Introduction

This annual report contains information about the activities, services, income and expenditure of Mesothelioma UK between April 2016 and March 2017.

Mesothelioma UK started in 2004 as a Macmillan Cancer Support funded project. Once established, the benefits of having a national approach to mesothelioma support and information prompted the launch of Mesothelioma UK as an independent charity. The charity commenced in 2009 but did not feel financially secure enough to expand services until 2012. Since then, thanks to an amazing army of fundraisers and a team of people with whom I am proud to work, Mesothelioma UK has been able to go from strength to strength.

Mesothelioma UK aims to:

• Be an essential one stop shop for up-to-date mesothelioma support, information and education
• Support the NHS to drive up standards and ensure equitable access to world class treatment, trials and care
• Help the UK to lead the way in making mesothelioma history through world class audit, research and clinical trials
• Raise the profile of mesothelioma to help prevent future cases of asbestos related disease

The Mesothelioma UK team works towards meeting the vision captured in our strategy The Next Five Years Strategy (2016-2021) – Dedicated to Making Mesothelioma Matter. The strategy follows five work streams.

1. Finance and fundraising
2. Driving up standards and equitable access
3. Support, information and education
4. Research, audit and evaluation
5. Prevention and awareness

Each year, following these five work streams, an action plan is devised to guide the activities of the team. This annual report will highlight, through each of these work streams, the achievements from 2016-2017. A significant development over the year has been the increase in the number of Mesothelioma UK Clinical Nurse Specialists from 7 to 13 and the introduction of two team leaders. The impact of the Mesothelioma UK nurse team is immense and the charity is committed, over the next few years, to increasing the numbers sufficiently to ensure that the whole of the UK is covered.

Thank you to all of the Meso UK team, nurses, operational team, trustees, advisory board, ambassadors and volunteers for all that you do and for your passion, hard work and enthusiasm. To our sponsors, donors and army of fundraisers, without you, none of this would be possible. To anyone living with or affected by mesothelioma, Mesothelioma UK promises to continue to do all that we can to improve treatment, care, support, information and awareness.

Liz Darlison
Director of Services and Consultant Nurse.
INTRODUCING THE TEAM

1. FINANCE AND FUNDRAISING
   - Fundraising exceeded target to reach over £820,000

2. DRIVING UP STANDARDS AND EQUITABLE ACCESS
   - Clinical Nurse Specialist posts are now in place across the UK
   - 13 Clinical Nurse Specialists saw new patients this year

3. SUPPORT, INFORMATION AND EDUCATION
   - 448 information packs were requested and sent out
   - 13,250 printed copies of the quarterly newsletter were distributed

4. RESEARCH, AUDIT AND EVALUATION

5. PREVENTION AND AWARENESS
   - Total page views on the website were 158,805

THE YEAR AHEAD - PLANS FOR 2017/18

Key achievements in 2016/2017:
INTRODUCING THE TEAM

Meet the Mesothelioma UK team

Operational Team:
The operational team is based at
Unit 116 Greenacres, The Sidings, Leicester LE4 3BR.

Liz Darlison,
Director of Services
Caroline Barry,
Benefits Advisor
Ghislaine Boyd,
Business Development Manager
Tracey Calvert,
Finance Officer
Jill Lemon,
Fundraising Manager
Mita Navekar,
Website Co-ordinator
Debbie Neale,
Helpline Co-ordinator and PA
Brushelle Noronha,
Apprentice Administration Assistant
Rubina Sheikh,
Administration Assistant

Communications Team:
Sandstar Communications
Dock, 75 Exploration Drive,
Leicester LE4 5NU

Board of Trustees:
Alida Coates
Ruth Davies
David Hetmanski
Dawn McKinley
Professor Mick Peake (chair)

Clinical Nurse Specialist Team
The Clinical Nurse Specialists are based in
NHS hospitals across the UK.

