



ISSUE 27, SUMMER 2018

# NLCFN Newsletter

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## MESSAGE FROM THE CHAIR



Welcome to the summer edition NLCFN newsletter. I hope you have all had a chance to enjoy the extraordinary sunshine we have been experiencing.

In its 19th year NLCFN is recognised as an influential voice in lung cancer and mesothelioma both nationally and internationally. This is due to your enthusiasm and passion in shaping and improving lung cancer and mesothelioma care.

NLCFN activities this year have seen a fantastic representation of NLCFN members at the annual workshop, of which a report will be presented later this year at the NLCFN conference. More recently, members participated in the Promoting Research in Oncology Nursing (PRON) workshop led by Professor Angela Tod; it too has been highly rated.

Your committee have been working diligently through their representation on national strategic groups and in creating a brilliant programme for the NLCFN Conference (1st & 2nd November). The conference is made possible by the excellent contributions from our invited speakers and support received from our sponsors.

As we celebrate 70 years of the NHS I invite you to take advantage of the early bird registration rates to attend the conference; the only event that is by and for UK LCNS'. This is your opportunity to broaden your knowledge and meet with your peers and our partner organisations.

This year's conference will see the launch of the e-learning modules for biomarkers and immunotherapy. Partnering with PCM Scientific we have developed this accredited programme to support your learning. The modules feature a range of interactive digital media and provide support with professional learning from the comfort of your own home at a time to suit you. Clinical skills, understanding and communication have been incorporated into each module.

The NLCFN is a dynamic, energetic community putting the needs of patients and LCNS' at the forefront of what we do. The benefits of membership are extensive, so please do take advantage of all there is on offer.

I look forward to seeing you in November.  
Vanessa Beattie, Chair NLCFN

## The National Lung Cancer Forum for Nurses



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## Lung Cancer: Building Hope in Challenging Times

1-2 November 2018  
The International Centre, Telford



## Just days left to secure 45% discount for conference registration...

Don't miss out on getting the early bird rate for our national conference. Rates change on 1<sup>st</sup> Sept 2018 so book now to secure your exclusive conference member discount. See <https://www.nlcfn.org.uk/annual-conference/rates> for details on conference rates.

This year's conference aims to inspire you to review the challenges and threats we are working under and explore new ways of working with patients and colleagues in this changing landscape.

The conference will explore the latest in lung cancer diagnosis and treatment, provide the latest updates on mesothelioma, review thymoma and neuro-endocrine tumours and their management, and, discuss the optimal lung cancer pathway.

We will also bring you the latest in lung cancer research and development and feature a debate on the issue of survivorship and the use of DS1500 forms. In the highly pressurised environment in which we work, it is also important to focus on our own health and well being as well as that of our colleagues and we will also be taking time to reflect on this and provide you with some advice and support to harness well-being and our own personal development.

Visit <https://www.nlcfn.org.uk/annual-conference/programme> for programme details.

### The venue

Telford international Centre (TIC) is a purpose built conference centre located in the heart of the Midlands with a contemporary, comfortable interior. The venue is located on the edge of Telford town centre, a purpose built town with a modern shopping complex, and recently added £250m convention quarter comprising of a leisure and entertainment complex. It includes a range of different hotels to suit all budgets all within a three minute walk of the venue.

TIC is just minutes from the M54 motorway and close the M6 motorway network. With over 1600 car parking spaces, direct trains from London and trains via Wolverhampton for the rest of the rail network, Telford is relatively easy to access.

For more information on the venue please visit the website at

<https://www.nlcfn.org.uk/venue-information>

### Blow your trumpet...submit an abstract



The conference provides an excellent opportunity for you to share best practice and experiences with your colleagues and peers in a friendly supportive environment.

It's easy to submit an abstract on a project you have been working on. We'll support you and provide help with poster production. There is an easy online submission process for you to submit you're abstract – see <https://www.nlcfn.org.uk/annual-conference/submitabstract> for details.

Abstracts must be submitted by 14<sup>th</sup> September 2018.

### Bursary Places

Once again the NLCFN are delighted to offer up to 10 travel bursaries to support travel and accommodation expenses up to the value of £100. This offer is available on a first come, first served basis. For details please see <https://www.nlcfn.org.uk/annual-conference/bursary>.

### Accommodation

There is a range of hotels to suit all budgets with four main hotels (The International, Holiday Inn, Premier Inn and Travelodge) being located within a three-five minutes walk from Telford International Centre – see <https://www.nlcfn.org.uk/annual-conference/accommodation> for details on how to book your accommodation.

# NEW – Launching at conference this year... Oncology Nursing in Practice – digital learning platform

In an exciting partnership with PCM Scientific the NLCFN is delighted to be able to announce the forthcoming launch of the Oncology Nursing in Practice digital learning platform.

