



MESOTHELIOMA UK

Annual Report and Financial Statements

Accounts and financials for Mesothelioma UK for period
ending 31st March 2022.

Mesothelioma UK Registered Charity Number:
1177039

Registered Address:
235 Loughborough Road, Mountsorrel, Loughborough, Leicestershire, LE12 7AS



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Foreword from the CEO



Our goal at Mesothelioma UK is twofold. We want everyone affected by mesothelioma to have access to optimal treatment and care, and we want to prevent mesothelioma from happening to future generations.

That we have been able to continue pushing towards this during 2021/22 is testament to the dedication of the many people who support our work. Not least those who left us legacies. These were instrumental in helping cushion us from the full financial impact of Covid. This report reveals a less secure year-end financial position, so it is timely to highlight the significant and long lasting impact of these and future legacies.

Despite the challenges there is much to celebrate. We said a grateful

farewell to Lorraine Creech our outstanding and hugely popular first Head of Nursing and warmly welcomed Leah Taylor into the post. Our nurse numbers have continued to grow over the year. We have focused on maximising their reach and impact and have discussions taking place in several areas of the UK where we have yet to establish ourselves. The virtual adaptations to nursing developed over the last two years are now well established and embedded across the Mesothelioma UK Nursing team. This has enabled a more flexible approach to many aspects of information giving, education and support.

Mesothelioma UK became members of the Association of Medical Research Charities. This enabled us to advertise and award our first independent research grants during this year. Mesothelioma UK Research Centre - Sheffield entered its second year, the team are committed and focused and have an impressive portfolio of Mesothelioma patient research. Consequently, Mesothelioma UK has been involved with the majority of mesothelioma patient research.

The Mesothelioma UK operations team moved into new offices in November 2021. The office and the facilities are better than anything we could have hoped for and provide a perfect work environment that has reinvigorated all of us. It is a continual challenge balancing the charity's growth with team recruitment; we have embedded a more flexible, virtual approach and are hugely

grateful for our new offices, having attractive and high standard facilities helps significantly.

This year we established a new Mesothelioma UK Clinical Expert Panel with health care professionals from across the UK and from all disciplines involved in mesothelioma treatment and care. The panel have been crucial to the charity's strategy, our plan of work and priority setting.

Whatever part you have played in Mesothelioma UK's success this year, whether you are a donor, fundraiser, ambassador, a member of our operations team, nursing team or a clinical expert, as you read this report, we hope you feel as grateful, proud and privileged as we do. Knowing you are doing and giving to something as worthwhile as Mesothelioma UK, helping to make our NHS the very best it can be, providing help and support for those living with mesothelioma is a fabulous cause that connects us all. Thank you for all that you have done and contributed.

Liz Darlison
CEO, Mesothelioma UK

Objectives and Activities

Mesothelioma UK remains the national charity dedicated to the asbestos related cancer mesothelioma.

Mesothelioma is a rare form of cancer caused by exposure to asbestos that affects the mesothelium. The mesothelium is a thin membrane that lines the inner surface of the chest wall, the abdomen and the testicles. The most common form of mesothelioma occurs in the chest. There is approximately one case of peritoneal (abdominal) mesothelioma to every 12 cases of pleural (chest) mesothelioma.

Mesothelioma UK provides specialist mesothelioma information, support, and education, and is dedicated to improving care and treatment for all UK mesothelioma patients and their carers.

The charity integrates into NHS front line services to ensure specialist mesothelioma nursing is available at the point of need. This is achieved through a growing network of specialist mesothelioma nurses, regionally based in NHS hospitals but funded by Mesothelioma UK.

The charity was launched in 2004 with initial financial support from

Macmillan Cancer Support and later from the Mick Knighton Mesothelioma Research Fund. We became an independent charity in 2008 and changed status from a Charitable Trust to a Charitable Incorporated Organisation in 2018.

The objective of the charity is to advance the health of mesothelioma patients, by funding specialist nursing posts, sponsoring research, advocating for patients and supporting access to treatment and clinical trials.



How We Work

In 2020/21 the charity organised its activities into “pillars”, and these have remained the same in this financial year.

Administration

Income Generation

Patient Support

Information

Research and Audit

Awareness

The administration and income generation pillars are internal and represent the work done by our dedicated operations team to ensure the charity is effective at delivering on its charitable aims.

The charitable work delivered by the organisation is divided into the remaining four pillars.

Patient Support which comprises much of our activity and spend. The flagship support we provide to patients is the funding of Mesothelioma Clinical Nurse Specialists (MCNS) in NHS trusts across the UK. The charity also provides a freephone support line number that connects patients who need support with our specialist nurses. Other patient support services include the provision of patient travel grants and the funding of specialist benefits advisors.

Information encompasses all the charity’s accredited patient information leaflets, as well as the information provided through our website.

Research and Audit including the funding of the Research Centre at Sheffield, and our research grant programme.

Awareness which is often in partnership and collaboration with other organisations to raise the profile of mesothelioma and awareness of the dangers of asbestos.

The trustees have had regard to the Charity Commission’s guidance on public benefit. The main activities undertaken to further the charitable purposes for the public benefit are as above.



Activities and Achievements

Although Covid restrictions were eased throughout the course of the year, it remained a very challenging environment in which to operate as a cancer charity. Patients continued to experience delays to treatment, our nurses coped with the effects of a lack of staff and our operational team fundraised in the context of an ever-tightening economy in the UK.

Despite these challenges, Mesothelioma UK, bolstered by the mesothelioma community across the UK, continued to support people affected by this cancer and make improvements in the care, treatment and management of mesothelioma.

Patient Support

Our Nurses



At the heart of everything we do at Mesothelioma UK is our desire to support mesothelioma patients through the most difficult time of their lives.

We recognise that everyone's experience of mesothelioma will be different and that their support needs will change over time. We have a range of services that support patients at different stages in their mesothelioma journey, from the point of diagnosis with a specialist nurse, through to our online support groups for carers and carefully researched information on end of life.

In March 2022 we said farewell to Lorraine Creech, our first ever Head of Nursing at Mesothelioma UK and a pioneer throughout her career.

The appointment of Leah Taylor as Lorraine's successor was announced in May 2022, after the period that this report relates to. Lorraine stepped up to the post in April 2020 and has left a lasting legacy.

Below she reflects on her time as our inaugural Head of Nursing.



Leah Taylor

Lorraine Creech



Looking Back on the Year as Head of Nursing

Our nurses are integral to the vision of Mesothelioma UK as we continue to forge ahead developing a “hub and spoke” approach to providing mesothelioma nurse leaders and mesothelioma clinical nurse specialists throughout the United Kingdom. It is important to reflect how the nursing workforce has developed during the past year, sharing skills and demonstrating their knowledge and expertise. The many facets of competence they display and the support they offer to patients and their families is fundamental to the roles of our nurses and the high level of respect in which they are held. It has been a pleasure to drive and facilitate this vision.

In March 2022 there were 34 Mesothelioma UK CNSs in post – 29 substantive posts and five adopted posts. In addition, there are two fostered or affiliated posts. All of these posts are embedded in the NHS and demonstrate partnership working with NHS Trusts.

Our nursing leadership has been strengthened by having the expertise of the three Team Leaders in Scotland and North and South England. Fixed project lead roles such as Sarah Morgan in Project Cymru and early collaborative work on Project Northern Ireland are helping us to move towards establishing a Mesothelioma UK footprint of in every Cancer Alliance in England and in the networks within the devolved administrations in the United Kingdom. These posts include sub-specialising nurses such as those working in the Armed Forces Project, Peritoneal and Thoracic Mesothelioma Nursing.

During the year it was also vital to create a culture and support mechanisms to recognise and support the voice of Mesothelioma UK Nursing especially as the Covid-19 pandemic has brought many challenges. The pandemic created difficulties for patients such as treatment delays, altered treatment regimes and remote consultations.

Two new online support groups were developed during the year and originated from calls to the Mesothelioma

Support line. They are the Carers Hour and the Younger Patients Support Group and are held monthly online.

In November 2021 it was helpful to hold our first Mesothelioma UK CNS professional forum on a face to face basis since the start of the pandemic as much of our education had been undertaken online. Whilst online learning is resourceful it cannot completely replace the benefits achieved from peer support and information sharing.

It is a requirement of Mesothelioma UK Clinical Nurse Specialists to identify and develop small scale research and audit studies to improve outcomes. During the year a vast amount of preparatory work has been put into the new digital Mesothelioma Health Companion app which allows patients to take more control in the management of their illness.

By enabling patients to record, monitor and communicate how they are feeling they can understand the impact the illness is having on their quality of life and seek ways to address concerns and improve their symptoms. This venture has been undertaken in partnership with DaSH Global and the Mesothelioma Health Companion app will launch in 2022.

An excellent example of small scale research has commenced by Kate Slaven, the Mesothelioma CNS at the Royal Papworth NHS Foundation Trust, Cambridge. Kate has received a grant from Lung Cancer Nursing UK and is exploring ‘Cough and Mesothelioma: the impact on quality of life’. I wish her well with this and I am sure it will be very well received.

It has been a privilege to lead the nurses and to hand over my Head of Nursing role to Leah Taylor who I know will be an excellent appointment. I am sure Leah will demonstrate her expertise in leadership and continue to develop the nursing workforce.

Facts & Figures

Total number of patients

1387

Total Armed Forces referrals

83

Total follow up contacts (all methods)

31135

Total face to face follow ups

1362

Total number of support groups attended

406

Virtual

271

Face
to face

135

Number of MTD meetings attended

904

Nursing Posts

During the year we continued to grow the number of Mesothelioma UK nurses.

Anna Morley joined us in Bristol with generous support from the Avon Mesothelioma Fund.

Lynne Hunter joined us in Edinburgh, previously funded by Macmillan Cancer Support as part of the Scottish Mesothelioma Network.

Two adopted (not fully funded) posts were created; Sam Williams at Aneurin Bevan and Tollene Riley at Epsom and St Helier.

We were very sad to say goodbye to two colleagues during the year, Angela Goldfinch in Essex and Maria Guerin Liverpool. We wish them both the best in their new roles.

Thank you to all our partners that have supported nurses throughout the year. Without you and your generous donors and fundraisers we wouldn't be able to make such a huge impact on the lives of mesothelioma patients across the UK.



The
Mavis Nye
Foundation



Asbestos ACTION



Highlight on Scotland

Working in partnership with Macmillan Cancer Support, Mesothelioma UK and NHS Scotland, The Scottish Mesothelioma Network (SMN) was established in 2019. The Network is comprised of a team of clinicians from across Scotland who collaborate to share best practice and provide high-quality clinical care, equitable access to clinical trials, information and support to all Scottish patients. Mesothelioma UK is proud to support five nurses across Scotland, in Glasgow, Edinburgh, Dundee, Aberdeen and Inverness.

Some of the successes of the year include:

Launching a Scottish Mesothelioma Network Newsletter. Primarily aimed at healthcare professionals and support agencies with a special interest in mesothelioma, it is also circulated across the Scottish lung cancer team and made available to patients and their families.

Scottish Patient and Carer Event. The second Patient and Carer event took place on 29th April 2021. This virtual event was attended by patients and carers, clinicians, support services, lawyers, health and safety experts, researchers, advocates and administrators. It featured trials and immunotherapy updates, patient stories, legal and support service updates and a session on Managing Breathlessness from the Pulmonary Rehab Team at Maggie's Inverness.

Health Care Professional Education Event. The third annual event took place on 28th October 2021. A range of speakers talked about the latest developments across Scotland in the fields of research, trials and treatment and legal and compensation pathways as well as a recent patient stories. The presentations are available to watch back on the SMN Website.

The decision to fund this treatment by the SMC creates a new standard of care

New treatment approval. In February 2022 the Scottish Medicines Consortium (SMC) issued approval for NHS Scotland to provide combination immunotherapy drugs Nivolumab and Ipilimumab as a first-line treatment for adults with non-resectable malignant pleural mesothelioma. This is the first new treatment for mesothelioma in 14 years. The decision to fund this treatment by the SMC creates a new standard of care and plans are under way to integrate it into treatment pathways across the country.

Recognition at Scottish Health Awards. The Scottish Mesothelioma Network won the Innovation Category Award at the Scottish Health Awards 2021. The award is run by the Daily Record in partnership with NHS Scotland and the Scottish Government. It recognises those working across NHS Scotland, and its partners, who go the extra mile delivering health and social care services to improve the health and wellbeing of others.



Highlight on Wales

Project Cymru is well into its second year. Sarah Morgan, Mesothelioma UK Senior Clinical Nurse Specialist has been leading the project and achieved incredible results against the very difficult backdrop of Covid-19 and unprecedented burden on the NHS.

Approximately 100 people are newly diagnosed with mesothelioma each year in Wales. The sparse population within a predominantly rural setting can impede access to services for some patients. Very early on in the project it became clear there was an urgent need to enhance mesothelioma services in Wales. Unlike Cancer Alliances in England, the service in Wales most closely resembles Scotland. As devolved nations, they operate under separate healthcare systems, with Wales having an additional legal commitment towards bilingual services.