Liz Darlison,
Consultant Nurse, Leicester

Clinical Nurse Specialist Team Leaders:
Anne Moylan,
Portsmouth
Lorraine Creech,
Manchester

Clinical Nurse Specialists:
Hannah Ball,
Oxford
Simon Bolton,
Yorkshire
Carolyn MacRae*,
Scotland
Christine Jones,
Plymouth
Karen Lord,
Leicester
Kate Slaven,
Cambridge
Leah Taylor,
North East
Helena Stanley,
Sheffield
Rachel Thomas*,
London
Joanne Hargraves*,
London
Louise Gilham*,
Kent
Sarah Morgan,
Wales
Mairead Dixon,
Manchester
Maria Guerin*,
Liverpool
Helen Wilkes*,
Southampton

*Appointed after April 2017
Mesothelioma UK Ambassadors

We currently have six wonderful ambassadors covering different parts of the country in East Anglia, Norfolk, Manchester, Gloucester, London, Yorkshire and Wales. They support the charity and give their time selflessly.

The main part of their role is:

- **To attend events and deliver a clear and concise message of gratitude to those who have held an activity/event or raised monies in support of the charity**
- **Wherever possible, to ensure that the name ‘Mesothelioma UK’ becomes more recognisable and commonplace, thereby becoming a part of the news agenda wherever possible, enabling us to build a stronger presence in social media arenas and to sit comfortably alongside the more familiar cancer charities**
- **Become familiar with the work of Mesothelioma UK in general, through our strategy, newsletter and website**
- **To help promote Mesothelioma UK through our website, other social media sites, Twitter and Facebook. Provide leaflets and/or flyers to distribute where possible and at events. Direct any press/PR enquiries to Mesothelioma UK Communications Team**
- **To have a good knowledge of the portfolio of support that Mesothelioma UK can offer, emphasising the need for continued funding to support everything that we wish to achieve in the future**
1. FINANCE AND FUNDRAISING

During 2016-2017 Mesothelioma UK received a total income of £820,745

Over the next five years, we aim to increase our income to £3 million per year by 2021

To achieve this we will expand the fundraising team, develop a legacy income stream, increase our corporate donors and fundraising campaigns, and source income from grants and trusts.

Total income for the year ended 31st March 2017:

<table>
<thead>
<tr>
<th>Source</th>
<th>% of income</th>
<th>£</th>
</tr>
</thead>
<tbody>
<tr>
<td>Donations and Grants</td>
<td>89</td>
<td>728,157</td>
</tr>
<tr>
<td>Legacies</td>
<td>10</td>
<td>85,164</td>
</tr>
<tr>
<td>Sponsorship Income</td>
<td>1</td>
<td>6,500</td>
</tr>
<tr>
<td>Investment Income</td>
<td>0</td>
<td>924</td>
</tr>
<tr>
<td><strong>Total income for the year</strong></td>
<td><strong>100</strong></td>
<td><strong>820,745</strong></td>
</tr>
</tbody>
</table>

Of the total above, £83,732 were restricted funds

Expenditure in the year ended 31st March 2017 expressed as a percentage of the total income generated:

<table>
<thead>
<tr>
<th>Source</th>
<th>% of income</th>
<th>£</th>
</tr>
</thead>
<tbody>
<tr>
<td>Research and audit</td>
<td>18</td>
<td>150,346</td>
</tr>
<tr>
<td>Clinical staff</td>
<td>25</td>
<td>202,165</td>
</tr>
<tr>
<td>Operational team</td>
<td>10</td>
<td>82,649</td>
</tr>
<tr>
<td>Accounting &amp; finance</td>
<td>1</td>
<td>10,745</td>
</tr>
<tr>
<td>Fundraising team and costs</td>
<td>9</td>
<td>72,665</td>
</tr>
<tr>
<td>Benefit advisor</td>
<td>3</td>
<td>26,028</td>
</tr>
<tr>
<td>Web and marketing team</td>
<td>2</td>
<td>16,506</td>
</tr>
<tr>
<td>Information expenses</td>
<td>3</td>
<td>24,410</td>
</tr>
<tr>
<td>Funded projects and services</td>
<td>4</td>
<td>31,038</td>
</tr>
<tr>
<td>Information events, training and conferences</td>
<td>5</td>
<td>40,509</td>
</tr>
<tr>
<td>Office costs and maintenance</td>
<td>3</td>
<td>27,643</td>
</tr>
<tr>
<td><strong>Total expenditure for the year</strong></td>
<td><strong>684,704</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Net income for the year</strong></td>
<td><strong>136,041</strong></td>
<td></td>
</tr>
</tbody>
</table>
Fundraisers are the largest financial contributors to Mesothelioma UK and we are extremely grateful to them all for their remarkable support.

