



# NLCFN Newsletter

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## MESSAGE FROM THE NEWS EDITOR

### Welcome to the Autumn Newsletter

I am not sure where the Summer went but I welcome you to a packed and positive Autumn newsletter.

As always please can I thank all of our contributors featured in this edition.

I am always so keen to cover all of the bases and our updates from our committee members and Liz Darlison from Mesothelioma UK indicate that there are varied exciting developments around service provision and increasing access to clinical trials ultimately improving the patient experience.

In this edition we have focused on London and Jane Lynch has kindly offered us an insight into her recent move to the private sector and detailed the work of the pan London Lung Cancer CNS group.

As a record number of Forum members leave to both attend and present at the World Lung Cancer Conference in Denver (6-9 September 2015) it is awesome to reflect on how the forum keeps moving on from strength to strength. It is clear that the UK Lung Cancer CNS are leading the way and there is a hunger to mirror some of the successes and hear more about UK / Forum member initiatives. Please make sure you don't miss out on the virtual experience and follow Jeanette Draffan's insights via the Forum Twitter feed and retweet wherever possible!

This will be my last Newsletter editorial as I am moving on to a new challenge, but I would like to thank the committee members past and present who have given me such a lot of encouragement and opportunity. What a great bunch of professional and patient-focused folk. It has been amazing. I am truly privileged and can't express my gratitude enough for believing in me when I didn't believe in myself!

One final thank you should go to Tricia Bryant for keeping me and the newsletter on track and making it such a professional publication.

Thanks,  
**Naomi Horne**  
**Newsletter Editor**



## The National Lung Cancer Forum for Nurses

**Direct NLCFN Telephone Number:** 01675 477607

**Email:** [info@nlcfn.net](mailto:info@nlcfn.net)

**Address:** NLCFN, Unit 2, Warwick House, Kingsbury Road, Curdworth, Sutton Coldfield, B76 9EE

## REGISTER TODAY TO SECURE YOUR PLACE AT THE NLCFN ANNUAL CONFERENCE

Our jam-packed programme features a range of topics and issues to support working lung-cancer nurse specialists in their every-day practice and support your professional development. With an interactive format and key plenary sessions on mesothelioma, acute oncology issues, managing patients on new treatments as well as sessions on bone management, nutrition and breathlessness the programme offers a wide range of learning opportunities.

Join us in our very own  
Mastermind session  
when we quiz the  
experts too



### Thursday 19th November 2014

10:00 **Registration, exhibition and refreshments**

**SESSION 1 Lung Cancer - Past Present and Future**  
Chairs: *Vanessa Beattie and Lesley Holland*

- 10:30 Welcome  
*Diana Borthwick, Chair NLCFN*
- 10:40 Keynote speaker - The role of the CNS –  
Past present and future  
*Alison Leary*
- 11:10 UKLCC – 10 years on... - past present and future  
*Mr Richard Steyn*
- 11:40 Roy Castle Lung Cancer Foundation – 25 years on...  
past present and future  
*Jesme Fox*
- 12:10 NLCFN Annual Award winner presentation  
*John White*
- 12:30 **Lunch and exhibition**

**SESSION 2 Mesothelioma Update**  
Chairs: *Liz Darlison and Naomi Horne*

- 13:30 Mesothelioma – the patient perspective  
Current UK-based clinical trials  
*Professor Dean Fennell*
- Tunnelled Indwelling Pleural Catheters –  
Troubleshooting  
*Gerry Slade, Mesothelioma CNS*
- Mesothelioma UK– Meet the team  
*Liz Darlison and Panel*
- Questions and Answers  
Video clips

15:00 **Refreshments and exhibition**

**SESSION 3 Update on Acute Oncology Issues - Integrating Care to Improve the Patient Experience**  
Chairs: *Alison Bennett and Carol Davies*

- 15:30 Acute oncology  
*Tom Newsom-Davis*
- 16:15 Oncology nurse's view  
*Michael Flynn*
- 16:45 Question and answers
- 17:00 **Bristol-Myers Squibb Satellite symposium**

