

### Fundraising

Metabolic Support UK continued to implement the 2018 fundraising strategy which aimed to diversifying its income streams. The impact of Covid-19 meant that community fundraising was more of a challenge but we were successful in securing a National Lottery Covid-19 grant of £93k. The organisations that provided funding towards Metabolic Support's activities in 2020/21 include:

- National Lottery Covid-19 Response Fund
- Sylvia Adams Charitable Trust
- Bionical
- Alexion
- Chiesi
- Moderna
- Alynlam
- Kyowa Kirin
- Agios
- Ultragenyx
- Amicus
- Takeda
- Audentes
- Immedica
- Reneo

Metabolic Support UK's community of fundraisers and donors continued to fundraise via a number of different activities across 2020-21 including remote fundraising. We continue to be grateful for the legacies received from our supporters

# METABOLIC SUPPORT UK

## TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)

### FOR THE YEAR ENDED 31 MARCH 2021

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#### Financial review

##### Financial Position at Year End

At the year end, Metabolic Support UK's accounts showed a surplus made up of unrestricted funds. This is due to the sale of a property and legacies received. Due to the uncertainty on the impact the covid-19 pandemic will have on the charity's income generation in 2021/22 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:

- Stabilising expenditure and focussing on digital service delivery and outputs
- Retaining and supporting the smaller existing staff team to deliver the strategy with the support of freelancers
- Further diversifying income streams to include trusts and foundations

#### Financial review

The Board of Trustees of Metabolic Support UK continue monitor the financial health of the charity.

The unrestricted reserves held by the charity is currently £584,393 higher than the policy of 6 months running costs (approximately £250,000) due to the sale of the property and legacies received. The Board committed to the planned investment of the funds into the development of the charity in the short to medium term, to create future suitability and increase the positive impact on the lives of those who are affected by Inherited Metabolic Disorders now and in the future.

The property that formed the charity's headquarters in Crewe was sold in the 2020/21 financial year.

At year ending March 2021, 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.

The trustees has assessed the major risks to which the charity is exposed, and are satisfied that systems are in place to mitigate exposure to the major risks.

#### **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.

The trustees, who are also the directors for the purpose of company law, and who served during the year and up to the date of signature of the financial statements were:

Dr R E Pugh MBChB FRCP

Mr P J Roper MIET CEng BSC Hons

Ms J R Godfrey

(Resigned 2 December 2020)

Mr J O'Hara Msc

Mr A Johnson

Dr R Vara

Dr E H Davies

Mr B Hopkins

Mr C Lander

(Appointed 2 September 2020)

# METABOLIC SUPPORT UK

## TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) *FOR THE YEAR ENDED 31 MARCH 2021*

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### **Recruitment and appointment of new trustees**

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

### **Induction and training of trustees**

New trustees are provided with information about the charity and its work and their role and responsibilities as trustees.

The trustees' report was approved by the Board of Trustees.



**Dr E H Davies**

Trustee

Dated: 28 January 2022

# METABOLIC SUPPORT UK

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

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I report to the trustees on my examination of the financial statements of Metabolic Support UK (the charity) for the year ended 31 March 2021.

### 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 Charities and Trustee Investment (Scotland) Act 2005 (the 2005 Act), the Charities Accounts (Scotland) Regulations 2006 (as amended) and the Companies Act 2006 (the 2006 Act). 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 2006 Act 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 2005 Act and section 145 of the Charities Act 2011 (the 2011 Act). In carrying out my examination I have followed the requirements of Regulation 11 of the Charities Accounts (Scotland) Regulations 2006 (as amended) and all the applicable Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act.

### Independent examiner's statement

Since the charity is required by company law to prepare its accounts on an accruals basis and is registered as a charity in Scotland your examiner must be a member of a body listed in Regulation 11(2) of the Charities Accounts (Scotland) Regulations 2006 (as amended). 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:

- 1 accounting records were not kept in respect of the charity as required by section 386 of the 2006 Act and Regulation 4 of the 2006 Accounts Regulations; or
- 2 the financial statements do not accord with those records; or
- 3 the financial statements do not comply with the accounting requirements of Regulation 8 of the Charities Accounts (Scotland) Regulations 2006 (as amended) and do not comply with the accounting requirements of section 396 of the 2006 Act other than any requirement that the accounts give a true and fair view which is not a matter considered as part of an independent examination; or
- 4 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 accounts 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.