This exciting development will bring you free online learning tools and resources for NLCFN members.

The new website resource will launch on 1st November 2018 and will feature interactive eLearning modules populated with learning stimuli such as videos, animation and quizzes. The materials incorporate course reading, links to guidelines and downloads plus assessment questions.

There is an emphasis on clinical applications of subject matter and guidance is provided on handling patient questions to assist with ongoing patient support programmes.

The materials have been produced in association with a dedicated NLCFN faculty and the programme is endorsed by the NLCFN. Accreditation is in process through the Royal College of Nursing (RCN).



Initial learning modules will include:-

- Biomarkers and their emerging role in lung cancer
- immunotherapy in lung cancer

Each module is provided at two learning levels - foundation and advanced level modules.

Modules have been created as a 1 hour learning experiences

- 30 minute interactive module
- 30 minute pre-reading and review materials

Visit our special exhibition stand at conference to find out more..

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## ITONF workshop and call for posters

You can now view the [presentations](#) made during the International Thoracic Oncology Nursing Forum's Workshop:

Excellence in Thoracic Oncology Care in Yokahama, Japan in October 2017.

Details are also now available on this year's programme which includes sessions on managing hopes and expectations, updates on immunotherapy and standard treatments treatments for lung cancer and mesothelioma, a discussion panel on global access to care and a session on technology and social media in healthcare.

For the first time this year, at the conclusion of the ITONF Workshop, a 2017-18 Year in Review: Scientific Poster Session will be hosted. Attendees will have the opportunity to display their previously presented posters from scientific meetings over the past two years (2017-2018) and four nurses will be selected in advance to present their work to the attendees in a brief presentation format.

For details please see <https://www.nlcf.org.uk/itonf-workshop-and-call-posters>

## NEWS, FEEDBACK AND PUBLICATIONS


**Turning the science of molecular diagnostics in lung cancer into a practical service - 26 June 2018**UNITED KINGDOM  
LUNG CANCER COALITION

The United Kingdom Lung Cancer Coalition (UKLCC) held a Clinical Advisory Group Meeting on 26/06/2018 in London to focus on turning the science of molecular diagnostics in lung cancer into a practical service.

Invited speakers clarified current clinical services throughout England, Wales and Northern Ireland with a view as to how emerging molecular diagnostic technology can be delivered in an optimal fashion, minimising inequalities in service provision.

A short independent report will be produced in order to define:

- the blocks to universal access to molecular pathology and pointers to what would need to be done to correct the situation
- the opportunities for collection, interpretation and application of data on molecular diagnostics to support optimal service delivery

In order to find out more about access to molecular diagnostics in your area, please complete the online NLCFN *Equity of Access Survey* (see box )

Lavinia Magee  
NLCFN committee member / UKLCC representative

**NLCFN MEMBER SURVEY  
Access to biomarker testing  
and novel treatments.**

**If you have not yet participated please help us by completing our survey as soon as possible.**

Says Vanessa Beattie, chair of the NLCFN. *"This is an important survey and will hopefully provide useful results which we can use to share with our partner organisations and campaign for equity of access to biomarker testing and treatment for lung cancer".*

**Please ensure you participate. The survey only takes a few minutes and can be accessed at**  
<https://www.nlcfn.org.uk/equity-access-survey>

**Global Lung Cancer Coalition**

In 2017, the Global Lung Cancer Coalition (GLCC) commissioned a new multi-national study to understand attitudes towards lung cancer and levels of symptom awareness among the public.

Data was provided by a poll undertaken in 25 countries. Details of the report are available at <http://www.lungcancercoalition.org/global-polling.html>

You can also download the [Spring/Summer newsletter of the GLCC](#)

**Care provided by specialist cancer nurses helps improve life expectancy of patients with lung cancer, says new study**

A [new study](#) presented at the Public Health England (PHE) Cancer Services Data And Outcomes Conference 2018 by Asst Professor Iain Stewart found that patients with lung cancer experience significantly better outcomes in terms of life expectancy, avoiding unnecessary hospital admissions and managing the effects of treatment when cared for by specialist lung cancer nurses.

The study can be downloaded at <https://www.sciencedirect.com/science/article/pii/S0169500218304823>



## Cancer Experience : approaches to capturing patient experience of cancer care conference – 2 June 2018

This was the first national conference to explore the patient experience of cancer care which was provided by Sheffield Hallam University, The University of Sheffield, Sheffield Teaching Hospitals and Sheffield Innovation and Research in Oncology Nursing.

Insight into several tumour sites and the patient experience was presented and there was a play about living with breast cancer hosted the evening before the event. The plenary session was presented by Dr Karen Roberts, Chief Nurse and AHP for Macmillan Cancer Support, providing an insight into 'understanding the different times of need after a cancer diagnosis-aspiring for excellence in care delivery.' This set the scene for a varied and excellent programme.