### Friday 20th November 2014

08:30 **Annual General Meeting**

**SESSION 4 NLCFN Sessions**  
Chairs: *Jackie Fenemore and Josie Roberts*

- 09:00 Poster Awards - Other Awards  
Research Interest Group Update  
*Angela Tod*
- Thoracic Surgical Group Update  
*Vanessa Beattie*
- Using Your Voice presentation  
*Lavinia Magee*
- WCLC Update  
*Diana Borthwick*

10:30 **Lunch and exhibition**

**SESSION 5 Immunotherapy - The future of lung cancer treatment?**  
Chairs: *Rachel Thomas and Lavinia Magee*

- 11:00 NLCFN does "Mastermind in Immunotherapy"  
Quiz Master *John White, LCNS Leeds*  
Contestants:-
  - *Dr Riaz Shah, Medical Oncologist, Maidstone & Tunbridge Wells*
  - *Dr Tim Benepal, Medical Oncologist, St George's, London*
  - *Jackie Hodgetts, Nurse Clinician - Melanoma, Christie Hospital Manchester*
- 11:40 Explaining the inexplicable: An overview and guide to immunotherapy in lung cancer treatment  
*Dr James Spicer*
- 12:20 Managing Patients on New Treatments –  
The Patient Experience  
*Jennifer Seddon, Guy's London and Guest Patient*

13:15 **Lunch and exhibition**

**SESSION 6 Symptom management**  
Chairs: *Jeanette Draffan and Diana Borthwick*

- 14:15 Bone management  
*Tim Benepal*
- 14:45 Management of breathlessness  
*Sara Booth*
- 15:15 Improving nutrition in lung cancer and mesothelioma  
*Mhairi Donald*
- 15:45 Summary and Close – NLCFN – Past Present and Future  
*Diana Borthwick*

## Location



Set in 40 acres of grounds close to the historic and beautiful city of Windsor, Beaumont Estate is the perfect venue for our conference and is ideally located close to London Heathrow and the major motorway networks.



This year we've ensured there is plenty of parking available and you'll enjoy the sumptuous surroundings of Beaumont Estate helping you to get into the festive spirit.

## Register Now before end of early bird rate on 12th September

Registration starts at £199 for members and includes conference registration, accommodation on 19th November, dinner on 19th November and all meals and refreshments. A limited number of twin rooms are available for those wishing to share and we are able to offer a small discount for those sharing.



**TO REGISTER, MAKE SURE YOU LOG IN TO THE WEBSITE AT**

<http://www.nlcf.org.uk/user/login>

**AND THEN VISIT**

<http://www.nlcf.org.uk/civicrm/event/register?reset=1&id=4>

## Call for Abstracts for 2015 Annual Conference

Submit an abstract for poster presentations on the following categories:

- Examples of achievement in improving patient care
- Developing good practice
- Implementing evidence based care
- Symptom management
- Nurse led initiatives
- Clinical leadership



See our website for full details and instructions on how to submit your abstract <http://www.nlcf.org.uk/content/submit-abstract>

**Closing date for submissions: 26th September 2015**

Posters will be judged at the conference and the winner(s) will receive a prize.

The NLCFN is grateful to all the sponsors, exhibitors and those who have provided an educational grant for the conference, who allow us to offer a substantial discount to members. Please show your support at conference by visiting their stands.

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### Charity

BTOG  
HASAG  
Mesothelioma UK  
Roy Castle Lung Cancer Foundation

## NLCFN Annual Award – opportunity to win £1500 and share your project experience

NLCFN members are invited to submit an abstract outlining a project or initiative devised by individuals or as a team, describing how the project affected patient care and outcomes. The work may have been adapted from other therapy and treatment areas but will be new to the lung cancer team. The initiative or project must have been implemented within the last 12 months. Visit our website for information on application criteria and to download the guidance notes and application form <http://www.nlcf.org.uk/content/AnnualAward>.

**Closing date for applications 26th September 2015**

Watch out for the next newsletter to learn more about last year's winners.