Each fundraiser has a goal in mind of what they want to achieve, whether it be to support the charity or in memory of a loved one. Either way, their personal reason is what drives them to support the vital work that we do and Mesothelioma UK is there to help them every step of the way.

Many of our corporate donors have supported us since we became a charity. Their financial donations are essential but so is their commitment to helping spread the word about the services, support and information that Mesothelioma UK provides.

Our fundraisers

Over 900 fundraisers took part in, or held events over the last year. They ran, walked, cycled, baked, drank tea, grew moustaches, shaved heads, knitted, danced and many many more, but they all had one thing in common - they supported Mesothelioma UK.

<table>
<thead>
<tr>
<th>Fundraising Events (532 in total)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Action Mesothelioma Day = 8 (2%)</td>
</tr>
<tr>
<td>Celebrations = 20 (5%)</td>
</tr>
<tr>
<td>Challenges = 41 (10%)</td>
</tr>
<tr>
<td>Charity Events = 24 (6%)</td>
</tr>
<tr>
<td>Fundraisers = 132 (30%)</td>
</tr>
<tr>
<td>Funerals = 20 (5%)</td>
</tr>
<tr>
<td>In Memory = 23 (5%)</td>
</tr>
<tr>
<td>Cycling = 25 (6%)</td>
</tr>
<tr>
<td>Walks-Runs = 137 (31%)</td>
</tr>
<tr>
<td>Initiatives = 102 (19%)</td>
</tr>
</tbody>
</table>

Target 2016/17

£800,000

Actual

£820,745

Fundraisers

£338,000

Corporate

Donations £94,321
Grants £31,872
Total £126,193

Other

Investment Income £924
Private Donations £85,061
Charity Donations £59,016
Memorials £126,387
Legacies £85,164
Total £356,552
Meso UK Fundraising Initiatives

We currently have three annual initiatives, Miles for Meso in March, Muffins for Meso in May and Grow a Mo in November. We are looking at ways to engage with our supporters and extend our event calendar. We hope to roll out a further two initiatives in 2017/18 - Meso August Amble & Septsober - Going Sober in September.

Money Raised

<table>
<thead>
<tr>
<th>Initiative</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Grow a Mo</td>
<td>£11,232.34</td>
</tr>
<tr>
<td>Muffins for Meso</td>
<td>£5,730.84</td>
</tr>
<tr>
<td>Miles for Meso</td>
<td>£18,326.07</td>
</tr>
</tbody>
</table>

How Many Got Involved

<table>
<thead>
<tr>
<th>Initiative</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Grow a Mo</td>
<td>41</td>
</tr>
<tr>
<td>Muffins for Meso</td>
<td>38</td>
</tr>
<tr>
<td>Miles for Meso</td>
<td>30</td>
</tr>
</tbody>
</table>

Christmas Card Sales

<table>
<thead>
<tr>
<th>Details</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>11 Designs</td>
<td>£2,557.50</td>
</tr>
<tr>
<td>1,405 packs sold</td>
<td></td>
</tr>
<tr>
<td>Best Seller Praying Angel</td>
<td></td>
</tr>
<tr>
<td>Online sales</td>
<td>£3,680.00</td>
</tr>
<tr>
<td>Sold at events</td>
<td>£1,942.14</td>
</tr>
<tr>
<td>Collection tins at events</td>
<td>£268.00</td>
</tr>
<tr>
<td>Total income</td>
<td>£5,890.14</td>
</tr>
</tbody>
</table>
2. DRIVING UP STANDARDS AND EQUITABLE ACCESS

Mesothelioma UK Advisory Board

The Mesothelioma Advisory Board is an expert advisory group that meets to discuss and make recommendations concerning the needs of mesothelioma sufferers. The Advisory Board was established and an inaugural meeting was held in April 2015. Meetings are held twice yearly. Members include: nurses, clinicians, patients, carers, asbestos group representatives and Mesothelioma UK Operations Team members. One of the key recommendations made by the board was the introduction of travel expenses for patients attending centres for treatment. This was approved by the Board of Trustees and the initiative was launched from 1 April 2017.