As Project Lead, Sarah has been advocating for patients across Wales, working to establish relationships across the spectrum, including health boards, cancer and asbestos charities and solicitors. She has also engaged the public via fundraisers, podcasts and TV and radio. She has established, and regularly co-hosts, a monthly virtual support group called CafeAASC, in collaboration with Asbestos Awareness Support Cymru ('AASC'). This, in addition to collecting patient stories and feedback forms, has given her a rounded view of the patient experience which supports the lack of equity highlighted by the data supporting and research done as part of the patient needs analysis.

Sarah was able to secure an administrative post which has been critical to distributing patient information across Wales and collating patient data. In addition to this, the patients in South Wales have benefited from an Adopted Mesothelioma UK CNS post, which provides a nominated Lung Cancer Nurse with access to the Mesothelioma UK team and resources.

A well-attended Patient Care and Carer event was held on Action Mesothelioma Day in South West Wales. A Mesothelioma Cymru Network Professionals educational event is planned for Spring 2023. The translation of key information into Welsh is ongoing and Project Wales has a regular update feature in the quarterly Mesothelioma Matters magazine.

In 2021, Sarah worked with WHSSC to submit a bid for an all-Wales Mesothelioma MDT funded as part of the NHS Wales. In early 2022 we heard that the bid was successful, with a view to having the MDT set up by April 2023. The process is now fully underway with the national documentation being developed, including: service specifications, national optimal pathway, national quality performance indicators, and referral proforma.

It is anticipated that there will be a dedicated Mesothelioma CNS within the core team for the MDT, and in order to ensure equitable access for all patients throughout Wales, discussions are in progress with Macmillan Cancer Support for two further Meso CNS posts who will work with the ten Lung Cancer MDTs across North, West and South Wales. These CNSs will ensure that all patients across Wales are discussed at the all-Wales Specialist Mesothelioma MDT, as well as sign-posting support and information available.

There is still much work to be done, but Mesothelioma services in Wales are moving forward, with 2023 promising to be a landmark year.

The bid for an all-Wales Mesothelioma MDT was successful and work is now underway to develop this vital service

Case Study - Building a Regional MDT

Simon Bolton is our clinical nurse specialist in Yorkshire



Simon Bolton is our mesothelioma clinical nurse specialist for North and West Yorkshire. His post was introduced to the region as a full-time post in November 2020.

There are seven hospitals across the region and his priority was to re-establish links with all hospitals and support the creation of a regional multi-disciplinary meeting (MDT).

Yorkshire has a long history with mesothelioma and asbestos, having been the site of two large asbestos factories as well as other related industries. Due to the high incidence of mesothelioma, the region is also the site of the first national mesothelioma nursing support service, introduced by Mavis Robinson in the 1990s.

The challenges faced today are in many ways similar to those that Mavis faced 30 years ago; to provide care and support to patients in the face of a devastating diagnosis, to advocate for better treatment for mesothelioma, and to spread the word to colleagues across the region and country that help is available for patients with this disease.

Recent years have seen a decline in mesothelioma activity across the region, and the primary objective of Simon's role is to support the establishment of a regional MDT, which will lead to best practice in treatment and support for patients, and a higher number of patients being referred to clinical trials.

The Covid-19 pandemic has had an impact on every facet of the NHS, but a silver lining is that it has normalised the use of virtual technology, meaning one of the main barriers to establishing the MDT, travel, could be overcome.

In the last year Simon has established a fortnightly meeting of a core group of healthcare professionals to review all mesothelioma cases across the region. The team includes consultant chest physicians, clinical and medical oncologists, thoracic surgeons, radiologists and Simon as the mesothelioma clinical nurse specialist. The meetings are led by Simon and the Leeds Lung Cancer MDT lead Kirsty Rodger who is a Consultant Respiratory Physician. Unfortunately they have not been able to secure the support of any pathology representative which prevents them from officially labelling the meeting as a formal Regional Mesothelioma MDT.

The first meeting took place in February 2021 and they have met virtually, every two weeks since, discussing an average of five cases per meeting. They are now able to provide a radiological stage for all mesothelioma cases, something that wasn't happening as a matter of routine as highlighted in the last National Mesothelioma Audit Report from 2020 where as a region, radiology staging was only 38.5%.

Screening and recruitment to clinical trials has significantly improved and the fortnightly meetings provide a forum to discuss upcoming trials considering whether they could be opened within the region. Of perhaps greater importance, the meeting ensures every person diagnosed in West and North Yorkshire can have their case reviewed in a dedicated mesothelioma meeting.

We look forward to continuing to work with colleagues across the region and we are confident that we will be successful in our aim of becoming an official Mesothelioma Regional MDT.

Benefits Advisors



We continued to provide two benefits advisors, Caroline Barry covering Leicester and Leicestershire, and Sarah Thomas covering the North East. Caroline continues to be funded through Leicestershire Citizens Advice, while during the year Sarah

Thomas became employed directly by Mesothelioma UK.

Over the past year our benefits advisors have been as busy as usual, dealing with the numerous complex challenges of supporting mesothelioma patients and their families to navigate the benefits system.

What has emerged from their work this year has been the continuing inequality of benefits advice throughout the UK, as well as the broader emotional support that our advisors give to the patient's family. Below Caroline Barry reflects on some of the challenges faced during the year.

"Throughout my time as a mesothelioma benefits advisor I've dealt with many complex situations, but one really stood out to me this year. As well as being the mesothelioma benefits advisor for Leicester and Leicestershire, I also give national coverage through the Mesothelioma UK Support Line to anyone across the UK who cannot access support locally. Although the provision of benefits advisors has improved in recent years, there are pockets in the UK where specialist advice is not available and unfortunately this can sometimes mean that unsuitable advice is given. In the course of assisting a client who contacted Mesothelioma UK through the supportline, I discovered that as a result of poor advice they had lost out on over £3,000 in unclaimed benefits, money that was not recoverable. For a mesothelioma patient trying to stay afloat following the devastating news of their diagnosis, this is a significant sum of money. Within a week of them contacting Mesothelioma UK I was able to successfully complete the applications that had been overlooked, and the relationship that we developed was very important in helping to navigate the system."

Facts & Figures

Total number of clients

183

Total lump sum payments identified

£2,021,159

Estimated annualised benefit

£1,805,571

Number of Armed Forces clients

1

Estimated annualised benefit Armed Forces

£11,889

Veterans UK lump sum

£140,000

Support Line

Alongside our nurses, providing a freephone Support Line is our core service for patients. The number of calls to the Support Line has been decreasing in recent year. This is due to better online information, increased technical literacy amongst patients, their families and carers, as well as the growing number of specialist nurses across the UK.

The Mesothelioma UK Support Line sits within a network of support services for mesothelioma patients and carers. It complements the care that mesothelioma clinical nurse specialists and wider healthcare teams give, and can provide additional information to that found on the web. Sometimes its role is simply to listen, as patients and their families work through the vast quantity of information given to them upon diagnosis.

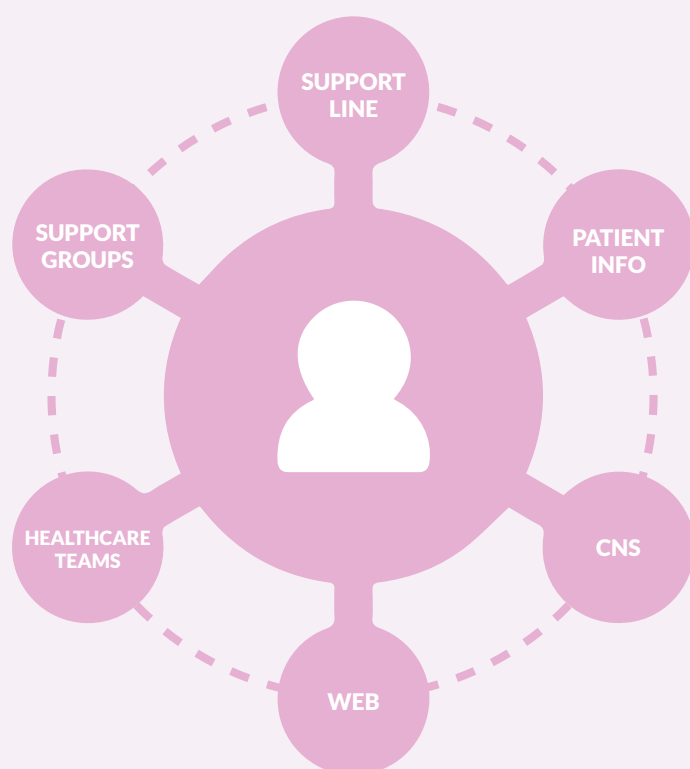
In 2021/22 the Support Line dealt with 567 calls, remaining level with the call volume of the previous year. The Covid-19 pandemic has fundamentally changed the

way people access support and we do not foresee a return to pre-pandemic call volumes.

However that does not waver our commitment to providing this support – those who do call often describe it as their “lifeline”. We continue to be available 8.30am to 4.30pm Monday to Friday.

As in previous years the majority of the callers (76%) are mesothelioma patients or family members. Just under 10% of the calls are from healthcare professionals looking for advice, showing how we can help to support mesothelioma patients that fall outside of our nurses care.

Providing access to a mesothelioma clinical nurse specialist over the phone, regardless of geography, remains a crucial element in combatting the “postcode lottery” of mesothelioma care.



The Support Line received

567

calls in 2021/22

Support Groups

As well as signposting patients to the many wonderful local support groups across the UK, Mesothelioma UK also runs three online support groups for specific groups. If you wish to receive more details, check our website or email support@mesothelioma.uk.com.

Carers' Hour

This group meets on the second Wednesday of the month at 2pm via Zoom. The main purpose is to provide a space specifically for carers to share experiences, concerns and ideas, as we recognise that they have needs distinct to those of the patient. As well as supporting each other, the group has had speakers on many of the aspects of caring for someone with mesothelioma including management of a chest drain, benefit available as a carer and end of life planning.

Young Patients and Carers Support Group

Mesothelioma is predominantly a disease of the over 70s, however it can occur in young people. We realised that the needs and experiences of those under 55 differs from a "typical" patient and that there was no support specifically tailored to this group. Our support group meets monthly on the first Wednesday of every month on Zoom to provide peer support and chat informally with a mesothelioma clinical nurse specialist.

Virtual Monthly Peritoneal Support Group

Our dedicated peritoneal mesothelioma clinical nurse specialist, Sam Westbrook, facilitates a monthly virtual support group meeting. The calls are well attended, and following feedback a second bi-monthly virtual group for multicystic mesothelioma patients has been established. This gives patients with multicystic mesothelioma a separate forum to share experiences and offer support. The group is joined regularly by an asbestos support group and a solicitor offering further discussions on their areas of expertise. Patients from overseas have since joined the group. Following these calls the clinical nurse specialist sends an email to the patient mailing list with information on the topics discussed, as virtual group calls are not for everyone.

Patient Travel Grant

Supporting patients to access clinical trials is something we continue to passionately support at Mesothelioma UK. Clinical trials are carried out to find out if there are new and better treatments for Mesothelioma.

The trials we supported were:

- ATOMIC at Addenbrookes in Cambridge
- BEAT Meso at Addenbrookes in Cambridge and The Royal Marsden in London
- MiST 3, 4 & 5 at the Royal Infirmary in Leicester

Patients in
clinical trials

22

Travel grants awarded

£13,332

Research and Audit

After successfully launching our first independent research round in 2020/21, research activity was slow to grow during 2021/22.

Although we awarded five grants as part of our initial grant round there were significant delays in the commencement of most of the grants, mainly due to Covid-related issues across the UK for healthcare professionals and researchers.

We remain members of the Association of Medical Research Charities, to whom we are grateful for their support and advice as we navigated the peer review process for the first time. We also owe a debt of gratitude to our Research and Scientific Committee who ensured that all applications were scrutinised and that we are funding high quality research.

The National Mesothelioma Audit was put out for tender in 2021/22. However after a robust tender process we decided that we were not in a position to move forward with awarding a contract at this time, due to financial restraints as well as changes and developments in accessing data within the NHS. We remain committed to the National Mesothelioma Audit and will continue to work with NHS digital and industry partners to find the right solution.

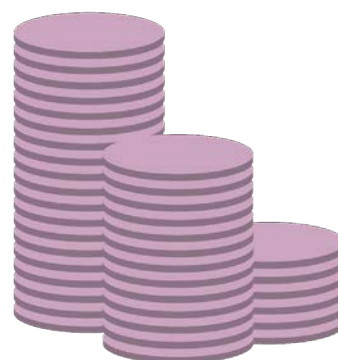
The Research Centre at Sheffield is now in its second year, with ten publications during the year and a successful grant award from our grant round. Our second independent grant round was launched in March 2022 and we look forward to another competitive round.

Grant Themes for 2022/23

Applications should detail a clinical research study within the following themes:

1. Improving the patient diagnostic pathway
2. Improving symptom control and/or Quality of Life (QoL)
3. Improving post-diagnostic monitoring and follow up
4. Improving access to diagnostics, treatment, information, trials or support

Studies must be focused solely on mesothelioma and we will consider observational studies, interventional studies, case note reviews or studies that evaluate an app or other technology, or a combination of methods.