## LUNG CANCER NEWS AND PUBLICATIONS

### New publication suggests improvements in lung cancer survival

There has been notable acceleration in improvement in survival from lung cancer during 2010–2012 according to a new report published in the British Journal of Cancer on 4th August 2015. The article, available at <http://www.nature.com/bjc/journal/vaop/ncurrent/full/bjc2015265a.html>, asks if England is closing the international gap in cancer survival. The report shows that for lung cancer, 1-year survival has improved rapidly since 2007/2008, with the annual improvement peaking at 2.2% per annum for patients diagnosed in 2010–2012. Five-year lung cancer survival also improved, but more slowly, at 1.1% per annum from 2010. The report concludes that survival has increased in England since the mid-1990s in the context of strategic reform in cancer control, however, survival remains lower than in comparable developed countries and continued investment is needed to close the international survival gap.

**Horizon scanning in lung cancer is increasingly positive with the advent of immunotherapies and in the next year the landscape will change again.** In the meantime here are some updates from NICE relating to Lung Cancer with the links. The NLCFN are stakeholders in the appraisal process so please note if you wish to contribute your comments are encouraged.

#### Suspected cancer: recognition and referral

NICE guidelines [NG12] Published date: June 2015

<http://www.nice.org.uk/guidance/ng12>

#### Nintedanib for previously treated locally advanced, metastatic, or locally recurrent nonsmallcell lung cancer

NICE technology appraisal guidance [TA347] Published date: July 2015

<https://www.nice.org.uk/guidance/ta347>

#### Future NICE appraisals:

Lung cancer (non-small-cell, non-squamous, metastatic) - nivolumab (after chemotherapy) [ID900]

NICE are undertaking two separate appraisals of nivolumab for non-small cell lung cancer

Nivolumab for treating metastatic, squamous, non-small-cell lung cancer after chemotherapy [ID811]. This appraisal has already begun.

Nivolumab for treating metastatic, non-squamous, non-small-cell lung cancer after chemotherapy [ID900]. This appraisal is expected to start in late October 2015

<https://www.nice.org.uk/guidance/indevelopment/gid-tag506>

Lung cancer (non-small-cell, anaplastic lymphoma kinase positive, previously treated) - ceritinib [ID729]

Anticipated publication date: January 2016

<http://www.nice.org.uk/guidance/GID-TAG478/documents/lung-cancer-nonsmall-cell-anaplastic-lymphoma-kinase-positive-previously-treated-ceritinib-id729-final-matrix2>

## MESOTHELIOMA NEWS

We are delighted to report Mesothelioma UK is going from strength to strength. Caroline Barry joined the team recently as our National Specialist Mesothelioma Benefits Advisor. This is a collaborative venture with the Citizens Advice Bureau giving Meso UK access to the best support and advice available across the UK. Please use the usual contact details if you would like to signpost patients to Caroline.

The charity now supports 10 Mesothelioma nurse specialist posts:

Leicester	Liz Darlson
Cardiff	Naomi Horne
Portsmouth	Anne Moylan
Manchester	Lorraine Creech
London	Sally Moore
Oxford	Hannah Ball
Bristol	Gerry Slade
Glasgow	Jan Devlin
North East	Leah Taylor
Sheffield	Helena Stanley

Due to some changes in post holders and additional funds a call for expressions of interest for additional posts is expected later this year; watch this space, we will be circulate news of opportunities through the NLCFN and BTOG. Through the BLF Research team the first Mesothelioma UK Research Grant (Up to £150k) has just been awarded (official announcement pending) we have pledged the same amount for the next two years too and again, keep in touch if you are interested in nurse research grant opportunities.



**MESOTHELIOMA UK**  
CHARITABLE TRUST - 1126083  
Supporting People With This Asbestos Cancer

**Helpline: 0800 169 2409**

**Website: [www.mesothelioma.uk.com](http://www.mesothelioma.uk.com)**

Our annual patient and carer day takes place on Friday October 2nd in Stratford on Avon, please help spread the word and encourage folk to attend. Registrations is free for patients and carers and are now being accepted. The full program and venue details are available on our website.