I had the opportunity of presenting my research project, 'What do people living with and surviving lung cancer need from the Recovery Package'. The RADIO Meso research, 'Receiving A Diagnosis Of MESOthelioma' was also presented.

### Do you have examples of policies and pathways for nurse-led clinics?

More and more colleagues are asking for support with setting up nurse-led clinics. If you have an example of a policy, business case, pathway for a nurse led clinic that you are willing to share via the NLCN website (will full credit to the authors) please submit your work to [info@nlcfn.net](mailto:info@nlcfn.net) and we will share on the website

### Funding for nurse education

Clydeside Action on Asbestos (CAA) is making funding available for nurse education. Applications for funding up to £500 at a time for educational opportunities related to mesothelioma can be made. Information can be found on the CAA website at <https://www.clydesideactiononasbestos.org.uk/>

Lucy Heycock, NHS Highlands

The day included many presentations and posters which all had relevance for improving the patient and carer experience including;

- the experiences of melanoma patients and their carers
- going home after treatment for malignant spinal cord compression
- long term follow up and lymphoma
- using film to develop a peer support intervention
- using innovations in digital health to optimise symptom management in patients with cancer
- support with empathy in an online health forum for breast cancer
- Women's experiences of high dose chemotherapy and stem cell transplant
- exploring the feasibility of conducting a randomised controlled trial of pre-habilitation
- information needs and treatment decision making experiences of people with dementia

The Online Health Forum, exploring how people with life shortening or life threatening illnesses use online forums to gain support inspired me to explore this further for patients and carers with lung cancer and is something I feel the NLCFN should explore further.

Hopefully the day will be repeated next year and it provided an excellent opportunity to network with nurses, AHPs', academics and students.

*Josie Roberts*  
Macmillan Lung Nurse Specialist

### In short... Articles to reflect on

Andreano A, Peake MD, Janes S, et al. 'The Care and Outcomes of Older Persons with Lung Cancer in England and US, 2008-2012.' *J Thorac Oncol* 2018;13(7):904-914.

<https://www.ncbi.nlm.nih.gov/pubmed/29727739> . This paper compares USA and England early diagnosis of NSCLC in older people

Hiom SC, Kumar HS, Swanton C, Baldwin DR and Peake MD. 'Lung cancer in the UK – addressing geographical inequality and late diagnosis.' *Lancet Oncology* 2018

[https://www.thelancet.com/journals/lanonc/article/PIIS1470-2045\(18\)30496-0/fulltext](https://www.thelancet.com/journals/lanonc/article/PIIS1470-2045(18)30496-0/fulltext)

## The National Lung Cancer Audit - Update

As the NLCFN committee member of the National Lung Cancer Audit I attended the Board meeting on 28/6/18

The National Lung Cancer Audit (NLCA) has now launched the National Mesothelioma Audit (21st June 2018). This document now includes the Welsh data and also the Peritoneal Mesothelioma data and is the from the last 3 years. This audit was funded by Meso UK and has been well received as factual evidence of Mesothelioma statistics and treatments.

The NLCA annual report of 2017 shows an increase in surgery to 17.5% from 16.7% in 2016. The Lung Cancer Clinical Outcomes Publication on surgery is extremely encouraging. This has shown a 98% - 30 day survival rate a 96% - 90 day survival rate and a 88% 1 year survival rate. This audit was from the 2015 data which included 123 Thoracic surgeons performing 5936 operations. The next surgical audit will include the 90 day readmission rate, cause of death data, and possibly some patient experiences.

The data on small cell surgery will not be included.

The NLCA has also undertaken a spotlight audit focusing on patients who did not receive surgery despite have early stage disease (stage 1-2) and also a good Performance Status (0-1). 58% of Trusts took part in this. The results show that 31% of those patients included chose NOT to have surgery. 2% of patients obtained a second opinion on surgery with 46% received curative Radiotherapy instead.

For the next audit there will be new measures. These will include :

- Pathological confirmation rate in all PS 0-2 patients
- Percent of active treatment received in PS 0
- Percent of patients who present as an emergency admission
- smoking status

The new spotlight audit for 2018 will be on Molecular Testing - which will look at the variability on which Trusts undertake this for their patients.

Finally you can follow [NLCA on Twitter](#) for updates as they occur

Jeanette Draffan  
Stockton on Tees

## Advanced Care Planning in Wales

Advanced Care Planning (ACP) is being promoted across Wales. So what is it and why is it being introduced? It is actually a very simple concept. The rationale behind ACP is; to discuss and record the patients views, it will help to make sure their wishes and preferences and their voice is continued to be heard if at some point in the future they are unable to speak for themselves.