Grant funding worth up to

£40,000
is available

Grants Awarded in 2021/22

April 2021 saw the first shortlisting round for our newly launched research grants.

Sixteen outline applications were received. These were shortlisted by the Research and Audit Scientific Committee (RASC) and eight applicants were invited to submit a full application.

Of the eight full applications received, five were approved by the RASC and put forward to the Board of Trustees.

The Board of Trustees, as recommended by the RASC, agreed to award grant funding to the following projects totalling £151,162.

Northumbria Healthcare

Nutrition & Activity in MESothelioma (NAMES)

Sheffield University

MINNOW study – Investigating the Mental health Implications of a mesothelioma diagNosis and developiNg resources to Optimise Wellbeing

North Tees and Hartlepool NHS Foundation

The journey from diagnosis to end of life care for patients with Malignant Pleural Mesothelioma (MPM) – a retrospective palliative care review

University of Leicester

Leveraging clonal genomics to augment diagnostic accuracy and forecast survival in mesothelioma

University of the Highlands and Islands

Use of pleural effusion to diagnose mesothelioma by detection of genetic anomalies



Research Completed During the Year



Improving the power and safety of white blood cells that have been taught to destroy mesothelioma.

Project Aims

Mesothelioma is a disease with a very poor prognosis. Targeted CAR T cell therapy could be a viable therapeutic intervention for this type of cancer. Demonstrating how IL-6 plays a role in the progression of mesothelioma could lead to a better understanding of the development of this disease. Armouring T4 CAR T cells with IL-6 inhibiting capabilities could improve the effectiveness of these T cells when targeting mesothelioma.

Outcomes

In the short term, this project has helped understand the importance of IL-6 signalling in mesothelioma. As a longer-term benefit, a great deal of data has been generated to support the argument for using RT4 immunotherapy to treat patients with mesothelioma in a clinical trial (currently in a phase I clinical trial to treat head and neck cancer).

This study was completed in June 2021.



Understanding the role of Mesothelioma UK clinical nurse specialists in meeting the palliative care needs of patients and families.

Project Aims

To explore the palliative care needs of people with mesothelioma and their families, and secondly to explore the role of Mesothelioma UK Clinical Nurse Specialists (MCNS's) in supporting patients with palliative care needs.

Outcomes

This study provides valuable insights into palliative care needs in mesothelioma, and the role of Mesothelioma UK clinical nurse specialists and others in meeting these palliative care needs. Patients with mesothelioma and their families have significant palliative care needs throughout the course of their illness. Mesothelioma UK CNS's play a crucial role in supporting patients and families palliative care needs and are highly skilled in providing this care. The recommendations from this study will inform changes to clinical practice, future research and policy which will impact on the experience of patients with mesothelioma and their families at the end of life.

This study was completed in July 2021.



Exploring clinical decision-making in mesothelioma treatment pathways across three NHS Trusts.

Project Aims

To develop a collaborative, evidence-based, patient-centred approach to mesothelioma clinical decision-making across three NHS Trusts: Oxford University Hospitals, Royal Berkshire, and Buckinghamshire NHS Foundation Trusts.

Outcomes

The research has the potential to influence policy and practice around mesothelioma clinical decision-making through the generation of evidence that identifies what some of the key barriers and challenges to clinical decision making in this patient group are. The study has led to the production of a number of recommendations that will be disseminated through peer reviewed publications and to Mesothelioma UK stakeholders.

This study was completed in May 2021.



The experience of long-term survival in people affected by pleural mesothelioma and their carers.

Project Aims

In this study we set out to find out in detail what it is like to live with pleural mesothelioma long-term from both the patient and their carer's point of view. Ultimately, we aimed to understand more about the care and support needs of this group of patients.

Outcomes

The research focuses on how people come to terms with a life limiting diagnosis with a poor prognosis when they go on to live with the condition for many years. Understanding of the ambiguous and uncertain nature of this situation can help in the way patients and their families are supported with pleural mesothelioma.

For participants, the focus on long-term survivors itself brought hope to them and was seen to shine a more positive light on the condition than is often the case. The study supports the drive to develop specialist regional mesothelioma multi-disciplinary meetings that will allow all people diagnosed with this rare condition to have their case reviewed by teams that have access to all available treatments and knowledge of current clinical trials, meaning that people have equal access to treatment and care regardless of where they live.

However, as well as the obvious benefits of undergoing treatment for patients and their families, the study also underlined the burden of treatment, both in terms of short and long-term side effects experienced, as well as the challenges of undergoing treatment at centres that can be at great distance from their homes.

This study was completed in March 2022.



Update from the Mesothelioma UK Research Centre at the University of Sheffield

Since establishing in July 2020, the Mesothelioma UK Research Centre at the University of Sheffield has continued with its substantial programme of research to benefit the care of people diagnosed with mesothelioma and their families.

The Research Centre is funded by Mesothelioma UK, initially for a term of three years. In 2021 the team completed a UK-wide Research Prioritisation Exercise for mesothelioma, and are now working on a portfolio of eight studies which respond to the top priorities for mesothelioma research.

The team have published ten peer review journal papers in 2021/22 and have presented their work at a wide range of national and international conferences.

The Research Centre have also been working hard to support other early career mesothelioma researchers and have provided mentoring and advice to aspiring academics.

The Research Centre is led by Prof Angela Tod and Prof Clare Gardiner who work with a team of researchers and PhD students, supported by a Patient and Public Involvement (PPI) panel.

More information about the Mesothelioma UK Research Centre can be found on their website:

www.sheffield.ac.uk/murc

Information

Our Growing Team

In July 2021 we employed our first employee with overall responsibility for our patient information service. Joelle Kirby is a qualified librarian with a background working in NHS trusts. Her remit is to enhance our patient information, ensuring we are getting the right information to patients and families at the right time to enable shared decision making.

PIF Accreditation

In April 2021 we were certified as a “trusted information creator” by the Patient Information Forum. The PIF TICK is a UK-wide quality mark for health information.



**Trusted
Information
Creator**

Patient Information Forum

Meso Matters Webinar

After a successful launch in November 2020 the Meso Matters Webinars continued throughout 2021/22.

Some of the speakers and topics included Dider Jean on heterogeneity in mesothelioma, Samantha Westbrook and Faheez Mohamed showcasing the UK Peritoneal Mesothelioma MDT, and Brendan Tully from Phillips Padlicelli LLP who spoke about American claim options for UK mesothelioma patients.

More information about past and upcoming webinars can be found here:

www.mesothelioma.uk.com/mesothelioma-matters-webinar

New Website Launched

In May 2021 we launched a revamped website. The overall aim of the new look was to make it easier for anyone affected by mesothelioma to find the information they need.

After many design sessions and after much feedback from our excellent Public Advisory Board, we finalised the design and went live in May 2021.

Expanding our Information Service

Each year we review our information provision, for clinical accuracy, but also to ensure we are meeting the information needs of mesothelioma patients, families, carers and healthcare professionals. As part of this review we have added, amalgamated and significantly reviewed titles.

Added:

- 'How cancer drugs are made available in the NHS': which talks about how all new drugs must go through a number of tests. If these show that the drug not only works but is also safe to take, then the process of approval and licensing for use in the NHS can begin.
- 'Energy Advice' – produced in response to rising energy bills.

Amalgamated:

- Two asbestos booklets now covered by the one title: 'Asbestos Exposure and Health Risks'.

Significantly revised:

- 'Surgery for Mesothelioma'. Was 'Surgery for Malignant Pleural Mesothelioma'. We wanted to soften the information so we:
 - outlined what to expect in the booklet more clearly to help navigation
 - added introductory paragraphs to sections to contextualise the information

Based on patient feedback we've also:

- added a new section on longer term recovery
 - addressed risks/benefits and stressed need to discuss with healthcare team
- 'Mesothelioma: A Guide to this Asbestos Cancer'. This is a revised version of 'What is Mesothelioma?' It's got a broader scope and covers: different types of mesothelioma, the role of asbestos, symptoms, treatment, benefits and compensation as well as information about the charity. It aims to provide a good introduction without overwhelming.

We have also started to use social media to promote our information service which has been received really well by our followers and supporters.



Awareness

Mesothelioma UK is proud to be involved in the wider UK mesothelioma and asbestos communities. Throughout the year we collaborated with many partner organisations on campaigns and events to raise awareness of mesothelioma, the dangers of asbestos and of the importance of clinical nurse specialists within the NHS.

In March 2022 we appointed our first ever Director of External Affairs, Saranjit Sihota and the charity and the trustees are really looking forward to the impact her experience and expertise will have on our work.

In 2021 The Work and Pensions Select Committee chaired by The Labour Party's Sir Stephen Timms launched an inquiry into the Health and Safety Executive's Management of Asbestos. The inquiry was initiated following research that had been undertaken by an organisation called Respublica on the prevalence and management of asbestos in the UK. Along with many other experts and organisations Mesothelioma UK gave oral and written evidence to this inquiry.

Due to Covid restrictions the formal hearings to provide oral evidence all took place virtually. Liz Darlison gave an honest and passionate account of the experience of patients and families that find themselves battling with mesothelioma due to asbestos exposure. She stressed the need to remove asbestos to protect future generations and prevent further deaths. Along with most of the other experts who gave evidence to the Select Committee, Mesothelioma UK called for a programme of phased removal of asbestos from all our buildings in the UK.



House of Commons
Work and Pensions
Select Committee

Making Meso Matter

ACTIONMESO

Following on from the success of the collaborative event with the UK Mesothelioma Alliance (UKMA) in 2020, on 1st July 2021 we again joined forces with mesothelioma organisations across the country for a virtual event.

This year the event was hosted live by broadcaster, academic and peritoneal mesothelioma patient, Kate Williams. Kate hosted an engaging and uplifting virtual event, including panel discussions, clinical trial updates and interesting facts and insights for anyone new to mesothelioma.

Speakers included Kevin Blyth, Consultant Respiratory Physician and Clinical Academic, Sanjay Popat, Consultant Thoracic Medical Oncologist and Professor of Thoracic Oncology, Alan Kirk, Consultant Thoracic Surgeon, Sarah Morgan, Mesothelioma UK Clinical Nurse Specialist in Wales, Sam Westbrook, Mesothelioma UK Clinical Nurse Specialist (peritoneal) and Nigel Shaddick, a mesothelioma patient who shared his experience of participating in a clinical trial. More than 1500 people tuned in live.



As part of Action Mesothelioma Day, we sold 'AMD Packs' which included seeds to be planted in memory of a loved one, a paper dove to write hopes and aspirations for the future. People could also purchase a name scroll that took over our website home page on the day itself.



Mesothelioma UK first launched the project Mesothelioma UK: Supporting our Armed Forces in 2016 with original funding from the government through the LIBOR fund. Since then we have supported hundreds of Armed Forces mesothelioma patients, by seeing them face-to-face at NHS hospital across the country, by supporting them to make benefits and compensation applications, and by educating the wider community on the prevalence of mesothelioma within the forces.

In 2020 we were lucky enough to win the Military and Civilian Health Partnership at the HSJ Awards. We had continued success in 2021/22 when Shadow Defence Minister Stephen Morgan asked the Secretary of State for Defence to make a statement regarding Mesothelioma UK's work and in response, Johnny Mercer stated the Ministry of Defence (MOD) are committed to the elimination of asbestos and will continue their engagement with Mesothelioma UK.

THE ARMED FORCES COVENANT FUND TRUST

Thanks to funding from the Armed Forces Covenant Fund Trust we will be able to continue this project into 2022/23.

Action Mesothelioma Day is about inspiring action and Nigel Shaddick was a truly inspirational speaker

Working With Partners



Mesothelioma UK continued to be an active member of Cancer 52, an alliance of rare and less common cancers. Throughout the year we worked on many projects, including four internal Covid-19 impact surveys, one general, two focused on patient impact and one on the priorities of CEOs.

An excellent video was produced entitled 'Cancer Patients Talk about Their Care' which includes mesothelioma patient Mavis Nye. You can watch the video here:

www.cancer52.org.uk/single-post/2020/07/09/cancer-patients-talk-about-their-care

We also continued to be a part of the successful Do You C Us? campaign in collaboration with Cancer 52 and Pfizer.



This campaign launched in 2020 and continued well into 2022. It was funded by pharmaceutical company MSD, and was supported by Mesothelioma UK, the Roy Castle Lung Foundation, Macmillan Cancer Support, Lung Cancer Nursing UK and the United Kingdom Lung Cancer Coalition.

The campaign identified that the threat of delayed diagnosis to lung cancer and mesothelioma patients has been particularly pronounced for three main reasons: confusion over symptoms, hesitancy over GP visitations and strained services. The campaign included a mix of broadcast and social media, bus stop posters, telephone box prints and pharmacy bag prints.

The campaign won an award for best Pharmaceutical Partnership at the Health and Safety Journal Awards.



One Cancer Voice is an informal group of cancer charities in the UK that came together at the height of the Covid-19 pandemic to ensure that cancer was not left behind.

During the year the group has collaborated on several different issues such as commenting on All-Party Parliamentary Groups for Radiotherapy, Health and Cancer's joint consultation: Solutions to the Covid induced cancer backlog and associated campaign #CatchUpWithCancer.