Clinical Nurse Specialist (CNS) Team

There are over 3,000 cancer nurse specialists in England alone; a majority of these posts work in lung, breast, bowel and prostate cancer services. Prior to 2012 there were none specialising in mesothelioma despite the growing evidence supporting their significant contribution to patient experience and outcomes. Mesothelioma UK is determined to address this inadequacy. Each Mesothelioma UK nurse is employed in an NHS hospital that agrees to a service level agreement (SLA) with Mesothelioma UK. The SLA outlines local, regional and national responsibilities for each post holder, all focused on ensuring equitable access to the best treatment, care and support available, irrespective of the patient’s location. The impact of CNS-led key activities is outlined here:

**Improving quality and experience of care**
- Managing complex, individual and changing information, and supporting needs of patients and carers
- Supporting patients in choices around treatment and care
- Enhancing recovery and delivering care flexibly and closer to home
- Facilitating set up of support groups

**Reinforcing safety**
- Delivering safe, nurse-led services
- Using vigilance of symptoms and drug toxicity to trigger rescue work
- Identifying and taking action to reduce risks
- Facilitating rapid re-entry into acute services, if appropriate

**Increasing productivity and efficiency**
- Intervening to manage treatment side effects and/or symptom control, preventing unplanned admissions
- Providing nurse-led services that free up consultant resource
- Empowering patients to self-manage their condition

**Demonstrating leadership**
- Educating the wider healthcare team and acting as a mentor
- Identifying and implementing service improvement and efficiencies
- Determining measurable outcomes, auditing practice, and sharing good practice and innovation

Mesothelioma UK intends to eventually support 30 Clinical Nurse Specialist (CNS) posts across the UK and up to April 2017, 13 have been appointed across the UK in the following locations:

Leicester - 2 (1 Nurse Consultant)
Portsmouth (Team Leader)
Manchester - 2 (1 Team Leader)
Sheffield
Newcastle
Oxford
Glasgow
Wales
Yorkshire
Plymouth
Cambridge
Mesothelioma UK CNS Achievements 2016/17

**Team Leader Posts**

A need was identified for two Team Leader posts to support the increasing number of Mesothelioma UK-funded specialist nurses. In 2016, Lorraine Creech was appointed to an additional post as Team Leader for the north of the UK and Anne Moylan to Team Leader for the south (this post is jointly funded by Mesothelioma UK and Hampshire Asbestos Support & Awareness Group (HASAG)).

**New Posts**

Clinical Nurse Specialist posts were established in Manchester, Leicester, Plymouth, Yorkshire and Wales.

**Patient Contacts**

This year the nurses saw 473 new patients. This reflected the growth from 8 to 13 nurses throughout the year in 10 regional locations.

**Mesothelioma UK Helpline Contacts**

609 of the contacts to the Helpline were dealt with by the CNSs and many of these were regarding access to clinical trials.

**Presentations**

66 presentations were delivered locally, regionally, nationally and internationally.

**Meetings**

The nurses attended 160 meetings representing Mesothelioma UK.

**Support Groups**

Mesothelioma UK Clinical Nurse Specialists attended 75 support groups.
Examples of patient and carer feedback

“I would like to thank you for all the support and advice you gave during the course of his illness. We came to rely on you being at outpatient appointments, helping to navigate our way through the process…held you in very high regard and was always pleased to see you.”

“Your help and advice made such a difference to the care … was able to receive. It was a tremendous help knowing you were there for us.”

“Thank you for your help over the past few months. You have been a lifeline to us.”

What is it like to be a CNS with Mesothelioma UK?

“Being a Meso UK nurse to me is an honour and privilege, and I have felt incredibly humbled by the reception of the South West and the support that they have given me. I never underestimate or take for granted, the gift of being allowed to accompany those afflicted with asbestos related disease as they walk their pathway, and equally, I never fail to be amazed at the support we, as a team, offer each other. It is, simply, the best job on the planet.”

Christine Jones, CNS
Services funded in 2016/17

MARS 2 pilot study – supporting patient travel expenses

The MARS 2 pilot study team approached Mesothelioma UK in late 2015 to explore the possibility of supporting travel expenses for patients participating in the study. Funding was agreed as well as guidelines for making claims. The charity received its first claim in November 2016.

The total claims processed this year was £1,726

West of Scotland Interventional Cancer Pain Service - cordotomy equipment funding

Mesothelioma UK exists to improve the quality of life for mesothelioma sufferers. In May 2016, the Mesothelioma UK Board of Trustees approved the sum of £24,500 for equipment purchase. This funding has enabled Interventional Cancer Pain Service to set up a much needed cordotomy service at Beatson West of Scotland Cancer Centre.