Michael Caputo FCA  
McLintocks (NW) Limited  
2 Hilliards Court  
Chester Business Park  
Chester  
Cheshire  
CH4 9PX

Dated: 28 January 2022

# METABOLIC SUPPORT UK

## STATEMENT OF FINANCIAL ACTIVITIES INCLUDING INCOME AND EXPENDITURE ACCOUNT

FOR THE YEAR ENDED 31 MARCH 2021

		Unrestricted funds 2021 £	Restricted funds 2021 £	Total 2021 £	Unrestricted funds 2020 £	Restricted funds 2020 £	Total 2020 £
	<b>Notes</b>						
<b><u>Income and endowments from:</u></b>							
Donations and legacies	<b>3</b>	327,583	-	327,583	302,082	-	302,082
Charitable activities	<b>4</b>	31,591	-	31,591	56,330	2,133	58,463
Investments	<b>5</b>	1,404	-	1,404	5,936	-	5,936
Other income	<b>6</b>	128,884	-	128,884	962	-	962
<b>Total income</b>		<b>489,462</b>	<b>-</b>	<b>489,462</b>	<b>365,310</b>	<b>2,133</b>	<b>367,443</b>
<b><u>Expenditure on:</u></b>							
Raising funds	<b>7</b>	-	-	-	147,716	-	147,716
Charitable activities	<b>8</b>	384,784	-	384,784	361,345	5,000	366,345
Other	<b>12</b>	15,534	-	15,534	-	-	-
<b>Total resources expended</b>		<b>400,318</b>	<b>-</b>	<b>400,318</b>	<b>509,061</b>	<b>5,000</b>	<b>514,061</b>
<b>Net incoming/(outgoing) resources</b>		<b>89,144</b>	<b>-</b>	<b>89,144</b>	<b>(143,751)</b>	<b>(2,867)</b>	<b>(146,618)</b>
<b>Other recognised gains and losses</b>							
Revaluation of tangible fixed assets		12,240	-	12,240	(50,000)	-	(50,000)
<b>Net movement in funds</b>		<b>101,384</b>	<b>-</b>	<b>101,384</b>	<b>(193,751)</b>	<b>(2,867)</b>	<b>(196,618)</b>
Fund balances at 1 April 2020		483,009	12,504	495,513	676,760	15,371	692,131
<b>Fund balances at 31 March 2021</b>		<b>584,393</b>	<b>12,504</b>	<b>596,897</b>	<b>483,009</b>	<b>12,504</b>	<b>495,513</b>

The statement of financial activities includes all gains and losses recognised in the year.

All income and expenditure derive from continuing activities.

The statement of financial activities also complies with the requirements for an income and expenditure account under the Companies Act 2006.

# METABOLIC SUPPORT UK

## BALANCE SHEET

AS AT 31 MARCH 2021

	Notes	2021 £	£	2020 £	£
<b>Fixed assets</b>					
Tangible assets	13		-		107,518
<b>Current assets</b>					
Cash at bank and in hand		601,047		398,026	
<b>Creditors: amounts falling due within one year</b>	14	(4,150)		(10,031)	
Net current assets			596,897		387,995
<b>Total assets less current liabilities</b>			596,897		495,513
<b>Income funds</b>					
Restricted funds			12,504		12,504
<u>Unrestricted funds</u>					
General unrestricted funds		584,393		495,249	
Revaluation reserve		-		(12,240)	
			584,393		483,009
			596,897		495,513


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 2021.

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 28 January 2022



Dr E H Davies  
Trustee

Company Registration No. 04267454

# METABOLIC SUPPORT UK

## NOTES TO THE FINANCIAL STATEMENTS

### FOR THE YEAR ENDED 31 MARCH 2021

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#### 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 (as amended) and "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)" (as amended for accounting periods commencing from 1 January 2016). 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 applying FRS 102 Update Bulletin 1 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, modified to include the revaluation of freehold properties and to include investment properties and certain financial instruments at fair value. 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 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 Incoming resources

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 2021

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### 1 Accounting policies

(Continued)

#### 1.5 Tangible fixed assets

Tangible fixed assets are initially measured at cost and subsequently measured at cost or valuation, net of depreciation and any impairment losses.