We signed an open letter to the public which was published in The Observer which was around the need to protect vulnerable cancer patients from Covid-19 while out in public after the lifting of social distancing regulations. You can read the full letter here: www.theguardian.com/world/2021/jul/18/cancer-patients-plea-to-public-keep-observing-covid-measures

A significant amount of work at One Cancer Voice, led by the Royal College of Physicians, went into supporting an amendment to the Health and Care Bill proposed in autumn 2021. The amendment was to the workforce planning section and proposed including a requirement for the Secretary of State to publish biannual, independent assessments of current and future workforce numbers. Mesothelioma UK were proud to support this amendment.



Income Generation

This has been another tough year, with people feeling the effects of Covid-19 coupled with the emerging cost of living crisis. However we have persevered with the support of our amazing community of fundraisers and donors. Year on year we are blown away by the innovation and determination of our fundraisers. Below are some of the highlights from the year.

Community Fundraising

London Landmarks

Mesothelioma UK took part in the iconic London Landmarks half marathon for the first time in September 2021. Ten runners raised an incredible £13,426. As one of the first events to happen face-to-face since 2019, our team were so proud to be at the finish line cheering on our incredible runners. The London Landmarks half marathon is one of the most scenic runs in the UK, bringing runners along the Thames, as well as past famous sights such as Nelson's Column, St Paul's Cathedral, the Tower of London and many more.

The GT Memorial Tour

Bognor Regis Motor Club organised a Classic Car Tour and Picnic in memory of Graham Thornton who passed away from mesothelioma in January 2020. His widow Clare Thornton sponsored the event through their company Hamnton Construction. The event was supported by local businesses including Matt's Hog Roast and by the Worthies Women's Institute. The crew headed across the New Forest to Breamore Countryside Museum, where they enjoyed a visit to the museum and ate their picnics. Although cloudy the rain held off as cars then headed for the highlight of the event, a visit to Duncan Hamilton's Showroom at Micheldever. As "petrolheads" the chance to get up close and personal with some very exotic machinery was a delight. Sadly, the rain then arrived, and everyone headed home tired but happy to have been back out socialising with like-minded individuals.

The event raised an incredible £10,198, and our unending thanks goes out to Graham's family, friends and of course the 73 people who took part in the tour.





Knitting For Meso

"Sadly it was not until after my husband Tony's death in 2008 I learned of Mesothelioma UK. At that time I was well aware that many many people had never even heard of mesothelioma, and I and my family decided to do what we could to raise both awareness and funds. Our very first fundraiser was to walk the then unopened section of the relief road between Weymouth and Dorchester. Now 14 years later it is amazing to see the growth and change in the charity and the important work it supports. It is a privilege to have been part of that growth."

Pam has been 'Knitting for Meso' for many years and has hand knitted and sold Christmas angels, Christmas puddings, tinsel wool pompoms along with Easter bunnies and so much more. She's given out collections pots to local businesses, stood in her local garden centre and supermarket doorways armed with information booklets and other meso materials with her trusty collection pot to help raise awareness and funds and she has braved it in all sorts of weather. She still flies the flag for meso and we are truly grateful for her support. It's these wonderful small but significant gestures that helps to raise much needed awareness among our local communities as well as raising funds. Thank you Pam, you are our Meso Star!



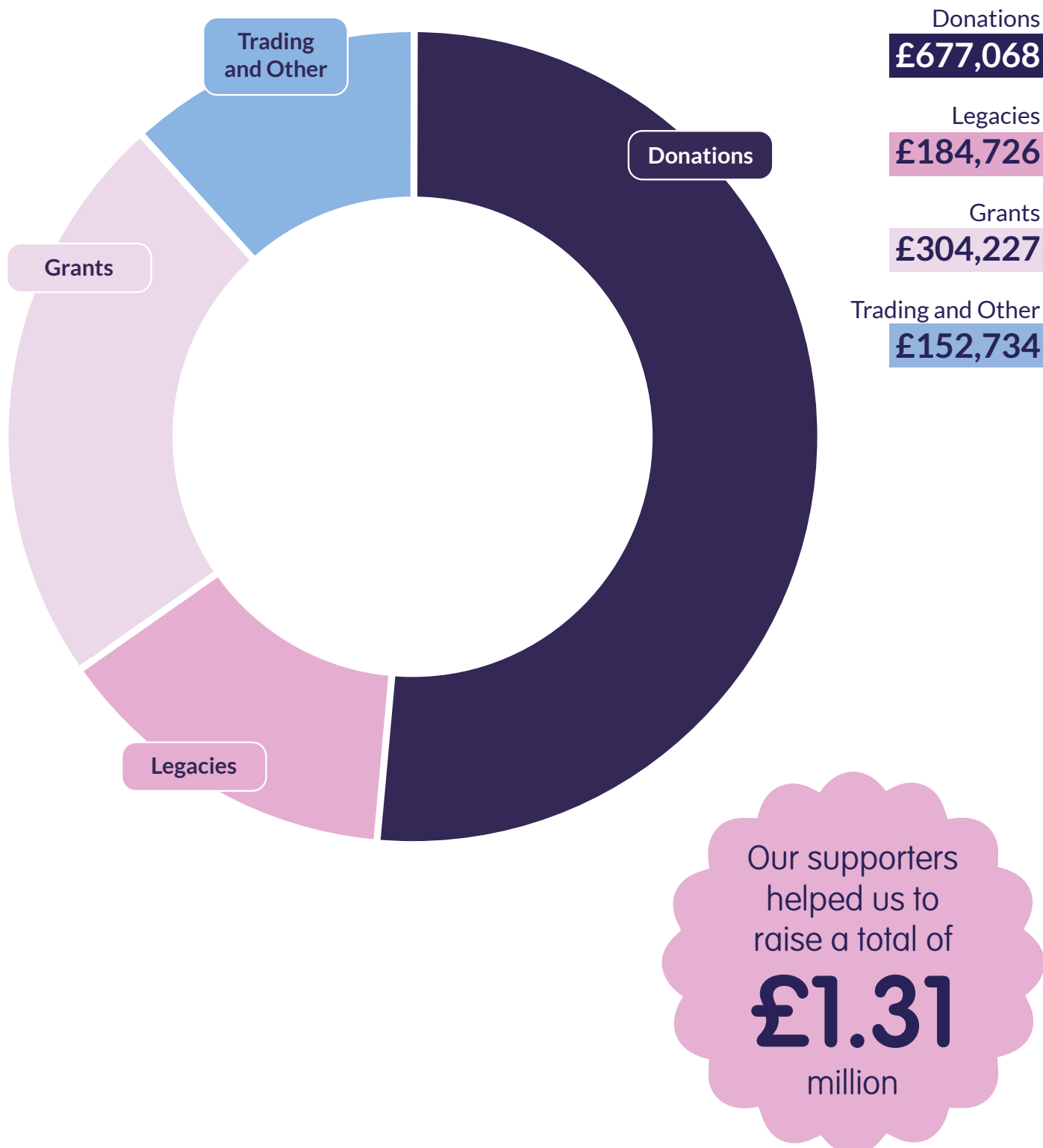
20 For 20

The 20 For 20 campaign returned in its second successful outing in September 2021. Led by the team at Sarcoma UK, Mesothelioma UK joined 19 other charities which represent rare and less common cancers, to come together as a group to raise awareness and conduct a major fundraiser through this innovative campaign. All the charities asked their supporters to sign up to the 20 For 20 challenge and take on 20 challenges over 20 consecutive days.

One of the individuals who decided to take up the challenge, was Reuben Gaunt, an eight-year-old whose grandfather Ray, was diagnosed with mesothelioma in June 2021. Upon learning about Ray's diagnosis, Reuben, along with his brother Jake and cousins Zak and Lukas, set up Team Grandad to look out for each other and practice positive thinking to help Ray get through his check-ups and treatments.

Eager to raise funds for Mesothelioma UK because of the help it had extended to Ray, Reuben and his family decided to complete various activities for a year as part of the challenge. Reuben opted to make 20 rugby passes a day for 20 days, given his enjoyment of the game, but more importantly, it was a way to pay homage to Ray who had played rugby during his time in the Navy when he was awarded a cap. Reuben achieved his target of the 20 days and also roped in a group of friends, family members and players from the Oulton Raiders and Sandal rugby teams. Upon completing their various challenges, Reuben and his supporters raised £760.00 for the charity.

How We Raised the Funds



How We Spent the Funds

Patient Support Costs

£866,276

Research & Audit Costs

£215,861

Admin & Operational

£197,605

Awareness Costs

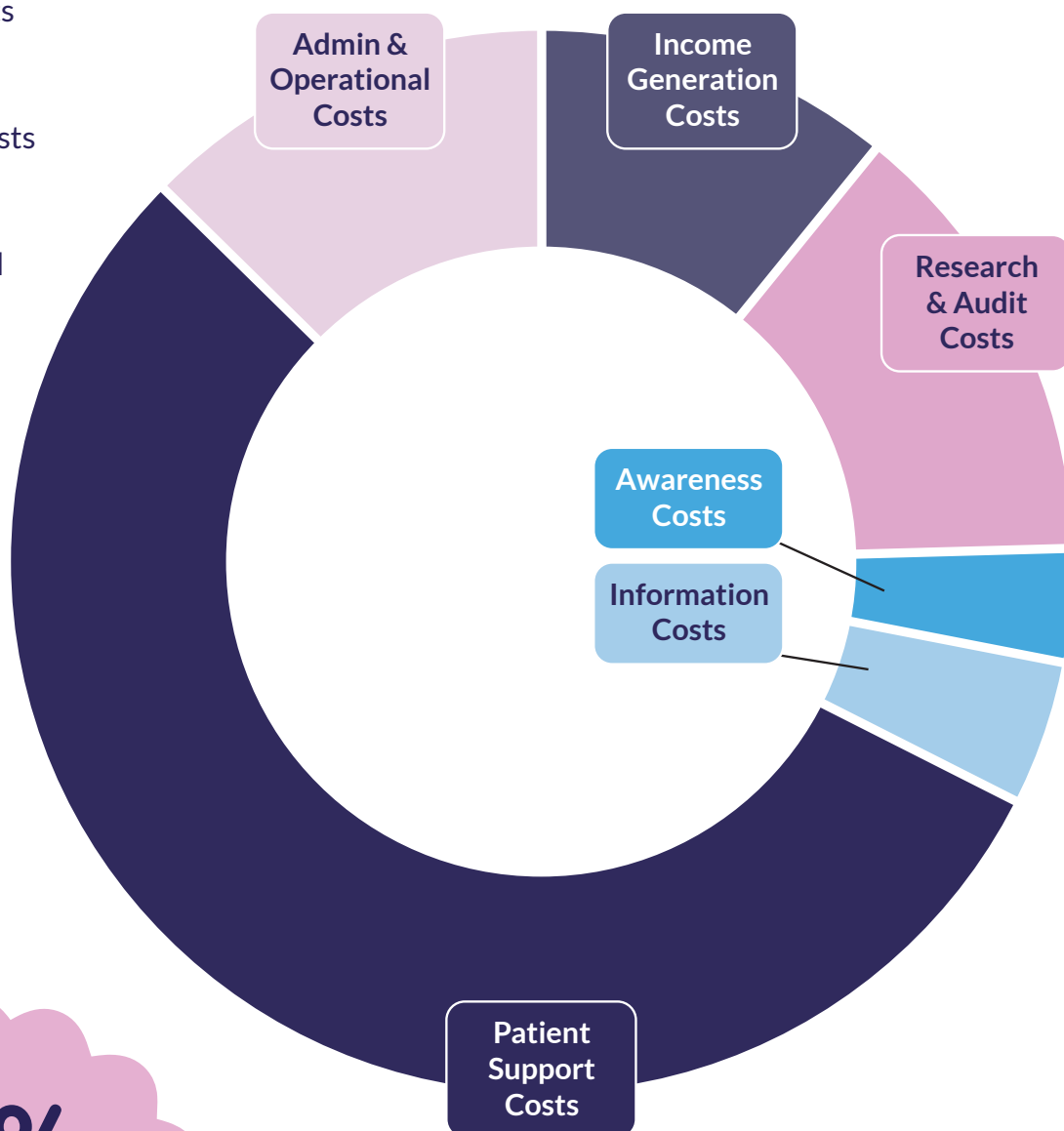
£54,510

Income Generation
Costs

£171,498

Information Costs

£69,126



55%

of all spending
was on patient
support

Volunteers



In September 2021 we launched a call for Mesothelioma UK volunteers. We held two action days over a weekend – one in Newcastle and one in Leeds. We have since followed them up with online meet and greet sessions, and a renewed call for volunteers.

We are just at the beginning of our plan to recruit volunteers across the country but have been amazed by the response. So far we've had people attending online inductions, making plans for the summer, and proof reading our patient information.

Legacies



Leaving a gift in your will is one of the most impactful things you can do to help future mesothelioma patients. That's why we call it The Power of Your Pledge.