The first patients received treatment in February 2017. The official launch date was in March 2017 and was attended by Lorraine Creech, Mesothelioma UK Team Leader.

This was Mesothelioma UK’s first equipment funding initiative and we hope that we can continue to support other centres to set up vital services in the future.
3. SUPPORT, INFORMATION AND EDUCATION

Helpline Activity

Our freephone Helpline is available from Monday to Friday with an answerphone facility for calls received out of hours. Both members of the administration team and our nurses share the task of answering the Helpline and took 3,667 calls in 2016/2017. Depending on the nature of the enquiry, callers are put in touch with their nearest nurse, sent information or directed to other organisations who can help.

The contacts received by the Helpline from April 2016 to March 2017 are as follows:-

- **Doctors/GPs:** 27 (1%)
- **Fundraising enquiries:** 528 (14%)
- **Nurses:** 128 (3%)
- **Others:** 338 (11%)
- **Patients:** 225 (6%)
- **Relatives/Carers:** 772 (21%)
- **Fundraising Manager:** 1598 (44%)

When the calls are taken they are allocated accordingly:
Information Distribution

448 Mesothelioma UK information packs were requested and sent out in 2016/2017. An unknown quantity were also distributed through the Mesothelioma UK CNS team, at conferences and through members of the National Lung Cancer Forum for Nurses.

Newsletter Distribution

In 2016/17, 13,250 printed copies of the newsletter were distributed. Electronic copies and a link to the online version were circulated to in excess of 1,500 contacts through the networks of partner organisations such as the British Thoracic Oncology Group, the National Lung Cancer Forum for Nurses and the charity’s own circulation lists.

Patient and Carer Conference

In May 2016, Mesothelioma UK’s annual Patient and Carer Day conference was attended by around 150 people, mostly patients and their family members/carers. With world-class speakers also attending, the day was a chance for patients to meet and share experiences with others, get the latest updates on mesothelioma treatments and ask questions to the healthcare professionals.

Mesothelioma Essential Update

In March 2017, Mesothelioma UK collaborated with the British Thoracic Oncology Group to deliver the Mesothelioma Essential Update conference in London. With 15 experts presenting to over 100 delegates, the day was a chance for healthcare professionals to learn about the latest developments in mesothelioma treatment and care.
Benefits & Finance Advice

Mesothelioma UK has a Citizens Advice Bureau Benefits Advisor employed as part of the team. During 2016/17, the Benefits Advisor supported 163 clients.

Benefits/Lump Sum Payments 2016/17

1. Helpline/ Direct Contact

<table>
<thead>
<tr>
<th></th>
<th>2016</th>
<th>2017</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Q1</td>
<td>Q2</td>
</tr>
<tr>
<td></td>
<td>Apr-Jun</td>
<td>Jul-Sep</td>
</tr>
<tr>
<td>Number of clients</td>
<td>32</td>
<td>27</td>
</tr>
<tr>
<td>Lump sum payments identified</td>
<td>£325,956.00</td>
<td>£213,347.00</td>
</tr>
<tr>
<td>Estimated annualised benefit</td>
<td>£209,141.40</td>
<td>£209,141.40</td>
</tr>
</tbody>
</table>

2. Casework

<table>
<thead>
<tr>
<th></th>
<th>2016</th>
<th>2017</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Q1</td>
<td>Q2</td>
</tr>
<tr>
<td></td>
<td>Apr-Jun</td>
<td>Jul-Sep</td>
</tr>
<tr>
<td>Number of clients</td>
<td>11</td>
<td>8</td>
</tr>
<tr>
<td>Lump sum payments identified</td>
<td>£211,631.00</td>
<td>£129,205.00</td>
</tr>
<tr>
<td>Estimated annualised benefit</td>
<td>£126,674.60</td>
<td>£107,354.00</td>
</tr>
</tbody>
</table>

3. Year Totals April 2016 to March 2017 (Helpline/ Direct Contact plus Casework)

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of clients</td>
<td>163</td>
</tr>
<tr>
<td>Lump sum payments identified</td>
<td>£1,971,321.00</td>
</tr>
<tr>
<td>Estimated annualised benefit</td>
<td>£1,263,766.96</td>
</tr>
</tbody>
</table>
"I wished to write a short note to express sincere thanks for all the help you gave to us to obtain benefits for my sister, diagnosed back in December 2016 with peritoneal mesothelioma.