Depreciation is recognised so as to write off the cost or valuation of assets less their residual values over their useful lives on the following bases:

Land and buildings	nil
Plant and machinery	33% straight line
Fixtures, fittings & equipment	15% straight line

The gain or loss arising on the disposal of an asset is determined as the difference between the sale proceeds and the carrying value of the asset, and is recognised in net income/(expenditure) for the year.

#### 1.6 Impairment of fixed assets

At each reporting end date, the charity reviews the carrying amounts of its tangible assets to determine whether there is any indication that those assets have suffered an impairment loss. If any such indication exists, the recoverable amount of the asset is estimated in order to determine the extent of the impairment loss (if any).

#### 1.7 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.

##### **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 2021

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### 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 Critical accounting estimates and judgements

In the application of the charity's accounting policies, the trustees are required to make judgements, estimates and assumptions about the carrying amount of assets and liabilities that are not readily apparent from other sources. The estimates and associated assumptions are based on historical experience and other factors that are considered to be relevant. Actual results may differ from these estimates.

The estimates and underlying assumptions are reviewed on an ongoing basis. Revisions to accounting estimates are recognised in the period in which the estimate is revised where the revision affects only that period, or in the period of the revision and future periods where the revision affects both current and future periods.

### 3 Donations and legacies

	<b>Unrestricted funds</b>	Total
	<b>2021</b>	2020
	£	£
Donations and gifts	327,583	302,082
	<u>          </u>	<u>          </u>

# METABOLIC SUPPORT UK

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2021

### 4 Charitable activities

	Fundraising income 2021 £	Membership 2021 £	Total 2021 £	Total 2020 £
Sales within charitable activities	31,591	-	31,591	58,463
Analysis by fund				
Unrestricted funds	31,591	-	31,591	56,330
Restricted funds	-	-	-	2,133
<b>For the year ended 31 March 2020</b>				
Unrestricted funds	51,238	5,092		56,330
Restricted funds	2,133	-		2,133
	53,371	5,092		58,463

### 5 Investments

	Unrestricted funds 2021 £	Unrestricted funds 2020 £
Interest receivable	1,404	5,936

### 6 Other income

	Unrestricted funds 2021 £	Unrestricted funds 2020 £
Other income	8,467	962
Coronavirus job retention scheme	27,607	-
National Lottery Coronavirus grant	92,810	-
	128,884	962

# METABOLIC SUPPORT UK

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2021

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### 7 Raising funds

	Total	Unrestricted funds
	2021	2020
	£	£
<u>Fundraising and publicity</u>		
Seeking donations, grants and legacies	-	8,095
Other fundraising costs	-	38,429
Staff costs	-	101,192
	<hr/>	<hr/>
Fundraising and publicity	-	147,716
	<hr/>	<hr/>
	<hr/>	<hr/>
	<hr/>	<hr/>

# METABOLIC SUPPORT UK

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2021

### 8 Charitable activities

	Direct charitable activities 2021 £	Restricted expenditure 2021 £	Total 2021 £	Total 2020 £
Staff costs	259,354	-	259,354	185,466
Depreciation and impairment	7,518	-	7,518	10,899
Rent, rates and cleaning	22,629	-	22,629	39,633
Insurance	1,632	-	1,632	2,829
Light & heat	3,791	-	3,791	4,416
Repairs & maintenance	2,045	-	2,045	1,699
Printing, postages and stationery	729	-	729	3,349
Telephone and IT costs	27,887	-	27,887	22,052
Meetings travel & accommodation	-	-	-	15,061
Sundries	2,943	-	2,943	1,131
Recruitment fees	10,000	-	10,000	-
Bank charges	1,047	-	1,047	2,264
Projects	24,266	-	24,266	25,352
Equipment hire	6,066	-	6,066	3,071
Marketing	1,458	-	1,458	23,464
Professional fees	5,992	-	5,992	-
	<u>377,357</u>	<u>-</u>	<u>377,357</u>	<u>340,686</u>
Share of support costs (see note 9)	3,444	-	3,444	-
Share of governance costs (see note 9)	3,983	-	3,983	25,659
	<u>384,784</u>	<u>-</u>	<u>384,784</u>	<u>366,345</u>
<b>Analysis by fund</b>				
Unrestricted funds	384,784	-	384,784	361,345
Restricted funds	-	-	-	5,000
	<u>384,784</u>	<u>-</u>	<u>384,784</u>	<u>366,345</u>
<b>For the year ended 31 March 2020</b>				
Unrestricted funds	361,345	-	361,345	361,345
Restricted funds	-	5,000	5,000	5,000
	<u>361,345</u>	<u>5,000</u>	<u>366,345</u>	<u>366,345</u>