It is a **voluntary** process of discussion and review to help an individual who has **capacity** to anticipate how their condition may affect them in the future and, **if they wish**, set on record **choices** about their care and treatment and /or advance decisions to refuse treatment in specific circumstances, so that these can be referred to by those responsible for their care or treatment in the event that they **lose capacity** to decide once their illness progresses.

Capacity, care planning and advance care planning in life limiting illness: a guide for health and social care (2010 )

### The strategic drivers of ACP

- It is an integral part of the Welsh Government's vision of achieving excellence for end of life care where people in Wales should have a healthy realistic approach to dying and should be appropriately planning for the event
- People who can be identified as approaching the end of their life should be given the opportunity to express their priorities and preferences
- 'Together for Health' End of Life Delivery Plan (2013) (2017)
- There are frameworks available to guide ACP

...continued

### *Advanced Care Planning in Wales continued*

**Wales IPADS.** This is one framework for Advanced Care Planning

Identify appropriate patients for ACP.

Prepare the ground.

Ask if the patient wishes to discuss ACP

Document the patient's wishes

Share with other people

I will provide further updates in the next newsletter; including changes Emma & I have made to incorporate ACP in our clinical practice. Further information [wales.pallcare.info](http://wales.pallcare.info) › Clinical

I'm delighted to confirm The All Wales Lung Cancer Forum (AWLCF) is holding its annual conference on Friday 5<sup>th</sup> October 2018 in the IBIS hotel Swansea. Registration is free (delegates will be charged £30 if they fail to attend). Please email [Sam](mailto:Sam) if you wish to book a place.

'The Rehabilitation and Optimisation Programme (POP)', I discussed in a previous newsletter has now ended. Despite positive evaluation from patients; disappointingly there is currently no funding available to continue the project.

Emma and I will soon be taking on the role of managing patients when they attend hospital to undergo CT guided biopsy. I will provide more information in the next newsletter.

Carol Davies

Macmillan Lung Cancer Specialist Nurse Nevill Hall Hospital South Wales

## Older People ERG

This group was established after the release of the Cancer Strategy - 'Achieving World-Class Cancer Outcomes: Taking the strategy forward' in May 2016. The meeting was attended by a good representation of multidisciplinary roles, including three patients.

The focus of the group is based upon sections 41 and 42 of the Cancer Strategy and the rising number of elderly cancer sufferers and equity of access to treatments, Dr Danielle Harari (Guys and Thomas's) has begun a pilot scheme of a new Toolkit (CRANE). This is a questionnaire like the HNA but is completed by patients over the age of 65, and specifically focuses on the needs and concerns of the elderly patient, including frailty and reduced cognitive function. It is currently in a paper format, but the aim is to have an electronic version for ease of sharing information throughout the MDT.

There was a good discussion around the table regarding access to a comprehensive geriatric assessment for elderly patients in the cancer setting. Many group members thought that this would be

highly beneficial in guiding the multidisciplinary teams in the level of treatment that could be offered but identified that due to a national shortage of Geriatricians and slender resources in both hospital and community settings, it was difficult to access this in a timely manner within the cancer 62 day pathway.

Pre-hab was also discussed as being highly beneficial in improving and maintaining performance status before and during treatment. Early introduction demonstrates the best results in getting patients successfully to and through treatment.

Rose Gray, Policy Manager at CRUK presented a new report: Advancing care, Advancing years: Treatment and caring for an ageing population (June 2018). The report highlights that treatment decision making doesn't always take in the relevant factors for the individual patient or are indeed being made by the relevant professionals.

Julia McAdam, Shrewsbury  
Sandra Wakelin, Maidstone



## Feedback on ASCO 2018

### **ASCO 2018 – Delivering discoveries, expanding the reach of precision medicine.**

I was delighted to attend ASCO in June, of which was the 54<sup>th</sup> annual meeting. I have been fortunate to attend and participate in various oncology conferences over the years but this was my first time attending ASCO and by far the largest. The conference centre (McCormick Place) is vast and needs to be to manage the 38,000 + delegates.

Specific tumour sites are represented and hold a place within the programme, of which contained educational; poster; oral sessions; Highlights of the day and plenary sessions along with (for the first time) workshops.

Delegates were able to 'interact' via smartphone devices and were encouraged to do. This was especially relevant to the workshops and operated well. I enjoyed the conference and met some lovely people along the way. Following are a few of my personal highlights to share with you:

#### **Talking with patients about risk and uncertainty.**

Co-chaired by Lesley Fallowfield and Valerie Jenkins. This workshop concentrated on specific strategies for explaining risk and uncertainty to patients. It helped delegates identify their own tolerances to risk and uncertainty and how these could influence the way we convey information to patients. The workshop was aided by viewing simulated consultations. As Professor Fallowfield articulated 'We need to help patients understand the data that demonstrates side effects, recurrence risk efficacy and impact of recurrence in terms of survival'.