The next Royal Marsden/Mesothelioma UK Principles of Mesothelioma Care (Online) course is due to run in February 2016. Please register if you are interested <http://www.royalmarsden.nhs.uk/education/school/courses/pages/mesothelioma-care.aspx>

Finally the team are busy planning parallel events for the IMIG 2016 meeting that is due to be held in Birmingham in May 2016 <http://imig2016.org/>. We hope the event is firmly fixed in your diaries, we so want to showcase to the global mesothelioma community the excellent holistic collaborative approach we have here in the UK and we welcome your ideas and comments.

Enjoy the rest of the summer folks and please keep in touch with Mesothelioma UK, we are here to support and help you with any aspect of Mesothelioma.

**Liz and all the Meso UK team.**



## RESEARCH NEWS

### NLCFN provides grants in excess of £6500 to support its members

#### IASLC World Conference on Lung Cancer, Denver, 6-9 September 2015



The NLCFN is delighted to have been able to offer a range of travel bursaries to eight of its members to support their attendance at the World Conference on Lung Cancer in Denver this year.

The bursaries were awarded following an open application process to all members of the NLCFN. All applicants who had abstracts accepted for presentation or poster display were awarded the travel bursaries.

The eight lucky recipients are:-

Karen Clayton  
John McPhelim

Carol Davies  
Jenny Mitchell

Matthew Johnson  
Sally Moore

Lavinia Magree  
Paula Tindale-Paul

We hope all members of the NLCFN who attended WCLC had a great time. Don't forget to tell us all about it – photos welcome too.

**Don't forget to submit your abstracts to the NLCFN conference - See page 3 for details (support provided for poster production)**

## National Lung Cancer Forum for Nurses Research Interest Group (RIG)

### The Research Interest Group (RIG)

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.

Any Forum member is welcome to attend or be on the circulation list for RIG activity. It doesn't matter whether people are research active or not. We will welcome input and ideas from any Forum member.

### Research activity

The RIG is expanding its activity in terms of research project involvement. More recent projects RIG members have been involved with include the following:

**MesoTRAP:** A feasibility study comparing video-assisted thoracoscopic partial pleurectomy with indwelling pleural catheter in patients with trapped lung due to malignant pleural mesothelioma. Led by Robert Rintoul in Papworth, Forum members will lead on the patient experience of this study if it is successful in gaining funding. The application was submitted to the NIHR RfPB programme.

**Mesothelioma and Radical Surgery 2 (MARS 2):** Again the Forum is leading on the patient experience element of this study. This element of the work was funded by John Pickering Partners Charitable Trust.

Patients have been recruited into MARS2 and the first patient experience interview has been conducted.

**Does proactive care management by a clinical nurse specialist improve outcomes for patients with lung cancer?** A comprehensive analysis of treatment and health outcomes using linked national data sources. This project is funded by the Dimpleby Trust and led by Dr Laila Tata in Nottingham. The study is due to complete next year.

### New Research training for Lung Cancer Nurses

The NLCFN RIG is working with Boehringer Ingelheim Ltd to develop some research training for clinically based nurses working in lung cancer. We hope the training will attract nurses who want to develop research skills and confidence, and ultimately their research activity. The intention is to develop a community of research interested lung cancer nurses linked to the Forum. Work is ongoing to design the training. The course will be residential and run over 2 days. More information will be available at the NLCFN conference. The goal is to run the training next spring.

### Submit an abstract to BTOG

Submissions for abstracts for BTOG 2016 is open until 1st October 2015. Nurses are welcome to submit abstracts that have been previously submitted to NLCFN 2015.