# METABOLIC SUPPORT UK

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2021

### 9 Support costs

	Support costs £	Governance costs £	2021 £	2020 £
Staff costs	-	-	-	18,596
Human resource fees	3,444	-	3,444	-
Independent examination	-	2,100	2,100	2,100
Accountancy	-	1,883	1,883	-
Trustees meeting expenses	-	-	-	4,963
	<u>3,444</u>	<u>3,983</u>	<u>7,427</u>	<u>25,659</u>
Analysed between Charitable activities	<u>3,444</u>	<u>3,983</u>	<u>7,427</u>	<u>25,659</u>

### 10 Trustees

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

### 11 Employees

The average monthly number of employees during the year was:

	2021 Number	2020 Number
Charitable	5	9
Fundraising	2	2
Administration	1	1
Total	<u>8</u>	<u>12</u>
<b>Employment costs</b>	<b>2021</b>	<b>2020</b>
	<b>£</b>	<b>£</b>
Wages and salaries	<u>259,354</u>	<u>305,254</u>

Total remuneration for the key management personnel of the charity was £88,677.

There were no employees whose annual remuneration was £60,000 or more.

# METABOLIC SUPPORT UK

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2021

### 12 Other

	Unrestricted funds	Total
	2021	2020
		£
Net loss on disposal of tangible fixed assets	15,534	-
	<u>15,534</u>	<u>-</u>

### 13 Tangible fixed assets

	Land and buildings	Plant and machinery	Fixtures, fittings & equipment	Total
	£	£	£	£
<b>Cost</b>				
At 1 April 2020	100,000	28,472	9,722	138,194
Disposals	(100,000)	-	-	(100,000)
At 31 March 2021	<u>-</u>	<u>28,472</u>	<u>9,722</u>	<u>38,194</u>
<b>Depreciation and impairment</b>				
At 1 April 2020	-	21,747	8,929	30,676
Depreciation charged in the year	-	6,725	793	7,518
At 31 March 2021	<u>-</u>	<u>28,472</u>	<u>9,722</u>	<u>38,194</u>
<b>Carrying amount</b>				
At 31 March 2020	<u>100,000</u>	<u>6,725</u>	<u>793</u>	<u>107,518</u>

### 14 Creditors: amounts falling due within one year

	2021	2020
	£	£
Other taxation and social security	2,051	7,046
Accruals and deferred income	2,099	2,985
	<u>4,150</u>	<u>10,031</u>

### 15 Retirement benefit schemes

The charity operates a defined contribution pension scheme for all qualifying employees. The assets of the scheme are held separately from those of the charity in an independently administered fund.

# METABOLIC SUPPORT UK

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2021

### 16 Analysis of net assets between funds

	Unrestricted 2021 £	Restricted 2021 £	Total 2021 £	Unrestricted 2020 £	Restricted 2020 £	Total 2020 £
Fund balances at 31 March 2021 are represented by:						
Tangible assets	-	-	-	107,518	-	107,518
Current assets/ (liabilities)	584,393	12,504	596,897	375,491	12,504	387,995
	<u>584,393</u>	<u>12,504</u>	<u>596,897</u>	<u>483,009</u>	<u>12,504</u>	<u>495,513</u>

### 17 Related party transactions

There were no disclosable related party transactions during the year (2020 - none).