**Developing a survivorship clinic** – Another first for ASCO. This was another practical session. As the co-chair Kevin Oeffinger said 'people are recognising that survivorship is much more than simply checking to make sure the cancer did not return'. The workshop aims were to provide participants with

practical solutions including what assessments could be used, the myriad types of challenges faced when starting a survivorship clinic/service, how to overcome them and how to measure the success of the clinic/service.

Throughout the programme there was focus on patient education as an essential element of quality cancer care. Highlighting that providing information conveys respect, assists patient and families/ carers to identify their own questions and concerns and acknowledges the importance of making decisions that are concordant with personal goals.

In one of the abstract sessions patient reported outcomes (PROs) were topical. It was discussed that the value of PROs could have drawbacks depending on methods used to assess the PROs. Abstract 6500 – Using a web based monitoring system to follow patients with lung cancer resulted in an overall survival that was significantly higher than that with routine follow up by CT scans alone. It was reported that a majority of lung cancer relapses are symptomatic somewhere between 75-90% and patients may have symptoms weeks before they are seen in clinic. An algorithm that reports twelve symptoms every week is utilised with notification of results being sent to nurses and oncologists. In a non randomised study survival of 98 patients after treatment for stage III/IV lung cancer was assessed with first results suggesting a 1 year survival 27% greater than for patients with standard follow up. Other studies have followed with plans for a larger study (> 1000) multicentre information studies in other cancers.

This is a whistle stop view of my experience !

Vanessa Beattie  
Chair, NLCFN

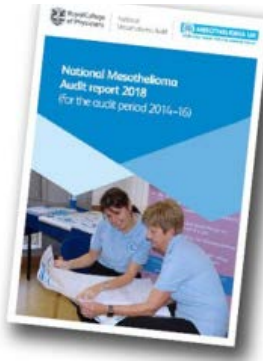


## MESOTHELIOMA NEWS



### Mesothelioma National Audit Report

The National Mesothelioma Audit report 2018 was published in June. This is the third audit of this type. It was funded by Mesothelioma UK and carried out independently by the Royal College of Physicians. Data is collated, maintained and quality assured by the National Cancer Registration and Analysis Service which is part of Public Health England (PHE).



The audit provides a national picture for England and Wales with the number of 7192 diagnosed. For the first time it included peritoneal mesothelioma data with 260 patients recorded in England which accounts for 4% of all mesothelioma. Two in 5 patients with peritoneal mesothelioma were still alive after one year.

Dr Susan Harden, National Mesothelioma Clinical Audit Lead commented on the report saying *“It is pleasing to see that more patients are receiving chemotherapy, however the report clearly identifies areas for improvement for mesothelioma patients. It is important that more patients are seen by cancer nurses and that MDTs manage a greater number of cases of mesothelioma. I welcome the report and hope that the recommendations are taken forward to reduce the variation in care that patients receive.”*

51% of patients with pleural mesothelioma received some form of anti-cancer treatment, more than ever before and 40% of patients had chemotherapy which was also an increase on previous audits. However, a network variation remains.

While an encouraging 81% of patients were discussed at multi-disciplinary team meetings, this is still short of the recommendation of 95% and it is vitally important that patients are assessed by specialist multi-disciplinary teams.

In pleural mesothelioma, pathological confirmation of diagnosis was achieved in 88%, only just short of the 90% target. However, only 54% had a sub-type recorded. Sub-types have different prognoses and treatment responses and sub-typing is often a criterion for clinical trial entry. The British Thoracic Society Mesothelioma Guideline published earlier this year recommended that pathologists report sub-types. The audit report states that networks should review their procedures if more than 10% are unspecified. Again, there is a wide variation in practice by network.

Access to a cancer nurse specialist also remains very variable across England. All patients should be seen by a cancer nurse specialist. This is the case for 93% of patients in Wales and it is important that the recommendation of 90% is also met in England. 54% were recorded in England with a variation from 28% to 62% by English networks. At least 80% of patients should have a clinical nurse specialist present at the time of diagnosis. A further part of this recommendation is that patients should be signposted to Mesothelioma UK resources including the Mesothelioma UK Helpline if there is not a locally available mesothelioma CNS.

Professor Mick Peake, Chair of the Board of Trustees, Mesothelioma UK said: *“This report shows that there is evidence of some improvements since the first report in 2008. However, wide variations remain between cancer alliances and it is clear that many lung cancer MDTs are managing a very small number of cases each year.*

*I hope that those responsible for providing and commissioning the services for patients suffering with mesothelioma will look at this report and seriously consider what implications it has for their own responsibilities for providing high quality care for all.”*

Lorraine Creech  
Mesothelioma UK CNS Team Leader

## Action Mesothelioma Day

6<sup>th</sup> July saw many healthcare professionals, charitable organisations and legal colleagues come together with patients to raise awareness of Mesothelioma and remember those patients who have died due to this disease. Action Mesothelioma Day is the first Friday in July each year and the number of events being held across the country have increased each year.