During the year we produced a powerful video of mesothelioma patients speaking about why leaving a legacy is so important. Watch here:

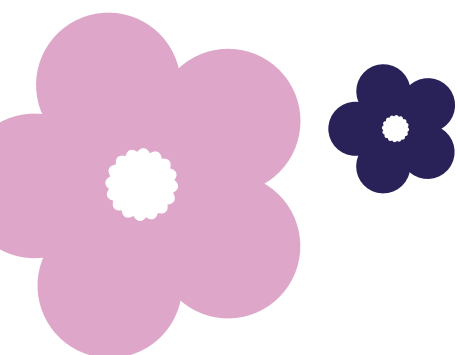
www.mesothelioma.uk.com/leave-a-gift-in-your-will

This year we received eight legacy donations totalling £184,726.

Receiving a gift in a will is an honour; it reminds us of the commitment and generosity of our supporters and helps us to plan for the future.

Mesothelioma UK is working with several firms of solicitors to offer a free will writing service.

There is no obligation to leave a gift to charity, but we ask people to make a pledge to leave a gift in their will to Mesothelioma UK. Since opening the free will writing service in 2019 we have provided a free will to more than 70 mesothelioma patients.



Events



Patient and Carer Day

Patient and Carer Day was held virtually for the second year in a row due to the on-going Covid-19 pandemic. On Friday 1st October 2021 we gathered online to listen to some of the leading lights in mesothelioma care, treatment and research. Presentations were given on a range of subjects from managing symptoms such as breathlessness to an update from the Mesothelioma UK Research Centre at Sheffield.

The participants were treated to a 'Breathe Sing for Lung Health Workshop' from Hannah Dye of Breathe Arts Health Research. One hundred and eighty six participants registered and overall feedback was very positive.

"Found the whole day really informative, loved the breatheahr.org personal stories that were told and the insight into peritoneal"

Attendee



Ladies Lunch

Ladies Lunch came back with a bang on International Women's Day, March 8th 2022. Held for the third time at the MacDonald Hotel in Manchester, this was the first face-to-face event Mesothelioma UK have held since the start of the Covid-19 pandemic.

Spirits were high as patients, families, healthcare professionals and members of the legal community gathered to celebrate women who have made mesothelioma matter.

The main event of the day was the panel session where Lorraine Creech asked questions of our invited guests; patients Caroline Twist and Mavis Nye, Director of Asbestos Compliance Limited, Collette Willoughby and Barbara Murray, a retired GP. We couldn't have delivered this event without our sponsors and supporters who helped us raise a whopping £4,350.00.

Governance

Reference and administrative details of the charity, its trustees and advisers
For the period ended 31st March 2022.

Legal and Administrative Details

Status

The organisation is a charitable incorporated organisation. Launched as a resource centre in 2004 it became a Charitable Trust in 2008 and re-registered as a Charitable Incorporated Organisation in 2018.

Governing Document

Since re-registering in 2018 the charity has operated with a constitution and the income and the property of the charity shall be applied solely towards the promotion of its objects as set out in its constitution.

Charity Number
1177039

Company Number
12541690

Principal Office
235 Loughborough Road,
Mountsorrel,
Loughborough,
LE12 7AS

Trustees

Prof N Maskell (Chair)
Prof M D Peake
D E McKinley
A L Coates
Dr A Aujayeb (resigned January 2022)
S E Hague
Dr D J Hetmanski
H Childs
M Waters
Prof K Blyth (appointed March 2022)

Independent Auditors

Magma Audit LLP
Unit 2, Charnwood Edge Business Park
Syston Road
Cossington
Leicester
LE7 4UZ

Chief Executive Officer

Liz Darlison

Operational Team

Faye Forde,
Director of Operations

Saranjit Sihota,
Director of External Affairs
(appointed March 2022)

Tracey Calvert,
Finance Manager

Jill Lemon,
Senior Fundraiser, Campaigns, Challenges and Legacies

Alyshia Riley,
Senior Digital Fundraiser

Mike Holmes,
Senior Corporate Relations Officer

Julie Morton,
Senior Administration Officer

Joelle Kirby,
Senior Editorial Officer

Sarah Thomas,
Senior Benefits Officer

Caroline Barry,
Benefits Advisor Leicester and Leicestershire
(funded via Citizens Advice Bureau)

Rachel Owen,
Events Officer

Beth Colbert,
Administration Officer

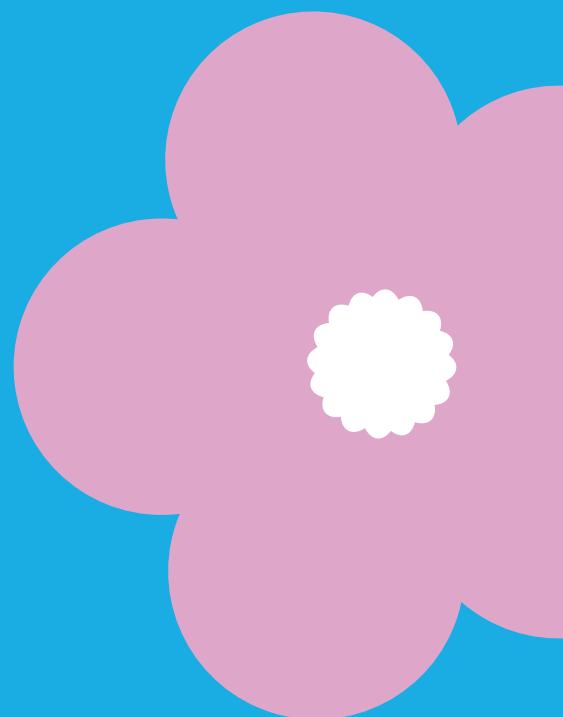
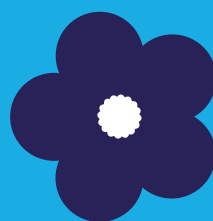
Hazel Curtis,
Finance Officer

Leah Scrimshire,
Fundraising Assistant

Dumitrita Gulian,
Finance Assistant

Abigail Wilson,
Business Administration Apprentice

Beverley Forrester,
Housekeeper



Subsidiaries and Related Parties

The Mesothelioma UK Trading Company was incorporated on 31st March 2020 with company number 12541690. It is the sole subsidiary of Mesothelioma UK and exists to raise trading income for the charity. All its profits were transferred to the charity.

Appointments to the Board

In January 2022 Dr Avinash Aujayeb resigned from the Board of Trustees. Following a process of advertisement Professor Kevin Blyth was appointed to the Board in March 2022.

Financial Review

Basis for Preparation

After making appropriate enquiries, the trustees have a reasonable expectation that the charity has adequate resources to continue in operational existence for the foreseeable future. The trustees have assessed the financial position of the charity in light of the continuing Covid-19 pandemic and wider economic uncertainty and concluded that the charity has sufficient resources to meet its liabilities as they fall due. For this reason they continue to adopt the going concern basis in preparing the financial statements.

How We Raised the Funds

The pie chart on page 27 gives a breakdown of how we raised £1,318,755 during the year. This has been the toughest year in our 18 year history as a charity, with the continued effects of the Covid-19 pandemic significantly impacting on our ability to raise funds. In the previous year, 2020/21 we were fortunate to have received a significant legacy and this enabled us to end of the year without using our reserves. This year we had to utilise £252,685 from our reserves. However, the good news is that our underlying income actually rose between 20/21 and 21/22. Income excluding legacies was £918,596 in the year 20/21 and it rose to £1,134,029 in 21/22. This is down to the hard work of our fundraising team, who have adapted over and

over again since the start of the pandemic, and of course to our tireless fundraisers who continue to amaze us each year with their commitment to supporting Mesothelioma UK. During the year we were supported by our partners across the UK who run support groups and other asbestos awareness charities. A total of £225,405 was raised through these organisations towards the cost of funding the specialist nurses.

How We Spent the Funds

The pie chart on page 28 shows how we spent our funds in 21/22. Expenditure rose from £1,364,695 in 20/21 to £1,574,876 in 21/22. Spending on charitable activities was £1,403,378, an increase of 14% on the previous year. As in previous years the largest was the patient support pillar, which is mainly comprised of the funding for the specialist nursing posts. With support from generous partners we were able to increase funding of the nurses by 25% to £722,844. The overall cost of raising funds was 13%, similar to pre-pandemic levels and still representing very good value for money.

We were fortunate to be able to grow our staff throughout the year, adding four members of staff, two of which are employed directly to support patients and two who are support staff. Our overall staff costs rose by £87,714 compared to the previous year. Expenditure on research fell compared to the previous year, most of which was due to the introduction of our new research grant programme as well as several on-going research projects concluding in 2021. Administrative and operational expenses rose by £58,454. This was largely due to expenses related to employing more staff, such as additional IT costs, as well as newly incurred costs due to moving offices.

Risks

The wider economic climate and the continued impact of the Covid-19 pandemic are the main risks facing the charity in the years ahead. For the first time in the history of the charity we have made a loss and had to use our reserves to meet our expenditure. However we recognise that in such a challenging financial situation, we have fared better than many other organisations, but we do expect to incur a loss in the next financial year also. Preparations are underway to prepare a four-year forecast that details how the charity will return to a healthy financial position where we are no longer reliant on reserves to meet expenses. The trustees continue to have confidence in the ability of the charity to manage the risks.

Reserves

As an organisation relying almost entirely on fundraising income, our policy is to hold adequate reserves to enable us to react to any unexpected adverse events. Our policy is that unrestricted reserves should cover at a minimum six months operating costs and at a maximum six months contracted charitable activities plus six months operational costs and salaries. This is known as the “reserves corridor”. As at 31st March 2022 that reserve corridor was £793,592 minimum to £1,167,179. The actual level of reserves held by the charity was £1,255,108. Although the actual figure was slightly over the maximum reserve, the trustees were happy that this will be utilised in the coming year.

Investments

Our investment portfolio is managed by Magma Wealth Management. As at 31st March 2022 our investments stood at £788,012. This includes cash funds of £15,992 and listed investments of £772,020. Our investment managers brief is to maximise the overall growth of the fund while ensuring that risk is managed to the agreed level. After changing to an Ethical Portfolio (final trades were completed on the 8th September 2021) the investments performed well initially, however the continued instability of the financial markets and inflationary concerns worsened by the war in Ukraine, have meant the portfolio has reduced by approximately 9.9% over 12 months. Ethical investments have tended to underperform the general market over 12 months as the best sector has been oil which cannot form part of the portfolio on ethical grounds and some of the worst sectors has been sustainable investments and technology which does form part. Over the longer term ethical funds probably offer better prospects than the general market as the globe morphs to a more sustainable model, but short term volatility can be expected to be higher due to the ethical screening.

Funds Held as Custodian

The charity holds funds on behalf of the Melu lunch club for mesothelioma and other lung patients. The funds held at the year-end were £517 (2021 - £517). The charity also holds funds on behalf of the UK Mesothelioma Alliance of £8,806 (2021- £21,535).

Looking Forward

Conclusions from Chair of the Board



The ongoing impact of the Covid pandemic coupled with global financial instability requires the Mesothelioma UK Senior Leadership Team and Board of Trustees to focus on the charity's income and sustainability.

To help achieve this, we have been working on a three-year strategy to guide us through this period of uncertainty and keep us working towards our vision of a future without mesothelioma. Key to this will be ensuring we have the right leadership, team, governance, and processes to sustain the charity's growth and development.

We look forward to branching out our services to include new strands of activity and our commitment to audit and our program of research will continue. With the recent appointment of the charity's first Director of External Affairs we aim to increase our impact, to support and work closer with partner organisations.

Our Head of Nursing will look to maximise the reach and depth of support provided by our nursing team, and we hope to strengthen our relationships with partner charities who provide funding for some of these posts.

Underpinning all the charity's work is our dedication and commitment to continue to do all that we can for those that need us. None of this could happen without our supporters, donors, and charity partners. We remain enormously grateful to them all.

A handwritten signature in black ink that reads 'Nick Maskell'. The signature is stylized with a large 'N' and a long horizontal line at the end.

Prof N Maskell
Chair of the Board of Trustees

Financial Statements

Statement of Trustees' Responsibilities

The Trustees are responsible for preparing the Trustees' report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

The law applicable to charities in England & Wales requires the Trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the Group and the charity and of their incoming resources and application of resources, including their income and expenditure, for that period. In preparing these financial statements, the Trustees are required to:

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles of the Charities SORP (FRS 102);
- make judgements and accounting estimates that are reasonable and prudent;
- state whether applicable UK Accounting Standards (FRS 102) have been followed, subject to any material departures disclosed and explained in the financial statements;
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the Group will continue in business.

The Trustees are responsible for keeping adequate accounting records that are sufficient to show and explain the Group and the charity's transactions and disclose with reasonable accuracy at any time the financial position of the Group and the charity and enable them to ensure that the financial statements comply with the Charities Act 2011, the Charity (Accounts and Reports) Regulations 2008 and the provisions of the trust deed. They are also responsible for safeguarding the assets of the Group and the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

Approved by order of the members of the board of Trustees and signed on its behalf by:



Prof N Maskell
Trustee
Date: 14th October 2022



D McKinley
Trustee
Date: 14th October 2022

Independent Auditors' report

Opinion

We have audited the financial statements of Mesothelioma UK Charitable Incorporated Organisation (the 'parent charity') and its subsidiaries (the 'group') for the period ended 31st March 2022 which comprise the Consolidated statement of financial activities, the Consolidated balance sheet, the Charity balance sheet, the Consolidated statement of cash flows and the related notes, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' (United Kingdom Generally Accepted Accounting Practice).