You gave us great encouragement and practical advice which has enabled my sister to receive all the benefits you outlined to me. We are so grateful at this difficult time to have some financial stability to allow my brother-in-law to spend as much time with her and the kids as possible. You are in our prayers."

"I just wanted to speak to you in person to thank you so much for what you have done for me. You have been amazing and I am quite overwhelmed."

"We would like to thank you for all the help you gave us regarding my husband’s benefits. He has had a lump sum and is getting the Industrial Injuries Disablement Benefit and Attendance Allowance every week. We cannot express how grateful we are to you. My husband is feeling good at the moment and long may that last. Again, thank you."
4. RESEARCH, AUDIT AND EVALUATION

Mesothelioma UK - British Lung Foundation (BLF) Research Grant

Mesothelioma UK has committed to support a yearly research grant of £150,000. The research project is administered by the research committee at the BLF. Mesothelioma UK has no involvement in the peer review process of applicants.

**Professor Dean Fennell, University Hospitals of Leicester**

Dean was awarded the first Mesothelioma UK – British Lung Foundation Research Grant in autumn 2015.

The research project is looking at a new approach to personalising therapy for mesothelioma patients using a targeted, drug based strategy. It has emerged, through genetic research, that a gene in mesothelioma – known as CDKN2 – is commonly inactivated by DNA mutation. Because of this, the cancer may become vulnerable to a new class of drugs (CDK4 inhibitors) that are anticancer.

We hope that this research will begin the process of developing a new and effective treatment for those who have relapsed, addressing a major unmet need for people with mesothelioma.

**Professor Luciano Mutti, University of Salford**

Luciano was awarded the second grant in autumn 2016.

Funding of £111,750 has been awarded to University of Salford to investigate hypoxia (low oxygen levels) in Malignant Pleural Mesothelioma (MPM).

This funding enabled the team to conduct a Phase 1 trial to investigate HypoxamiRs as a New Target for Treatment of Malignant Pleural Mesothelioma (MPM) and how they trigger signalling pathways that increase the spread of cancer. The idea is to disrupt the capability of tumour cells to live on in hypoxic conditions and thus prevent further growth of the cancer cells.

We look forward to updates on this important piece of research.
Nursing Research Grants

Mesothelioma UK launched a new research scheme in 2016 to fund nurse-led research to improve patient experience and care for people with mesothelioma.

The scheme attracted some high quality applications. The first award was made in spring 2016 to a project entitled ‘Receiving a diagnosis of mesothelioma: Improving the patient experience.’

The successful application focuses on the experience of receiving a diagnosis of mesothelioma. It was from a team made up of clinical and academic nurses from Sheffield and Oxford.

The project seeks to understand more about the experience of receiving a diagnosis of mesothelioma, from the perspective of patients and their family, and using that information to improve healthcare practice. The findings will be used to develop draft recommendations for care.

National Mesothelioma Audit

In 2016, Mesothelioma UK funded the Royal College of Physicians (RCP) London to produce the second National Lung Cancer Audit on pleural mesothelioma. The report used data from over 2,000 patients and set out recommendations for trusts in relation to mesothelioma patients.

We were delighted to collaborate with the RCP on this report which provides valuable insights and will hopefully result in improved treatment, care and outcomes.

The report is available to download on our website at www.mesothelioma.uk.com

Without Mesothelioma UK funding, this national audit would not continue.
5. PREVENTION AND AWARENESS

Communication & Public Relations

Since April 2016, Sandstar Communications has supported Mesothelioma UK with its communications and PR needs. Sandstar manages the charity’s social media accounts and website content, keeping them up to date and engaging. We have used traditional PR to raise awareness of the charity and build a strong reputation resulting in local, regional and national press coverage.

Twitter

**Number of followers:**
Increased from 1,003 (31 May 2016) to **1,438** (31 March 2017)

**Top tweet (most impressions):**
August 2016
Impressions **9,437**

@KezDugdale: We can’t let cancer turn into deprivation disease

**Retweets:**
2,060 over the year, with an increase each quarter and an average of 40 retweets per week.
**Facebook**

Mesothelioma UK operates a public-facing Facebook page and a Peritoneal Mesothelioma group page.