For more information visit <http://www.btog.org/poster-abstracts.htm>

**Angela Todd, RIG Chair**

## PROFESSIONAL DEVELOPMENT AND SUPPORT

### Nursing and Midwifery Council (NMC) Revalidation – Are you ready?

#### Top Tips

- If you have not already done so, read and familiarise yourself with the new code available at <http://www.nmc.org.uk/standards/code/>
- Register at NMC on line at <https://online.nmc-uk.org/Account/Register>. This is easy to do and will give you your revalidation/renewal date
- Make a note that in October 2015 the NMC expect to launch revalidation (following pilot feedback)...The first nurses to revalidate will be those with a renewal date of April 2016. Is this you?
- Identify gaps in your development
- Competency frameworks are a key for reference to underpin practice in advanced/specialist roles.... Evidence of competence, in particular around history taking, physical examination, ability to diagnose, ability to determine when onward referral needed, ability to prescribe, radiology competence.
- Autonomous practice? Do you have authority to make decisions and freedom to act in accordance with professional knowledge base.
- Prepare your evidence of learning and ongoing development
  - o Remind yourself on the principles of reflective practice. Undertake some reflective practice on your own and with colleagues and patients
  - o Make sure you can demonstrate a combination of theory and practice (professional qualifications, practice based learning, assessment and advancing skills with robust frameworks including parameters for your practice area).
  - o Protocols, policies and guidelines for practice with clear parameters outlined where possible incorporating pathways. If not already in place take action
  - o Prudent healthcare - Right people, right skills, right place. Consider what you do and can/should you work differently?
  - o Use peer review as specialist practitioners, link in with those in other organisations, work together on "skills like" passport for competence achievement
  - o Use the NLCFN website to support you to prepare for revalidation
  - o Use your cancer network to help you with aspects of service development, professional support to help you set up some collaborative working



**Make sure you attend the NLCFN annual conference.**  
**The only conference specifically for lung cancer nurse specialists**

**Adapted from work by Gillian Knight**  
**Macmillan Lead Cancer Nurse /**  
**Prif Nyrs Cancer Macmillan**  
**South Wales Cancer Network**

### Using Your Voice (UYV) Project 2015

We are pleased to report that 25 Lung Cancer Nurse Specialists have registered to take part in UYV 2015, and extend grateful

thanks to the Lilly Oncology Team involved for their co-ordination and support of this project. Registration for 2015 has now closed.

An abstract on the UYV Project was submitted to WCLC and has been accepted for oral presentation in Denver on 07/09/2015. Further information on UYV can be obtained via the NLCFN website under the Member's Resources Section. Do have a look. An update will also be provided at the NLCFN Conference 2015 when you can consider registering for 2016.



**Lavinia Magee**  
**NLCFN Committee member,**  
**on behalf of the UYV Workshop Group**

### November is lung cancer awareness month

Lung cancer awareness month takes place every November in the UK.

Do you know of any activities going on in your area to support the campaign?

Let us know and we'll help promote your activities via our website.

**Contact: [info@nlcfn.net](mailto:info@nlcfn.net) with your information.**

Visit the Roy Castle Lung Cancer Foundation for information on a toolkit you can obtain to support your local campaigns.

## Focus on London

### The Pan London Lung CNS Group

The National patient experience Survey consistently demonstrates that Trusts with the worst experience tend to be concentrated in London and the surrounding areas. This may indicate that the needs of patients in London may be dissimilar to that elsewhere in the Country. Eight of the capital's NHS trusts score in the bottom 10 patient experience league table of trusts in England [2014]. But Macmillan says the 'enormous efforts' of London trusts to improve their patients' experience of care are beginning to show results. Carol Fenton, Macmillan's General Manager in London, says: "After four years of London trusts featuring in the bottom 10 of our league table, signs of improvement are visible, but there remain significant areas where improvement is needed. London trusts and their dedicated staff are making enormous efforts, but too many cancer patients in the capital are not yet getting the care they deserve".

There continues to be unacceptable variation in patient experience across the capital, and London continues to fall behind the rest of the country. Our goal in London must be to have the best cancer patient experience of any capital city in the world. London needs to have a more joined-up cancer system along the whole pathway of care; from diagnosis through to specialist treatment and ongoing care. This would allow patients to experience seamless care no matter where they are first diagnosed or treated.

London Cancer and London Cancer Alliance were formed, as two Integrated Cancer Systems (ICS) following a merge of the previous 5 London Cancer Networks. This consists of two groups of providers with the aim of providing

comprehensive, integrated cancer patient pathways and services. All the London Trusts and various feeder Trusts surrounding the Capital are members of one or the other.