In our opinion the financial statements:

- give a true and fair view of the state of the Group's and of the parent charity's affairs as at 31st March 2022 and of the Group's incoming resources and application of resources, including its income and expenditure for the period then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Charities Act 2011.

Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the Auditors' responsibilities for the audit of the financial statements section of our report. We are independent of the Group in accordance with the ethical requirements that are relevant to our audit of the financial statements in the United Kingdom, including the Financial Reporting Council's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Conclusions relating to going concern

In auditing the financial statements, we have concluded that the Trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the Group's or the parent charity's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the Trustees with respect to going concern are described in the relevant sections of this report.

Other information

The other information comprises the information included in the Annual report other than the financial statements and our Auditors' report thereon. The Trustees are responsible for the other information contained within the Annual report. Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon. Our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the course of the audit, or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether this gives rise to a material misstatement in the financial statements themselves. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact. We have nothing to report in this regard.

Matters on which we are required to report by exception

We have nothing to report in respect of the following matters where the Charities (Accounts and Reports) Regulations 2008 requires us to report to you if, in our opinion:

- the information given in the Trustees' report is inconsistent in any material respect with the financial statements; or
- the parent charity has not kept sufficient accounting records; or
- the parent charity financial statements are not in agreement with the accounting records and returns; or
- we have not received all the information and explanations we require for our audit.

Responsibilities of trustees

As explained more fully in the Trustees' responsibilities statement, the Trustees are responsible for the preparation of the financial statements and satisfied they give a true and fair view, and for such internal control as the Trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error. In preparing the financial statements, the Trustees are responsible for assessing the Group's and the parent charity's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the Trustees either intend to liquidate the Group or the parent charity or to cease operations, or have no realistic alternative but to do so.

Auditors' responsibilities for the audit of the financial statements

We have been appointed as auditor under section 144 of the Charities Act 2011 and report in accordance with the Act and relevant regulations made or having effect thereunder.

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an Auditors' report that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud. The extent to which our procedures are capable of detecting irregularities, including fraud is detailed below:

Based on our understanding of the Group, and the parent charity and the sector, we have identified that the principal risks of non-compliance with laws and regulations related to UK tax and legislation and breaches of the Charities Act, and we have considered the extent to which non-compliance might have a material effect on the financial statements.

We also considered those laws and regulations that have direct impact on the preparation of the financial statements such as the Charities Act 2011 and provisions of the Charities SORP (FRS 102). We have evaluated management's incentives and opportunities for fraudulent manipulation of the financial statements (including the risk of override of controls) and determined that the principal risks were related to posting inappropriate journal entries, and management bias in accounting estimates. Audit procedures performed included:

- enquiries with management for consideration of known or suspected instances of non-compliance with laws and regulations and fraud.
- challenging assumptions made by management in their accounting estimates, in particular in relation to depreciation charges.
- identifying and testing journal entries, in particular any journal entries posted with unusual account combinations, journal entries crediting revenue, journal entries crediting cash and journal entries with specific defined descriptions.

There are inherent limitations in the audit procedures described above. The more removed non-compliance with laws and regulations is, from the events and transactions reflected in the financial statements, the less likely we would become aware of it. Also, the risk of not detecting a material misstatement due to fraud is higher than the risk of not detecting one resulting from error, as fraud may involve deliberate concealment by forgery or intentional misrepresentation, for example, or through collusion.

A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council's website at: www.frc.org.uk/auditors-responsibilities. This description forms part of our Auditors' report.

Use of our report

This report is made solely to the charity's trustees, as a body, in accordance with Part 4 of the Charities (Accounts and Reports) Regulations 2008. Our audit work has been undertaken so that we might state to the charity's trustees those matters we are required to state to them in an Auditors' report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charity and its trustees, as a body, for our audit work, for this report, or for the opinions we have formed.

Magma Audit LLP

Statutory Auditor
Unit 2, Charnwood Edge Business Park
Syston Road
Cossington
Leicester
LE7 4UZ

Date: 14th October 2022

Magma Audit LLP are eligible to act as auditors in terms of section 1212 of the Companies Act 2006.

Consolidated Statement of financial activity for the period ended 31st March 2022

	Note	Unrestricted funds 2022 £	Restricted funds 2022 £	Total funds 2022 £	Total funds 2021 £
Income from:					
Donations and legacies	4	786,229	392,699	1,178,928	1,326,597
Other trading activities	5	133,789	-	133,789	134,056
Investments	6	5,388	-	5,388	6,278
Other income	7	650	-	650	11,124
Total income		926,056	392,699	1,318,755	1,478,055
Expenditure on:					
Raising funds	8	171,498	-	171,498	133,165
Charitable activities	9	1,061,555	341,823	1,403,378	1,231,530
Total expenditure		1,233,053	341,823	1,574,876	1,364,695
Net (expenditure)/income before net gains on investments		(306,997)	50,876	(256,121)	113,360
Net gains on investments	15	3,436	-	3,436	161,684
Net (expenditure)/income		(303,561)	50,876	(252,685)	275,044
Transfers between funds	19	(103)	103	-	-
Net movement in funds		(303,664)	50,979	(252,685)	275,044
Reconciliation of funds:					
Total funds brought forward		1,558,772	87,485	1,646,257	1,371,213
Net movement in funds		(303,664)	50,979	(252,685)	275,044
Total funds carried forward	19	1,255,108	138,464	1,393,572	1,646,257

Consolidated Balance sheet as at 31st March 2022

	Note	2022 £	2021 £
Fixed assets:			
Tangible assets	14	13,442	7,227
Investments	15	772,020	739,639
		785,462	746,866
Current assets:			
Debtors	16	196,587	442,077
Investments	17	189,000	273,000
Cash at bank and in hand		422,438	319,285
		808,025	1,034,362
Creditors: amounts falling due within one year	18	(199,915)	(134,971)
Net current assets		608,110	899,391
Total assets less current liabilities		1,393,572	1,646,257
Total net assets		1,393,572	1,646,257
Charity funds:			
Restricted funds	19	138,464	87,485
Unrestricted funds	19	1,255,108	1,558,772
Total funds		1,393,572	1,646,257

The financial statements were approved and authorised for issue by the Trustees and signed on their behalf by:



Prof N Maskell
Trustee
Date: 14th October 2022



D McKinley
Trustee
Date: 14th October 2022

Charity Balance sheet as at 31st March 2022

	Note	2022 £	2021 £
Fixed assets:			
Tangible assets	14	13,442	7,227
Investments	15	772,021	739,640
		785,463	746,867
Current assets:			
Debtors	16	189,062	442,077
Investments	17	189,000	273,000
Cash at bank and in hand		422,438	319,285
		800,500	1,034,362
Creditors: amounts falling due within one year	18	(192,391)	(134,972)
Net current assets		608,109	899,390
Total assets less current liabilities		1,393,572	1,646,257
Total net assets		1,393,572	1,646,257
Charity funds:			
Restricted funds	19	138,464	87,485
Unrestricted funds	19	1,255,108	1,558,772
Total funds		1,393,572	1,646,257

The parent charity's net movement in funds for the period was a deficit of £252,685 (2021: surplus £275,044).
The financial statements were approved and authorised for issue by the Trustees and signed on their behalf by:



Prof N Maskell
Trustee
Date: 14th October 2022



D McKinley
Trustee
Date: 14th October 2022

Consolidated Statement of Cash Flows for the period ended 31st March 2022

	2022 £	2021 £
Cash flows from operating activities:		
Net cash used in operating activities	136,158	(7,312)
Cash flows from investing activities:		
Dividends and interest from investments	5,388	6,278
Purchase of tangible fixed assets	(9,448)	(5,657)
Proceeds from sale of investments	686,176	280,604
Purchase of investments	(715,121)	(232,084)
Net cash provided by/(used in) investing activities	(33,005)	49,141
Cash flows from financing activities		
Net cash provided by financing activities	-	-
Change in cash and cash equivalents in the period	103,153	41,829
Cash and cash equivalents at the beginning of the period	319,285	277,456
Cash and cash equivalents at the end of the period	422,438	319,285

The notes on pages 45 to 72 form part of these financial statements.

Notes to the Financial Statements for the period ended 31st March

1. General information

Mesothelioma UK Charitable Incorporated Organisation is an unincorporated charity registered with the Charity Commission. It's registered office address is 235 Loughborough Road, Mountsorrel, Loughborough, Leicestershire, LE12 7AS and it's registered number is 1177039.

2. Accounting policies

2.1 Basis of preparation of financial statements

The financial statements have been prepared in accordance with the Charities SORP (FRS 102) - 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 2015), the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) and the Charities Act 2011.

The financial statements have been prepared to give a 'true and fair' view and have departed from the Charities (Accounts and Reports) Regulations 2008 only to the extent required to provide a 'true and fair' view. This departure has involved following the Charities SORP (FRS 102) published on 16th July 2014 rather than the Accounting and Reporting by Charities: Statement of Recommended Practice effective from 1st April 2005 which has since been withdrawn.

Mesothelioma UK Charitable Incorporated Organisation meets the definition of a public benefit entity under FRS 102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy. The Consolidated statement of financial activities (SOFA) and Consolidated balance sheet consolidate the financial statements of the charity and its subsidiary undertaking. The results of the subsidiary are consolidated on a line by line basis.

2.2 Fund accounting

General funds are unrestricted funds which are available for use at the discretion of the Trustees in furtherance of the general objectives of the Group and which have not been designated for other purposes. Restricted funds are funds which are to be used in accordance with specific restrictions imposed by donors or which have been raised by the Group for particular purposes. The costs of raising and administering such funds are charged against the specific fund. The aim and use of each restricted fund is set out in the notes to the financial statements.

Investment income, gains and losses are allocated to the appropriate fund.

Notes to the Financial Statements for the period ended 31st March 2022 (continued)

2.3 Income

All income is recognised once the Group has entitlement to the income, it is probable that the income will be received and the amount of income receivable can be measured reliably.

For legacies, entitlement is taken as the earlier of the date on which either: the Group is aware of probate has been granted, the estate has been finalised and notification has been made by the executor(s) to the Group that a distribution will be made, or when a distribution is received from the estate. Receipt of a legacy, in whole or in part, is only considered probable when the amount can be measured reliably and the Group has been notified of the executor's intention to make a distribution. Where legacies have been notified to the Group, or the Group is aware of the granting of probate, and the criteria for income recognition have not been met, then the legacy is treated as a contingent asset and disclosed if material.

Donated services or facilities are recognised when the Group has control over the item, any conditions associated with the donated item have been met, the receipt of economic benefit from the use of the Group of the time is probable and that economic benefit can be measured reliably. In accordance with the Charities SORP (FRS 102), the general volunteer time is not recognised and refer to the Trustees' report for more information about their contribution.

On receipt, donated professional services and donated facilities are recognised on the basis of the value of the gift to the charity which is the amount the Group would have been willing to pay to obtain services or facilities or equivalent economic benefit on the open market; a corresponding amount is then recognised in expenditure in the period of receipt.

Grants are included in the Consolidated statement of financial activities on a receivable basis. The balance of income received for specific purposes but not expended

during the period is shown in then relevant funds on the Balance sheet. Where income is received in advance of entitlement of receipt, its recognition is deferred and included in creditors as deferred income. Where entitlement occurs before income is received, the income is accrued.

Income tax recoverable in relation to donations received under Gift Aid or deeds of covenant is recognised at the time of the donation.

Income tax recoverable in relation to investment income is recognised at the time the investment income is receivable.

Other income is recognised in the period in which it is receivable and to the extent the goods have been provided or on completion of the service.

Notes to the Financial Statements for the period ended 31st March 2022 (continued)

2.4 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 allocated on the portion of the asset's use.

Fundraising costs are those incurred in seeking voluntary contributions and do not include the costs of disseminating information in support of the charitable activities. Support costs are those costs incurred directly in support of expenditure on the objects of the charity and include project management carried out at Headquarters.

Costs of generating funds are costs incurred in attracting voluntary income, and those incurred in trading activities that raise funds.

Charitable activities and Governance costs are costs incurred on the charity's operations, including support costs and costs relating to the governance of the charity apportioned to charitable activities.

2.5 Going concern

The Trustees assess whether the use of going concern is appropriate, i.e. whether there are any material uncertainties related to events or conditions that may cast significant doubt over the ability of the charity to continue as a going concern. The Trustees make this assessment in respect of a period of at least one year from the date of authorisation for issue of the financial statements and have concluded that the group has adequate resources to continue in operational existence for the foreseeable future and there are no material uncertainties about the group's ability to continue as a going concern, thus they continue to adopt the going concern basis of accounting in preparing the financial statements.

2.6 Tangible fixed assets and depreciation

All assets costing more than £500 are capitalised.

