LONDON ASBESTOS SUPPORT **AWARENESS GROUP LTD** FOR LONDON & THE SOUTH EAST





**Freephone Helpline** 0808 278 2515 www.lasag.org

### LASAG Advisors

### Marika Townsend marika.lasag@gmail.com

Educated to Masters level, I have worked with cancer patients most of my nursing career. I worked as a Clinical Nurse Specialist for the last 17 years in both palliative care and lung cancer. My knowledge and experience has enabled me to support patients and families medically, emotionally and practically throughout their cancer journey.

It seemed a natural progression after my retirement as a lung cancer CNS to work with LASAG where I am able to use much of my previous experience to support victims of asbestos related disease.

### **Yvonne Miah** yvonne.lasag@gmail.com

Having completed my initial nursing training in the early 1980s, I continued my education up to PG Diploma/MSc in Advanced Clinical Practice (cancer nursing) at the University of Surrey.

I completed 33 years in the health service, having worked at St Francis Hospice and in numerous hospitals. After retiring, I found it difficult to leave it all behind, so I felt well placed with my past knowledge and experience to undertake the role with LASAG as an advisor. I thoroughly enjoy establishing this role and have set up support groups in the locality, to be able to make some small improvement for those whose lives are affected by asbestos exposure.

### We are delighted to introduce Alison Blake, our latest advisor, who is due to join us in June 2017

### **Alison Blake** alison.lasag@gmail.com

I managed a very successful Asbestos Support Group in the East of Scotland, before moving South to Kent. I have many years experience supporting hundreds of sufferers both emotionally and practically and my empathetic and friendly personality helps put people at ease.









# **Our First Six Months**

October 2016 saw the launch of LASAG which is a new asbestos support group helping people in London and the South East who suffer from mesothelioma and other asbestos related diseases.

LASAG is a project of The London Hazards Centre (LHC), a registered charity. LHC has campaigned since 1984 on asbestos safety issues and hosts the annual Action Mesothelioma Day in London to raise awareness of asbestos related diseases.

Following discussions with other support groups around the country, the LHC, in conjunction with three specialist law firms, decided to set up LASAG to help meet gaps in provision across London and the South East. This was primarily to provide help and support to sufferers in their own homes, but also to assist in setting up support groups in localities where they were most needed.

# **Asbestos Support & Benefit Advisors**

LASAG currently employs two advisors, Marika Townsend and Yvonne Miah, who are former Lung Cancer Nurse Specialists. Between them they have over forty years' experience working with asbestos related disease sufferers and their families.

Since commencing their employment with the charity, Marika and Yvonne have undergone further training to help them deal with the administrative side of the role. They have also consulted other support groups and regularly attend educational conferences to keep their knowledge updated.

In November 2016 they both attended the National Lung Cancer Forum for Nurses in Birmingham and in January 2017 they attended BTOG in Dublin. Both events enabled them to share details of the LASAG service and to network with other professionals involved with the health, social and legal aspects of mesothelioma and asbestos related diseases.



They also attended the invaluable facilitator training course for those setting up support groups provided by Roy Castle Lung Foundation.

They have maintained links with Clinical Nurse Specialist colleagues who have been very supportive of the new charity. So far they have seen over 50 sufferers and provided practical advice and assistance with state benefits and compensation schemes.



As former Lung Cancer Nurse Specialists, Marika and Yvonne are very experienced in dealing with sufferers of mesothelioma and other asbestos related conditions, and understand the impact such diseases have on individuals and their families both physically and psychologically. The specialist knowledge they bring to the role enables them to signpost to other services as needed, and to help sufferers understand the often bewildering medical investigations to which they have been subjected, and which have led to their diagnosis.

They are available to provide ongoing support to individual sufferers. Psychological support is an important element of the service they provide. Support is also available for bereaved relatives. They maintain close liaison with other key professionals involved in the care and management of the sufferer.

### Support Groups



Yvonne and Marika hosted their very first mesothelioma support group on the borders of Essex and London.

It was held with a very generous contribution from Toby Carvery, who provided free premises and refreshments.

Also in attendance was Joanne Walker, CNS at Queen's Hospital, Romford. It was a resounding success. The feedback was extremely positive with people travelling from as far afield as Southend on Sea.

The support group will continue monthly on the last Thursday of each month between 11 am - 1 pm at Toby Carvery Moby Dick, Whalebone Lane, North Dagenham RM6 6QU. (Future meetings: 29<sup>th</sup> June, 27<sup>th</sup> July, 31<sup>st</sup> August, 28<sup>th</sup> September & 26<sup>th</sup> October 2017)

Yvonne was interviewed by Time 107.5 radio station, for whose support we are very grateful. As you can see, they made her feel very relaxed whilst she was talking into a microphone.