### The LCNS Group

The Group is patient focused with an emphasis on the impact of the CNS on patient pathways and Service development, without the influence of individual Organisational constraints. Given the large population in a concentrated geographical area, it was felt this could be the London Faction feeding into the NLCFN similar to that of other groups across the UK. The aim of the Group is to help improve the experience of patients and carers in London, with a diagnosis of Primary Lung cancer and Mesothelioma, through sharing of expertise and best practice, pooling of resources and positively influencing patient pathways.

Since its inception, this has proved a popular Forum for networking and support. Meetings are quarterly, at a central location, not affiliated with any NHS Organisation and in the evening, thereby negating any issues that may arise from individual Organisations. New and exciting initiatives are discussed, with a different topic explored at each meeting. Looking to the future, we hope to develop some of the concepts, develop strong links with the NLCFN, whilst maintaining the enjoyment of the meetings.

**Jane Lynch, Lung Cancer Clinical Nurse Specialist, London**

### Is working as a CNS in private practice different to NHS?

**Jane Lynch, Lung Clinical Nurse Specialist/Service Lead, The Harley Street Clinic**

*Last year, I left a very prominent, senior (Band 8) CNS role, heading a team of Lung CNS's in a large London NHS Trust, in order to set up this service. Why?*

*Initially I was approached by the Private Organisation, having been recommended as a source of expertise in lung management. I developed a good understanding of what was required and was therefore instrumental in shaping the JD before starting. The prospect of being given a blank canvas to set up a service is something we don't often get a chance to do and looked a challenging and exciting project, as was the prospect of working in the unknown territory outside of the NHS.*

*My role is a combined role of Lung Service lead as well as CNS/key worker for patients with lung cancer. The remit was very much about bringing together the key stakeholders involved in the pathway and creating a world class expert lung service.*

*Clinically, the same highly specialist skills are utilised. Private care does not change how patients respond psychologically, symptomatically or, emotionally following a cancer diagnosis. The majority of patients we diagnose and treat from the UK have private health insurance, alongside a self-paying minority. Through strong international links, we are exposed to a far reaching wider audience.*

*The Consultants, the majority of whom have large NHS practices, value and respect the expert specialist support in often difficult situations. With the patient case load numbers larger than my previous NHS practice, the clinical demands for a high level of expertise remain similar.*

*There are of course some differences. The ready availability of diagnostic's ensures the anxiety related to the associated waiting times for tests and subsequent results is dramatically reduced. This provides improved patient experience and immense professional satisfaction.*

*Although economics is an aspect of private healthcare, it is not at the heart of it. With improved patient experience associated with improved treatment outcomes, we know the presence of a CNS is crucial, (LUCADA, NCPES) leading to satisfaction for the patients and healthcare professionals. This therefore identifies a quality Organisation, in that it provides the best the NHS has to offer in terms of patient experience, combined with the best private healthcare offers in terms of rapid access to cutting edge treatment and diagnostics.*

*Of course, the advanced level impact that the cancer CNS makes is not confined to direct clinical care. As highlighted by Macmillan (2010), key contributions include "innovation, project management and change management... leadership within the MDT and wider cancer team". Influencing and the execution of clinical pathways is a pivotal role of the CNS, and although the concept is a familiar one in the NHS for senior nurses, within the Consultant- led world of private practice, this is not so developed.*

*However, this is changing. Private medical Institutions, dealing with patients and Organisations on a national and international level are keen to showcase available expertise and recognise CNS is crucial in helping lead the way. The private organisation I work for is a large organisation with a great amount of expertise concentrated in a small geographical area, providing expert medical/ surgical care but in a fragmented manner.*

*Setting up and developing the expert MDT has led to a decrease in silo practice, with recognised specialists in the area getting together ensuring uniformity of care and improved outcomes. There are some challenges.*