A review for impairment of a fixed asset is carried out if events or changes in circumstances indicate that the carrying value of any fixed asset may not be recoverable. Shortfalls between the carrying value of fixed assets and their recoverable amounts are recognised as impairments. Impairment losses are recognised in the Statement of Financial Activities.

Tangible fixed assets are carried at costs, net of depreciation and any provision for impairment. Depreciation is provided at rates calculated to write off the cost of fixed assets, less their estimated residual value, over their expected useful lives.

Depreciation is provided on the following bases:

Fixtures and fittings	15% reducing balance
Computer equipment	33.33% reducing balance

Notes to the Financial Statements for the period ended 31st March 2022 (continued)

2.7 Investments

Fixed asset investments are a form of financial instrument and are initially recognised at their transaction cost and subsequently measured at fair value at the Balance sheet date. Investment gains and losses, whether realised or unrealised, are combined and presented as 'Gains/(Losses) on investments' in the Consolidated statement of financial activities.

Investments in subsidiaries are valued at cost less provision for impairment.

2.8 Interest receivable

Interest on funds held on deposit is included when receivable and the amount can be measured reliably by the Group; this is normally upon notification of the interest paid or payable by the institution with whom the funds are deposited.

2.9 Debtors

Trade and other debtors are recognised at the settlement amount after any trade discount offered. Prepayments are valued at the amount prepaid net of any trade discounts due.

2.10 Cash at bank and in hand

Cash at bank and in hand includes cash and short-term highly liquid investments with a short maturity of three months or less from the date of acquisition or opening of the deposit or similar account.

2.11 Liabilities and provisions

Liabilities are recognised when there is an obligation at the Balance sheet date as a result of a past event, it is probable that a transfer of economic benefit will be required in settlement, and the amount of the settlement can be estimated reliably.

Liabilities are recognised at the amount that the Group anticipates it will pay to settle the debt or the amount it has received as advanced payments for the goods or services it must provide.

Provisions are measured at the best estimate of the amounts required to settle the obligation. Where the effect of the time value of money is material, the provision is based on the present value of those amounts, discounted at the pre-tax discount rate that reflects the risks specific to the liability. The unwinding of the discount is recognised in the Consolidated statement of financial activities as a finance cost.

2.12 Financial instruments

The Group only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at their settlement value with the exception of bank loans which are subsequently measured at amortised cost using the effective interest method.

2.13 Operating leases

Rentals paid under operating leases are charged to the Consolidated statement of financial activities on a straight line basis over the lease term.

2.14 Current asset investments

Current asset investments are cash or cash equivalents with a maturity date of less than one year valued at fair value.

Notes to the Financial Statements for the period ended 31st March 2022 (continued)

2.15 Pensions

The Group operates a defined contribution pension scheme and the pension charge represents the amounts payable by the Group to the fund in respect of the period.

3. Critical accounting estimates and areas of judgement

Estimates and judgements are continually evaluated and are based on historical experience and other factors, including expectations of future events that are believed to be reasonable under the circumstances.

Critical accounting estimates and assumptions:

The charity makes estimates and assumptions concerning the future. The resulting accounting estimates and assumptions will, by definition, seldom equal the related actual results. The estimates and assumptions that have a significant risk of causing a material adjustment to the carrying amounts of assets and liabilities within the next financial year are discussed below.

Useful economic lives of tangible assets

The annual depreciation charge for tangible fixed assets is sensitive to changes in the estimated useful economic lives and residual values of the assets. The useful economic lives and residual values are reassessed annually. They are amended when necessary to reflect current estimates, based on technological advancement, future investments, economic utilisation and the physical condition of the assets. See note 14 for the carrying amount of the fixture and fittings and computer equipment, and note 2.6 for the useful economic lives for each class of assets.

Residual legacies

There is some uncertainty in the value of residual legacies recognised due to the time lapse between when probate has been granted and the final distribution is made.

Donated services and facilities

The Group has been donated the use of the premises they operate from. The fair value of the donated facility has been arrived at based on the amount the Group would pay in the open market for an alternative. This has been calculated on an estimated average rate per square foot. While this is considered a reasonable reliable approach there is some uncertainty due to multiple factors affecting the rental value of the property including the size, the age and demographical area.

Notes to the Financial Statements for the period ended 31st March 2022 (continued)

4. Income from donations and legacies

	Unrestricted funds 2022 £	Restricted funds 2022 £	Total funds 2022 £	Total funds 2021 £
Donations	576,595	100,473	677,068	548,173
Legacies	184,726	-	184,726	559,459
Grants	12,001	292,226	304,227	218,965
Donated services and facilities	12,907	-	12,907	-
Total 2022	786,229	392,699	1,178,928	1,326,597
Total 2021	1,053,790	272,807	1,326,597	

Donated services and facilities comprise of the use of premises the Group operates from. The donation represents the deemed market rent of the property.

Notes to the Financial Statements for the period ended 31st March 2022 (continued)

5. Income from other trading activities

Income from non charitable trading activities

	Unrestricted funds 2022 £	Total funds 2022 £	Total funds 2021 £
Advertising sales	122,029	122,029	120,000
Speaker fees	-	-	1,063
Shop sales	11,760	11,760	12,993
Total 2022	133,789	133,789	134,056
Total 2021	134,056	134,056	

The advertising sales represents income from Mesothelioma UK commercial relationships which includes:

- commission from the UK National Asbestos Register.
- income raised from members of Mesothelioma UK Trading Ltd's legal panel, who make a payment to Mesothelioma UK Trading Ltd, in return for the inclusion of their name and logo on our website and legal advice leaflet. Their logo is also included on the Mesothelioma Matters magazine, and they each have space for one article in one of the quarterly magazines per year.

Notes to the Financial Statements for the period ended 31st March 2022 (continued)

6. Investment income

	Unrestricted funds 2022 £	Total funds 2022 £	Total funds 2021 £
Dividends received	3,227	3,227	2,006
Bank interest received	2,161	2,161	4,272
Total 2022	5,388	5,388	6,278
Total 2021	6,278	6,278	

Notes to the Financial Statements for the period ended 31st March 2022 (continued)

7. Other incoming resources

	Unrestricted funds 2022 £	Total funds 2022 £	Total funds 2021 £
Coronavirus job retention scheme income	-	-	1,124
Coronavirus rates grant	-	-	10,000
Rental Income	650	650	-
Total 2022	650	650	11,124
Total 2021	11,124	11,124	

Notes to the Financial Statements for the period ended 31st March 2022 (continued)

8. Expenditure on raising funds

Costs of raising voluntary income

	Unrestricted funds 2022 £	Total funds 2022 £	Total funds 2021 £
Fundraising costs	13,967	13,967	4,973
Will writing	4,260	4,260	2,655
Charitable events	7,726	7,726	970
Christmas card purchases	3,015	3,015	1,610
Online shop expenses	2,598	2,598	9,188
Website and social media	3,352	3,352	3,308
Stripe and online giving fees	10,430	10,430	7,798
Print and design magazine	1,526	1,526	1,357
Travel expenses	742	742	-
UHL staff costs	50,616	50,616	56,270
Finance manager	486	486	1,005
Wages and salaries	63,423	63,423	38,656
National insurance	4,316	4,316	2,322
Pension costs	4,093	4,093	2,256
Total 2022	170,550	170,550	132,368
Total 2021	132,368	132,368	

Other trading expenses

	Unrestricted funds 2022 £	Total funds 2022 £	Total funds 2021 £
Administration expenses	948	948	797
Total 2021	797	797	

Notes to the Financial Statements for the period ended 31st March 2022 (continued)

9. Analysis of expenditure by activities

	Direct costs 2022 £	Support costs 2022 £	Total funds 2022 £	Total funds 2021 £
Administration and operational costs	-	197,605	197,605	139,151
Patient support costs	866,276	-	866,276	692,744
Information expenses	69,126	-	69,126	48,258
Research and audit costs	215,861	-	215,861	285,987
Armed Forces project	-	-	-	21,999
Awareness costs	54,510	-	54,510	43,391
Total 2022	1,205,773	197,605	1,403,378	1,231,530
Total 2021	1,092,379	132,368	1,231,530	

Notes to the Financial Statements for the period ended 31st March 2022 (continued)

9. Analysis of expenditure by activities (continued)

Analysis of direct costs

	Patient support costs 2022 £	Information expenses 2022 £	Research & audit costs 2022 £	LIBOR project 2022 £	Awareness costs 2022 £	Total funds 2022 £	Total funds 2021 £
Staff costs	20,667	25,791	17,104	-	28,322	91,884	68,578
Provision for nursing services	561,721	-	-	-	-	561,721	446,188
Nurses meetings	3,516	-	-	-	-	3,516	78
Website and social media	5,027	6,703	-	-	1,676	13,406	13,234
Patient support sundries and other support costs	6,747	-	-	-	-	6,747	2,150
Patient travel	13,333	-	-	-	-	13,333	12,540
Printing and design magazine	-	7,630	-	-	6,104	13,734	12,211
Meso passport	-	-	-	-	-	-	3,336
Provision for grants for research	-	-	19,168	-	-	19,168	121,744
More study	-	-	-	-	-	-	2,736
Project Wales	3,303	-	-	-	-	3,303	-
Research centre main award	-	-	164,295	-	-	164,295	114,680
Other research costs	-	-	1,071	-	-	1,071	4,109
Armed Forces project expenses	2,715	-	-	-	-	2,715	19,209
Awareness costs	-	-	-	-	4,643	4,643	2,114
Information expenses	-	14,018	-	-	-	14,018	5,302
Patient carer day	2,338	2,338	-	-	-	4,676	4,374
Clinical trials app	6,000	-	-	-	-	6,000	-
UHL staff costs	32,248	12,646	13,737	-	13,737	72,368	65,924
Finance manager	-	-	486	-	-	486	980
Travel expenses	-	-	-	-	28	28	-
Benefits advisors	47,538	-	-	-	-	47,538	48,451
Team leaders	161,123	-	-	-	-	161,123	132,345
Health research manager	-	-	-	-	-	-	12,096
Total 2022	866,276	69,126	215,861	-	54,510	1,205,773	1,092,379
Total 2021	692,744	48,258	285,987	21,999	43,391	1,092,379	

Notes to the Financial Statements for the period ended 31st March 2022 (continued)

9. Analysis of expenditure by activities (continued)

Analysis of support costs

	Total funds 2022 £	Total funds 2021 £
Staff costs	75,249	39,439
Depreciation	3,233	3,170
Marketing and adverts	2,176	4,609
Bank charges	788	530
Subscriptions	4,882	2,652
Rent	15,402	10,250
Postage and stationery	3,680	1,806
Office expenses	4,083	1,681
Telephone and internet	4,427	4,867
Storage	742	778
Repairs and maintenance	2,844	80
Governance	10,881	7,682
Insurance	746	660
Investment manager costs	6,567	6,012
Travel expenses	554	351
IT Support and other IT costs	14,223	5,065
Legal and professional fees	13,874	8,609
CRM expenses	4,129	2,938
Finance manager	8,749	17,860
Training	1,087	-
Light, power, heating	2,500	-
Water rates	500	-
Educational conferences	300	-
UHL staff costs	15,989	20,112
Total 2022	197,605	139,151

Notes to the Financial Statements for the period ended 31st March 2022 (continued)

10. Grants payable and similar to institutions and related support costs

	Total funds 2022 £	Total funds 2021 £
Mesothelioma Clinical Nurse Specialists (MCNS) to various NHS Trusts	561,721	446,188
Mesothelioma Clinical Nurse Team Leaders to various NHS Trusts	161,123	132,345
University Hospital Leicester - Operational staff	156,981	142,306
Citizens Advice Bureau	47,538	48,451
LCNUK Grant: Oxford Brookes University - Patients Experiences of follow up care	-	5,210
NLCFN Grant: Oxford Brookes University - Exploring clinical decision making in Mesothelioma treatment pathways	-	24,911
University of Southampton - Genomics of Peritoneal Malignancy	-	5,535
University of Sheffield - Research centre main award	164,295	114,680
University of Sheffield - Healthcare workers & Mesothelioma (MAGS)	(2,997)	-
University of Sheffield - Evaluation of role of MCNS's	-	41,733
University of Sheffield - Gendered Experiences of Mesothelioma (GEMS)	(5,771)	10,209
University of Sheffield - MINNOW	6,996	-
University of Sheffield - Impact of Mesothelioma for Armed Forces	-	34,146
Patient travel grants to individuals	13,333	12,540
University of Sheffield Long Term Survivors Research grant	2,488	-
Northumbria Healthcare research grant - HELP MESO	7,282	-
North Tees and Hartleport NHS research grant: Palliative Care Review	737	-
University of Leicester research grant - Leveraging Clonal Genomics	5,000	-
University of Highlands and Islands research grant - Diagnosing Mesothelioma using Pleural Effusions	5,433	-
Total 2022	1,124,159	1,018,254

Notes to the Financial Statements for the period ended 31st March 2022 (continued)

11. Auditors' remuneration

	2022 £	2021 £
Fees payable to the Group's auditor in respect of:		
The auditing of accounts of associates of the Group	6,600	4,884
All non-audit services not included above	1,647	1,470

12. Staff costs

	Group 2022 £	Group 2021 £	Charity 2022 £	Charity 2021 £
Wages and salaries	210,467	135,386	210,467	135,386
Social security costs	13,561	7,870	13,561	7,870
Pension costs	14,937	7,995	14,937	7,995
	238,965	151,251	238,965	151,251

The average number of persons employed by the charity during the period was as follows:

	Group 2022 No.	Group 2021 No.
Support staff	12	7

No employee received remuneration amounting to more than £60,000 in either year.