In 2015, 2,697 patients were newly diagnosed with mesothelioma and in 2016 2,496 patients died due to mesothelioma (Cancer Research UK). Far from seeing a decrease in the number of patients being diagnosed with mesothelioma we are in fact seeing an annual increase in patients being diagnosed. We are also seeing more teachers, health professionals, retail assistants and clerical staff being diagnosed with mesothelioma indicating that this continuing upwards trend of mesothelioma diagnoses has not reached a plateau yet.

Treatment options continue to be limited with platinum doublet chemotherapy remaining the standard of care for first line treatment. Whilst there has been much media and social media interest in immunotherapy as a treatment for mesothelioma the jury is out whilst we wait for the results of clinical trials such as Confirm which is looking at Nivolumab vs placebo in the 3<sup>rd</sup> line setting and Promise a 2<sup>nd</sup> line trial looking at Pembrolizumab vs oral Vinorelbine. We also await the outcome of a Phase II Clinical Trial looking at Nivolumab vs Cisplatin/Pemetrexed which closed to recruitment early this year. In my clinical practice I have seen very mixed results with immunotherapy in mesothelioma with a number of patients experiencing stable disease, however, I have also had a number of patients who have had no benefit from immunotherapy and their mesothelioma continues to progress.

So on the 6<sup>th</sup> July we gathered at Guy's Chapel in the grounds of Guy's Hospital to remember those patients who had died over the last year and to give thanks for those patients still living with mesothelioma. The order of the service was

designed with the help of the patients who attend the Guy's and St Thomas' (GSTT) Mesothelioma Support Group and saw readings from the wife of one of the patients who attends support group and Sophia Holden (Lung Cancer CNS) and Harry Steinberg QC. The Guy's Chaplain read out the names of those patients who had died and a minutes silence was held to remember them. After the service there was a joint LASAG/GSTT Support Group Mesothelioma Awareness event with a number of speakers presenting on mesothelioma. The key note speaker was Linda Reinstien Chair of the Asbestos Disease Awareness Organisation (ADAO) gave a insightful and emotive talk on her own personal experience of losing her husband due to mesothelioma and the work her organisation is doing to raise awareness of the dangers of asbestos in the USA. Very challenging as President Donald Trump does not believe that asbestos is dangerous. Professor James Spicer (Medical Oncologist at Guy's) gave a very informative presentation on clinical trials in mesothelioma. There were also presentations from LASAG on their work over the last year and an emotional insight into the journey of a mesothelioma patient from a member of the GSTT Mesothelioma Support Group.

Across the UK there were many other similar events many led by local clinical nurse specialists. All these events were very well attended and brought to the forefront the importance of continuing to raise awareness of mesothelioma and the dangers of asbestos exposure.

Mesothelioma UK is the only National Charity dedicated to the support and care of patients and their families with mesothelioma currently funding a total of 18 Mesothelioma CNS posts across the country to ensure that as many patients as possible have access to a specialist nurse.

A real highlight this year was the feature of a beautiful garden at the RHS Hampton Court Flower Show. The garden designed by David Donnay and Carol Klien was part of the Everest sponsored charity gardens which saw three charities have a garden designed for them. The public then had to vote for their favourite garden and Mesothelioma UK won the most votes meaning Everest Windows donated £4000 to Mesothelioma UK. What a wonderful way to celebrate the service offered by Mesothelioma UK to patients and carers and a great opportunity to raise awareness of this cancer.

## Action Mesothelioma Day continued

My role as a Mesothelioma CNS has been so rewarding, I have had the opportunity to project manage the Mesothelioma Awareness Event, present to a Barristers Chambers on my role and the experience of mesothelioma patients. I have also been able to support patients from the point of diagnosis which has meant that patients have information about potential treatment options from an early stage in their journey. This provides patients with hope and improved patient experience.

At NLCFN Conference 2018 in Telford there is a designated part of the programme to mesothelioma which will be an interesting update as World Lung will have taken place in September and there may be some early indications of outcomes from clinical trials in mesothelioma.

Rachel Thomas, London

## INFORMATION FOR PATIENTS

### **New information leaflets now available from Roy Castle Lung Cancer Foundation**



It can be difficult for patients and their loved ones to retain information after an initial diagnosis of lung cancer, so to meet this need, [Roy Castle Lung Cancer Foundation](#) works with healthcare professionals to produce a range of peer-reviewed information materials.

