



Terms of Reference

The UK Mesothelioma Alliance (UKMA) was established in 2017 to bring together mesothelioma stakeholders as one voice to raise awareness of mesothelioma through agreed projects.

Key Beliefs and Objectives:

The UKMA believe that:

- Equitable access to treatment and care wherever patients are in the UK is crucial to improve outcomes and
- Raising awareness of mesothelioma and the dangers of asbestos is vital to both increase early diagnosis and reduce exposure to asbestos.

Members and Meetings:

Membership of the UKMA is open to all non-commercial mesothelioma stakeholders including but not limited to mesothelioma patient/carer advocates and campaigners; mesothelioma charities; asbestos support groups; asbestos campaigners and trade unions. Other organisations may be co-opted onto the UKMA from time to time e.g. for the duration of an asbestos-related campaign. Anyone wishing to become of a member of the UKMA can send a formal request via the UKMA Chair, Dawn Mckinley – info@ukmesoalliance.org. Members will meet 4 times/year – 2 in person and 2 by teleconference.

Agreed Projects-First Actions:

1. Create a national service specification/optimal pathway for mesothelioma
2. Identify a co-ordinated approach to Action Mesothelioma Day and awareness of the dangers of asbestos.

Terms of Funding:

The UKMA has agreed that initial funding for agreed projects and first actions will be provided by charitable funds. These include donations from members of the UKMA and from external charitable trusts. On-going funding considerations will be discussed and agreed as required to ensure that the UKMA always remains impartial. Any funding received will be ring-fenced in a separate budget line held by Mesothelioma UK on behalf of the UKMA. Further information can be found at www.ukmesoalliance.org.

Contact Details for UK Mesothelioma Alliance:

Dawn Mckinley – Email info@ukmesoalliance.org - Phone 0116 2965230 – Website www.ukmesoalliance.org

Background: In the UK about 2,500 people a year are diagnosed with mesothelioma. It is also known as 'diffuse' or 'malignant' mesothelioma. Mesothelioma is a form of cancer that affects the Mesothelium.

The mesothelium is a thin membrane that lines the inner surface of:

1. The chest wall, where it is known as the pleura
2. The abdomen where it is known as the peritoneum
3. The testicles

The mesothelium also surrounds organs within these cavities for example the heart, lungs and intestines. It is far more common to have mesothelioma in the chest than in the abdomen. There is approximately 1 case of peritoneal mesothelioma to every 12 cases of pleural mesothelioma. Mesothelioma is more common in men than in women and nearly half of the people diagnosed with the disease are over 75 years old. (Source:

<http://www.mesothelioma.uk.com/information-and-support/about-mesothelioma/> August 2017)

Exposure to asbestos is responsible for up to 9 out of 10 mesothelioma cases. There are thought to be other rare causes of the disease but none are fully understood at this time. The disease has been described in medical literature since 1870 although the first suspicion linking asbestos and mesothelioma did not appear in the UK until 1935 and a definite link was not reported until 1960. (Source: <http://www.mesothelioma.uk.com/information-and-support/about-mesothelioma/causes/> August 2017)

UK Mesothelioma Alliance Members List:

- Action on Asbestos Industrial Injury & Disease (formerly Clydeside Action on Asbestos)
- Asbestos Awareness and Support Cymru (A.A.S.C)
- Asbestos Campaigner - Scotland
- Asbestos in Schools / Joint Union Asbestos Committee
- British Thoracic Oncology Group (BTOG)
- Erase Meso
- GMB
- HASAG
- International Ban Asbestos Secretariat
- June Hancock Mesothelioma Research Fund
- Mavis Nye Foundation
- Mesothelioma UK
- Lung Cancer Nursing UK
- TUC

Co-opted Organisation:

- Glynis Gale Foundation
- Institute of Occupational Safety and Health (IOSH)