Notes to the Financial Statements for the period ended 31st March 2022 (continued)

13. Trustees

During the period, no Trustees received any remuneration or other benefits (2021: £NIL).

There were no travel and accommodation costs for conferences and meetings paid to Trustees during the period (2021: NIL).

14. Tangible fixed assets

Group

	Fixtures and fittings £	Computer equipment £	Total £
Cost or valuation			
At 1st April 2021	3,787	14,809	18,596
Additions	-	9,448	9,448
At 31st March 2022	3,787	24,257	28,044
Depreciation			
At 1st April 2021	2,416	8,953	11,369
Charge for the period	206	3,027	3,233
At 31st March 2022	2,622	11,980	14,602
Net book value			
At 31st March 2022	1,165	12,277	13,442
At 31st March 2021	1,371	5,856	7,227

Notes to the Financial Statements for the period ended 31st March 2022 (continued)

14. Tangible fixed assets (continued)

Charity

	Fixtures and fittings £	Computer equipment £	Total £
Cost			
At 1st April 2021	3,787	14,809	18,596
Additions	-	9,448	9,448
At 31st March 2022	3,787	24,257	28,044
Depreciation			
At 1st April 2021	2,416	8,953	11,369
Charge for the period	206	3,027	3,233
At 31st March 2022	2,622	11,980	14,602
Net book value			
At 31st March 2022	1,165	12,277	13,442
At 31st March 2021	1,371	5,856	7,227

Notes to the Financial Statements for the period ended 31st March 2022 (continued)

15. Fixed asset investments

Group

	Listed investments £
Cost or valuation	
At 1st April 2021	739,639
Additions	715,121
Disposals	(686,176)
Revaluations	3,436
At 31st March 2022	772,020

Charity

	Investments in subsidiary companies £	Listed investments £	Total £
Cost or valuation			
At 1st April 2021	1	739,639	739,640
Additions	-	715,121	715,121
Disposals	-	(686,176)	(686,176)
Revaluations	-	3,436	3,436
At 31st March 2022	1	772,020	772,021

Notes to the Financial Statements for the period ended 31st March 2022 (continued)

15. Fixed asset investments (continued)

Principal subsidiaries

The following was a subsidiary undertaking of the charity:

Name	Company number	Registered office or principal place of business	Principal activity
Mesothelioma UK Trading Ltd	12541690	England and Wales	Sponsorship and advertising sales

Class of shares	Holding	Included in consolidation
Ordinary	100%	Yes

The financial results of the subsidiary for the year were:

Income £	Expenditure £	Profit/(Loss)/ Surplus/ (Deficit) for the year £	Net assets £
122,029	948	121,081	1

Notes to the Financial Statements for the period ended 31st March 2022 (continued)

16. Debtors

	Group 2022 £	Group 2021 £	Charity 2022 £	Charity 2021 £
Due within one year				
Trade debtors	30,175	2,200	30,175	2,200
Other debtors	16,643	6,810	16,643	6,810
Prepayments and accrued income	149,769	433,067	142,244	433,067
	196,587	442,077	189,062	442,077

17. Current asset investments

	Group 2022 £	Group 2021 £	Charity 2022 £	Charity 2021 £
Cash on deposit	189,000	273,000	189,000	273,000

Current asset investments consists of fixed rate deposits with high street banks and building societies maturing in April 2022 and July 2022.

Notes to the Financial Statements for the period ended 31st March 2022 (continued)

18. Creditors: Amounts falling due within one year

	Group 2022 £	Group 2021 £	Charity 2022 £	Charity 2021 £
Trade debtors	72,375	70,002	72,375	70,002
Amounts owed to group undertakings	-	-	6,223	1,501
Other taxation and social security	11,984	3,992	6,637	3,242
Other creditors	13,420	25,375	13,420	25,375
Accruals and deferred income	102,136	35,602	93,736	34,852
	199,915	134,971	192,391	134,972

	Group 2022 £	Group 2021 £	Charity 2022 £	Charity 2021 £
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Deferred income

Resources deferred during the period	11,672	-	11,672	-
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The deferred income are funds received in advance from fundraising challenges yet to take place at the year end. The events are scheduled to take place in 22/23.

Notes to the Financial Statements for the period ended 31st March 2022 (continued)

19. Statement of funds

Statement of funds - current period

	Balance at 1 April 2021 £	Income £	Expenditure £	Transfers in/out £	Gains/ (Losses) £	Balance at 31 March 2022 £
Unrestricted funds						
General funds	1,558,772	926,056	(1,233,053)	(103)	3,436	1,255,108
Restricted funds						
Grants and donations for nurses	61,468	264,948	(248,672)	103	-	77,847
Armed Forces project	1,354	-	(1,354)	-	-	-
Bristol Myers Squibb	2,106	-	(2,106)	-	-	-
Project NI	-	24,557	-	-	-	24,557
Grants and donations for research	-	82,006	82,006	-	-	36,060
Donations for other restricted projects	22,557	21,188	(7,685)	-	-	-
	87,485	392,699	(341,823)	103	-	138,464
Total of funds	1,646,257	1,318,755	(1,574,876)	-	3,436	1,393,572

Notes to the Financial Statements for the period ended 31st March 2022 (continued)

19. Statement of funds (continued)

Statement of funds - prior period

	Balance at 1st April 2020 £	Income £	Expenditure £	Gains/ (Losses) £	Balance at 31st March 2021 £
Unrestricted funds					
General funds	1,187,758	1,205,248	(995,918)	161,684	1,558,772
Restricted funds					
Grants and donations for nurses	101,555	151,368	(191,455)	-	61,468
Armed Forces project	75,602	-	(74,248)	-	1,354
The National Lottery	-	46,806	(46,806)	-	-
Bristol Myers Squibb	-	21,508	(19,402)	-	2,106
Grants and donations for research	4,012	18,682	(22,694)	-	-
Donations for other restricted projects	2,286	34,443	(14,172)	-	22,557
	183,455	272,807	(368,777)	-	87,485
Total of funds	1,371,213	1,478,055	(1,364,695)	3,436	1,646,257

Notes to the Financial Statements for the period ended 31st March 2022 (continued)

19. Statement of funds (continued)

Unrestricted funds are available to be spent for any purposes of the charity.

Purposes of restricted funds

Grants and donations for nurses

Various grants and donations were received during the year towards the payment of grants to trusts for the provision of mesothelioma clinical nurse specialists.

Armed Forces project

The Armed Forces project was grant income being funded by the chancellor using LIBOR funds. All funds were fully utilised in 2021/22.

The National Lottery

The National Lottery funding was part of the coronavirus community support fund. The funds were to support the charity to help deliver services through the Covid-19 pandemic. The funds were used to provide a telephone helpline support service. All funds were fully utilised in 2020/21.

Bristol Myers Squibb

The charity received two grants from Bristol Myers Squibb. The funds were used to provide IT and equipment to enable staff to continue to provide services while working from home during the Covid-19 pandemic, and to provide continued support through the telephone helpline support service. All funds were fully utilised in 2021/22.

Project NI

These are ring-fenced donations to enable Mesothelioma UK to expand its services to include Northern Ireland. The project will commence when sufficient funds have been received.

Grants and donations for research

The majority of the funds were from a grant from the Medical Research Charity Support Fund, for research carried out by several PHD students. The balance was received for use on general research and was fully utilised on the charity's other research projects.

Grants for other restricted projects

A large amount of funding was received for the purpose of the construction of an armed services memorial. This will be commissioned when sufficient restricted donations have been received. £10,000 was a grant from Takeda UK to help fund our patient support costs during the Covid-19 pandemic. Other donations were received and restricted for expenditure on patient travel expenses, peritoneal services and services in Wales.

Notes to the Financial Statements for the period ended 31st March 2022 (continued)

20. Analysis of net assets between funds

Analysis of net assets between funds - current year

	Unrestricted funds 2022 £	Restricted funds 2022 £	Total funds 2022 £
Tangible fixed assets	13,442	-	13,442
Fixed asset investments	772,020	-	772,020
Current assets	669,561	138,464	808,025
Creditors due within one year	(199,915)	-	(199,915)
Total	1,255,108	138,464	1,393,572

Analysis of net assets between funds - prior year

	Unrestricted funds 2021 £	Restricted funds 2021 £	Total funds 2021 £
Tangible fixed assets	7,227	-	7,227
Fixed asset investments	739,639	-	739,639
Current assets	946,877	87,485	1,034,362
Creditors due within one year	(134,971)	-	(134,971)
Total	1,558,772	87,485	1,646,257

Notes to the Financial Statements for the period ended 31st March 2022 (continued)

21. Reconciliation of net movement in funds to net cash flow from operating activities

	Group 2022 £	Group 2021 £
Net income/expenditure for the year (as per Statement of Financial Activities)	(252,685)	275,044
Adjustments for:		
Depreciation charges	3,233	3,170
(Gains)/losses on investments	(3,436)	(161,684)
Dividends, interests and rents from investments	(5,388)	(6,278)
Decrease/(increase) in debtors	329,490	(104,362)
Increase/(decrease) in creditors	64,944	(13,202)
Net cash provided by/(used in) operating activities	136,158	(7,312)

22. Analysis of cash and cash equivalents

	Group 2022 £	Group 2021 £
Cash in hand	422,438	319,285
Total cash and cash equivalents	422,438	319,285

Notes to the Financial Statements for the period ended 31st March 2022 (continued)

23. Analysis of changes in net debt

	At 1st April 2021 £	Cash flows £	At 31st March 2022 £
Cash at bank and in hand	319,285	103,153	422,438
Liquid investments	273,000	(84,000)	189,000
	592,285	19,153	611,438

24. Contingent asset

The charity has been notified of an entitlement to legacies of which the charity is unable to measure reliably the value of amounts due and therefore no provision has been made in the accounts.

25. Pension commitments

The group operates a defined contribution pension scheme. The assets of the scheme are held separately from those of the Group in an independently administered fund. The pension cost charge represents contributions payable by the charity to the fund. At the balance sheet date £4,097 (2021 - £1,357) were payable to the fund and are included in creditors.

Notes to the Financial Statements for the period ended 31st March 2022 (continued)

26. Operating lease commitments

At 31st March 2022 the Group and the Charity had commitments to make future minimum lease payments under non-cancellable operating leases as follows:

	Group 2022 £	Group 2021 £	Charity 2022 £	Charity 2021 £
Not later than 1 year	461	1,122	461	1,122
Later than 1 year and not later than 5 years	346	806	346	806
	807	1,928	807	1,928

27. Related party transactions

Group

A L Coates is a Trustee of the parent charity and a partner at Irwin Mitchell Solicitors. During the period £26,857 (2021: £18,905) was receivable by the group from Irwin Mitchell Solicitors being £15,000 (2010: £15,000) sponsorship income plus £11,857 (2021: £3,905) from fundraising events and donations. Also during the period the group acquired will writing and other professional services from Irwin Mitchell Solicitors at a cost of £11,388 (2021: £1,435).


H Childs is a Trustee of the parent charity and a partner at Royds Withy King Solicitors. During the period £17,982 (2021: £16,100) was receivable by the group from Royds Withy King Solicitors being £15,000 (2021: £15,000) sponsorship income plus £2,982 (2021: £1,100) in donations.

Prof M D Peake is a Trustee of the parent charity and Trustee of the British Thoracic Oncology Group (BTOG). During the period BTOG paid rent to the parent charity of £650 (2021: £NIL) and received amounts for recharged expenses of £828 (2021: £1,968).


All transactions with related parties are at arms length and in accordance with the parent charity's objectives.

28. Contributions of volunteers and supporters

The charity is grateful for the unstinting efforts of volunteer fundraiser's who take part in a wide range of sponsored events and other fundraising activities. The vast majority of income comes from private individuals making donations, participating in sponsored events, or leaving legacies.

A group of people are gathered at a celebratory event, possibly a fundraising gala. In the foreground, a man in a white shirt is seated at a table, looking towards the right. Behind him, several other people are visible, some standing and some seated. The room is decorated with numerous balloons, many of which feature the Mesothelioma UK logo. A banner in the background reads "HEATH JAMES". The overall atmosphere is festive and supportive.

“Can I just thank you
for all the support you
have given me over
these past months.
Getting me through
this difficult period in
my life I could not have
wished for a better
mentor than yourself.”



Mesothelioma UK could not do any of this without the ongoing support of our fundraisers, donors, corporate partners and legacies. Please, please continue to do all you do for the charity, it is your contribution that enables us to reach out and to do all we can to help those living with mesothelioma.



MESOTHELIOMA UK

Mesothelioma Charitable Incorporated Organisation

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www.mesothelioma.uk.com

Registered Charity Number 1177039