The charity has recently updated its information leaflet on 'Immunotherapy and lung cancer treatment' to explain clearly what immuno-oncology is and what options it offers to patients. It outlines how the three currently-licensed drugs available to UK patients work to 'switch on' the immune system, and how these drugs can reduce symptoms, prolong life and improve quality of life.

The second leaflet, 'Understanding bone metastasis and lung cancer', updates previously-available information. It explains how metastatic tumours are formed, how they affect patients, and which areas of the body may be affected. There are sections on how healthcare professionals assess metastasis, treatment options and pain management.

These, and other information leaflets, are available free from the Foundation. Copies of each will be among the materials available at Roy Castle Information Day events held throughout the UK over the course of the year – full details via the Foundation website.

Both new leaflets also include details of the charity's nurse-led Freephone helpline, on 0800 358 7200.



## RESEARCH NEWS

### The Research Interest Group

The National Lung Cancer Forum for Nurses (NLCFN) is keen to develop research and evaluation activity to help improve care and services within lung cancer. With this goal in mind the NLCFN established a Research Interest Group (RIG) in 2010. This RIG aims to facilitate collaboration and dialogue between clinical and academic colleagues and bring together experienced researchers and nurse specialists with a declared interest in lung cancer and research.

#### New members welcome!!!!

Any Forum member is welcome to attend or be on the circulation list for the RIG. It doesn't matter whether people are research active or not. We will welcome input and ideas from any Forum member. If you would like to join the RIG or would like more information please contact .....  
Tricia/red hot irons contact

2017 has been a great year for new research activity. We have also been able to support the funding of some new projects by NLCFN members. See details below.

### Promoting Research in Oncology Nursing (PRON)

The Promoting Research in Oncology Nursing (PRONS) Meeting was held in Crewe on 29/30<sup>th</sup> June.

The research training evaluated very well and was an enjoyable experience. We will share evaluation results in the next newsletter.

#### Angela Tod

*Chair of the NLCFN Research Interest Group. Professor of Older People and Care, School of Nursing and Midwifery, University of Sheffield.*

### NLCFN Small Grants

The 2018 Small Grants scheme was launched on 1<sup>st</sup> June with the opportunity for successful projects to be awarded up to £5,000 in support of their work.

For more information please go to <https://www.nlcf.org.uk/smallgrants>. The closing date for applications is 14<sup>th</sup> September, 5pm.

### Mesothelioma UK Research Grant

The 2018 Mesothelioma UK Nursing Research Grant have been awarded. Two applications were successful in obtaining funding. The recipients are:

- Catherine Henshall, Oxford Brookes University will conduct a study on "Mesothelioma patients' experiences of follow-up care across three NHS trusts".
- Karen Lord, Leicester University Hospitals NHS Trust/Mesothelioma UK. Will conduct research on 'Living well' with mesothelioma: Improving the patient experience. A qualitative study".

Amy Kerr was funded in 2017. Amy is from Heart of England NHS Trust in Birmingham. She will be presenting some findings of her work at IASLC in Toronto in September. Amy's study is to run a prospective single blinded study of patients undergoing diagnostic surgery for suspected mesothelioma. The study will assess the accuracy of Structured Light Plethysmography to differentiate mesothelioma from benign pleural disease.

### Joint RIG / Thoracic Sub-group meeting

On 13<sup>th</sup> June 2018 the RIG and Thoracic Sub-group of NLCFN had their second joint meeting. The focus was on follow-up care after lung cancer surgery. The discussions were very valuable in identifying research priorities for the future and key concerns for practice.

### Research database

The NLCFN RIG has set up a database of research projects that NLCFN members are actively involved in. This will detail research projects and outputs. Do let us know of any research projects that should be added to the database.

Please contact Tricia via [info@nlcf.net](mailto:info@nlcf.net).

## MEMBER NEWS

### Opportunity to get your work recognised and bag £1,500! NLCFN Annual Award

The NLCFN invites applications for the 2018 Annual Award. This is a fantastic opportunity for current NLCFN members to showcase a project or initiative they have been involved with. The project should relate to the care of patients with lung cancer/mesothelioma and/or their carers **and** to the role of the lung cancer nurse specialist.



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Open to all current members of the NLCFN the NLCFN Annual Award is £1,500 and exists to recognize and celebrate the achievements of NLCFN members.

Members are invited to submit a proposal outlining a project or initiative devised by individuals or as a team, describing how this has affected patient care and outcomes.

#### Application criteria

The project must be related to the care of patients with lung cancer/mesothelioma and/or their carers and an aspect of service delivery related to the role of the lung cancer nurse specialist.

The project or initiative must fit into any the following criteria

- Completed project within the last 12 months
- Current project
- Proposal or development of a project

See the website for [terms and conditions](#)

All applications must be received **by 28th September 2018**. [Apply online NOW](#).