We are delighted to announce that our first monthly East Kent support group will take place on 11 July 2017 between 2 pm - 4pm at A.R.C.A. Hall (Ashford Road Community Association) 151 Ashford Road, Thanington Without, Canterbury CT1 3XR. (Future meetings: 15<sup>th</sup> August, 12<sup>th</sup> September & 10<sup>th</sup> October 2017)

The group is supported by Cancer Nurse Specialists, Toni Flemming and Beverley Brawn, who cover East Kent, and Mesothelioma Warrior, Mavis Nye.

Work has been ongoing to try and set up local support groups and/or link individuals with already established support groups.

Kent already has two very successful lung cancer and mesothelioma groups run by Denise Hodges, Lung Cancer Nurse Specialist at Medway Maritime Hospital, to which LASAG has been able to contribute, both financially and practically, and will continue to do so.

Maidstone and Tunbridge Wells NHS Trust has also recently started a new support group for lung cancer and mesothelioma sufferers. Marika attended their first meeting in Paddock Wood.

Individuals who live close to London are encouraged to attend the well-established support group at Guy's & St Thomas' Hospital, led by Rachel Thomas, Lung Cancer Nurse Specialist.

# **Patient Feedback**

"After being diagnosed with mesothelioma there was of course an initial shock as the reality of it sank in. There followed a great amount of concern and confusion as to 'where do I go from here?'. An advisor arrived and answered many questions and explained what I was entitled to. Without this I was totally unaware of any assistance and felt relieved that there were people available to discuss every aspect of my future. Many thanks to LASAG for taking the time to palliate an otherwise devastating illness." **Terry Elliott** 

"Marika, I have benefited greatly from your visits which have become an essential lifeline for me as a cancer sufferer. The charity is a very important part of the overall support required by patients affected by asbestos related diseases." **Andy Nicholson** 

"We would like to thank you and say how grateful we are for your support and coming to visit us so promptly following our phone call to your office. Also for your expertise and the efficient way you dealt with the filling out of the countless forms on the day you came to see us. We appreciate the fact that we will be able to contact you for any help and advice that we may need in the future. You are continuing to do wonderful work and it is so reassuring to know that there is someone who has genuine knowledge of our situation to turn to for expert help and advice. Many thanks." **Tony & Peggy Old** 

"I was given a booklet about LASAG when my diagnosis was confirmed of Mesothelioma so gave them a call and was contacted by Marika Townsend. We made an appointment and she came to see me at my house and I was really impressed with her knowledge that she had about cancer and what LASAG could do to help me. All my options were explained to me in clear layman's terms and Marika helped me fill in all the forms needed to put a claim in for compensation, she also called the DWP and made a claim on my behalf for PIP. Once this was done she gave me my options for contacting a solicitor so that I could pursue a civil compensation claim. I am very grateful to LASAG as you need support at a time like this and Marika has given support and advice ever since." **BM** 

"Yvonne came to see us. She was very helpful giving us all the advice on welfare benefits and other support numbers to help make things easier. She was in regular contact with visits and phone calls. Indeed all through Norman's treatment and end of life and his passing, the LASAG team have been brilliant. I still get phone calls asking me how I am." Valerie Humphrey



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11<sup>th</sup> May 2017

TO WHOM IT MAY CONCERN

RE: LONDON ASBESTOS SUPPORT AWARENESS GROUP FOR LONDON AND THE SOUTH (LASAG)

I have referred several mesothelioma patients to the above group for help and advice with claiming compensation and benefits relating to their disease.

The advisors are retired Lung Cancer Clinical Nurse Specialists and due to this their professional knowledge and experience of mesothelioma is extensive.

I have had nothing but positive feedback from my patients who have been helped by LASAG. From my perspective I feel that because the service is run by professionals who I know and trust, I can refer patients to them confident in the knowledge that they will be given the best advice and support.

Denise Hodges Macmillan Lung Clinical Nurse Specialist

# Fundraising

LASAG is dependent on charitable funds and to this end, in January, the cornflower, which is a symbol of hope, was launched as the charity's emblem.

Please help us to raise funds for LASAG by purchasing cornflower seed packets which are available at a cost of £1 each.

Please phone the freephone helpline on 0808 278 2515 to purchase the seed packets.

Additional donations have kindly been forthcoming from sufferers and their families.

Should you wish to make a donation, please make cheques payable to 'LASAG Ltd' or refer to our website: www.lasag.org

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# Thank You

This newsletter would not be complete without thanking the people who have kindly given their very generous support to our new venture, including:

- British Lung Foundation
- Roy Castle Lung Foundation
- West Midlands Asbestos Support Group
- All of the Lung Cancer Nurse Specialists across London & the South East
- Toby Carvery, Moby Dick
- Time 107.5 Radio

# **In Conclusion**

We are continuing to develop and learn with the generous help of others.



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# LASAG LTD NEWSLETTER