### Number of Likes:

Increase from 393 (31 May 2016) to **835** (31 March 2017)

### Top post (biggest reach):

September 2016 Reach: **6.5k** (31 March 2017)

*It's ready! Our first ever strategy detailing who we are, what we do and what we aim to achieve over the next five years. Take a look and let us know your thoughts. www.mesothelioma.uk.com*

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**Website**

The first half of the year saw the website gaining an average of **12,707** page views per month. The second half of the year saw an average of **13,858**.

<table>
<thead>
<tr>
<th>Total page views for the period from 1 April 2016 – 31 March 2017</th>
<th>158,805</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mesothelioma Homepage</td>
<td>31,897 views</td>
</tr>
<tr>
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<td>Supporting Us</td>
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<td>Information and support/patient information</td>
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<td>Information and support/patient-family experiences</td>
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<td>Information and support/support groups</td>
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**Press releases**

12 press releases were produced and distributed, resulting in 39 pieces of coverage in the media including national and local newspapers, publications for healthcare professionals, television, radio and online.

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Leicester Action Mesothelioma Day 2016
- A Service of Reflection and Hope

The Leicester Service of Reflection and Hope, held at Leicester Cathedral, was very well attended with over 100 people turning out in support. It was a warm sunny day which bought with it both optimism and hope to those attending. The cathedral, as always, is a perfect place for quiet reflection.

The Reverend Peter Hobson welcomed all into the cathedral and the service of Reflection and Hope began after introductions were made by Master of Ceremonies, the Reverend Mark Burleigh from Leicester Hospitals.

Lady Jennifer Gretton opened the service, paying tribute to all those who are no longer with us and to those who are living with mesothelioma.

Professor Michael Peake and Professor Dean Fennell gave updates both nationally and locally about treatments/trials, data and the current working projects that are going on around the country in the mesothelioma community.

Mesothelioma sufferer, Linda Lakin then spoke of her experience and journey of living with a mesothelioma diagnosis and how it has affected her family life. She spoke of the treatments she has received so far, the support she has received and how she is forever hopeful with all the new trials and treatments that are now emerging. Her story was both moving, brave and full of positivity.

Brian Wallis, a mesothelioma widower who lost his wife Rosemary several years ago, kindly read the passage ‘Rejoice and give eternal thanks for you know that we live forever’.

Liz Darlison, Director of Services for Mesothelioma UK, gave an update about the vital work that the charity does and continues to do to make mesothelioma matter. The Deputy Lord Mayor, councillor Rashmikant Joshi, kindly said the closing words.

Reverend Mark Burleigh then closed the service and led everyone out into the cathedral grounds where Linda Lakin and Lady Jennifer Gretton released the doves in hope for a future without asbestos. A strawberry cream tea was then served inside the cathedral.
The Year Ahead

Mesothelioma UK’s 5 Year Strategy - *Dedicated to Making Mesothelioma Matter* clearly outlines the charity’s ambition to reach an annual income of £3 million to enable a significant increase in services, the appointment of up to 30 nurses covering all of the UK and a minimum of £1 million per annum for investment into mesothelioma research.

The forthcoming year, 2017/18 represents year two of the strategy.

**Priorities for this year**

1. To move Mesothelioma UK’s operational team to serviced offices outside of the NHS
2. Reregister Mesothelioma UK with the charity commission as Charity Incorporated Organisation
3. Re-launch [www.mesothelioma.uk.com](http://www.mesothelioma.uk.com) - the charity’s website
4. To increase income to £1,125,000
5. To allocate funds to five more NHS trusts to host a Mesothelioma UK CNS bringing the total to 18
6. To increase funds available for annual research grants to £225,000
7. To further develop the National Mesothelioma Audit
8. Repeat the 2012 Mesothelioma Experience Survey
9. To support the development of the UK Mesothelioma Alliance
10. To establish a comprehensive package of support and services for Armed Forces personnel and veterans

None of this would be achievable without the support of our amazing supporters, fundraisers, and our private and corporate donors. We are extremely grateful for all that you do to support the charity and want to assure you that we are totally *dedicated to making mesothelioma matter!*