## Queens Nursing Institute Award



At a ceremony attended by over 300 community nurses on 25 June 2018 we are delighted to inform you that Karen Clayton, NLCFN committee member was awarded the Queen Elizabeth the Queen Mother Award for Outstanding Service.

The event was hosted by actor Stephen McGann of BBC's *The Midwife*. He spoke passionately about the work of community nurses and his own experience of the care they brought to members of his own family

QNI chief executive Crystal Oldman paid tribute to the collective knowledge, experience and passion of the recipients as a testament to the quality of nursing taking place.

Congratulations to Karen from everyone at NLCFN.



## Call for Trustees

The National Lung Cancer Forum for Nurses board of trustees invite applications for new trustees to sit on its board to help the charity sustain and grow and provide effective corporate governance.

The Board of trustees has ultimate responsibility for directing the affairs of the charity, and ensuring that it is solvent, well-run, and delivering the charitable outcomes for which it has been set up. Day to day management of the charity's affairs is in the hands of an Operational NLCFN Committee. Board membership is voluntary and unpaid though standard class travelling expenses incurred as a result of NLCFN business are reimbursed.

Following a recent trustee skills audit the trustees have identified skill gaps and are thus particularly keen to receive applications from those with expertise in charity finance/accountancy and/or charity law and governance and/or business development/fundraising.

Applicants are advised to review the [role of the charity trustee](#) before applying. Applicants are requested to complete the online [application form](#). All applicants will be reviewed by the trustees and a shortlist of applicants may be invited for interview. The shortlist of applicants will be submitted for approval by the operational committee. All appointments are subject to ratification by the membership.

## Annual General Meeting

The next annual general meeting of the NLCFN will take place on 2 November 2018 from 09:00 – 09:30 at Telford International Centre.

As a member this is your opportunity to ensure your views and opinions are taken into account and allows you the chance to share your views and help shape the future of the organisation. If you can't attend the meeting please make sure you use your vote.

Full details of the agenda and resolutions will be sent out during early October 2018.



## Social media

Are you following NLCFN on Twitter? You can follow us at [@nlcfn](#). We post regular messages and help keep you up to date with current news and information.

Our Twitter feed includes a range of organisations and individuals whom we follow to help you to keep up to date with current topical news and events related to nursing, lung cancer and mesothelioma care.

Help us achieve our goal to double our followers by the end of the year

## Want to make contact with other members?

Do you want to make contact with other members or find other lung cancer nurse specialists in a specific area. As a member, all you have to do is [login](#) to the website and then go to our [members directory](#) and you can search for and contact other members directly.

Make sure that your contact details are up to date by checking your profile when you login.

## EVENTS

### IASLC World Conference on Lung Cancer

**Toronto, 23-26<sup>th</sup> September 2018**

This year the International Association of the Study of Lung Cancer will take place in Toronto. We anticipate that there will be a big presence from the NLCFN. Recent research grant holders will be submitting abstracts, as will many other NLCFN members.

### Are you attending the IASLC World Conference on Lung Cancer?



If you'd like to stay in touch with other Forum members while you are at conference let us know your contact information via [info@nlcfn.net](mailto:info@nlcfn.net) providing details of the dates you are attending, your hotel/location while you are at the conference and also your mobile phone number and we'll add your details to a closed WiFi accessible e-communication platform so that you can network with each other, arrange to meet up and stay in touch.

### Nurse Education Day 29/10/18

Following an excellent Education Day for Lung Cancer Nurses in Scotland held in Glasgow in March, the Scottish Lung Cancer Nurse Forum is planning another education day in Edinburgh (final venue TBC). Supported by Pharma, this will be free to delegates and cover a variety of topics from clinical updates, examples of service developments and current 'Hot Topics'. For more information, please contact [Lucy Heycock](#) or [Kirsty Docherty](#)

## DATES FOR THE DIARY

**13 September 2018**

**5<sup>th</sup> Mesothelioma and Lung Cancer Study Day**

<https://www.boyesturner.com/event/mesothelioma-lung-cancer-study-day-2-2>

**23-26 September 2018**

**18<sup>th</sup> World Conference on Lung Cancer, Toronto, Canada**

<https://wclc2018.iaslc.org/>

**19 – 23 October 2018**

**European Society for Medical Oncology, Munich, Germany**

<https://www.esmo.org/Conferences/ESMO-2018-Congress>

**1-2 November 2018**

**National Lung Cancer Forum for Nurses Annual Conference**

<https://www.nlcfn.org.uk/annual-conference>

**5-7 December 2018**

**British Thoracic Society, London**

<https://www.brit-thoracic.org.uk/bts-learning-hub/bts-summer-and-winter-meetings/winter-meeting-2018/>

**23-25 January 2019**

**BTOG**

<https://www.btog.org/uncategorized/1485/>