*The role can be an isolated one, lacking the support from the large team of healthcare professionals associated with a department / speciality within the NHS. In order to maintain the strong nursing links built up within the NHS, I developed and chair the Pan- London LCNS forum, providing a supportive Forum for London based LCNS's and maintaining strong links with NLCFN.*

*Also, within the Organisation, some senior staff members struggle with the strategic leadership aspect of the role. There can be a lack of understanding regarding the high levels of expertise the CNS can contribute to shaping the Organisations cancer strategy, attributed perhaps, being used to a more traditional model of nursing. This is a challenge to thrive on, leading in the management of change!*

*For me, introducing and expanding this service from nothing, to a now thriving, expert MDT team, streamlining patient care pathways leading to improved outcomes and being recognised as pivotal to this change is a very satisfying element if this new venture.*

# MEMBERS NEWS NEWS NEWS NEWS NEWS

## Call for applications for new NLCFN committee members



The NLCFN committee is the main standing committee responsible ensuring the members needs are met and the charitable aims are delivered. We are currently seeking applications for new members of the committee, the first to start immediately upon appointment and the second starting in January 2016. If you are enthusiastic and committed to high value care for people with lung cancer and you wish to support your colleagues and peers why not consider joining the committee.

The work involves attending 4 committee meetings per year, the annual conference and getting involved in managing a specific area of NLCFN projects such as acting as representative of the NLCFN on another charity or board. You will also be required to be involved in regular email correspondence with your fellow committee members.

The work is unpaid though standard class travel expenses are reimbursed.

The committee offers a great platform to get more involved in the work of the organisation and help develop your own professional career in the lung cancer field as well as furthering the cause of high quality management and support of people with lung cancer.

Applicants must have support and approval from their line manager for attendance at committee meetings and the work of the NLCFN.

If you are interested in applying please read the Terms of Reference available at (URL) and submit your application via the operations team at [info@nlcfn.org](mailto:info@nlcfn.org) using the application form available via our website at <http://www.nlcfn.org.uk/NewCommitteeMembers> on or before 18 September 2015.

## Our Annual Award Winner 2014 gives us an update on his progress

Our team were fortunate to be awarded the 2014 NLCFN Annual Award of £1500.

The award was won for the establishment of The Leeds Lung Cancer Survivorship Clinic which was introduced in April 2014.

It is joint clinic run by the Lung Cancer Nurse Specialists (including the Thoracic Surgical Nurse Specialist) and the Lung Cancer Respiratory Physicians with the support of the outpatient nursing team.

Patients are seen 3, 6 and 18 months after completion of treatment. If adjuvant therapy is delivered then the first visit is at 6 months. CT scans are performed at 6 and 18 months post treatment.

The Lung Cancer Nurse consultation is guided by findings from the Distress Thermometer and the QoL tool. This is completed on arrival in the clinic with the outpatient nurse available to help complete the forms. The consultation includes a review of

the patient's concerns together with an assessment of any psychosocial and lifestyle issues. Appropriate referrals are made and may include referral to the Smoking Cessation service, Social Services or Welfare Rights.

The medical consultation focuses on a review of the status of lung cancer and late effects of treatment. Documentation is made of pre-and post-treatment physiology, COPD management review (where appropriate) and any other chronic disease management review.

The money from the award has gone towards the costs of devel-

oping a DVD to give to patients undergoing lung resection and to show at the Patient Education Programme which happens weekly and to give to patients having lung resection who are unable to attend. The filming involved one of the members of our support group who kindly gave up their time on at least 4 separate days, using the thoracic surgical unit's facilities, the physiotherapist and the nurse specialists being recorded until they managed to get their lines right!!

We will aim to show the DVD at the Annual Conference.

**John White, Leeds**

**Don't miss out on your opportunity to submit an application for the NLCFN Annual Award for your chance to be awarded up to £1500 in support of your project**

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

For full details on the application criteria and to download the application form visit <http://www.nlcfn.org.uk/content/AnnualAward>

## Conference

95% of those who attended the conference last year felt that it had been organised and managed effectively.

Suggestions for future topics includes the following, some of which feature in this year's conference:-

- New developments with drug therapy and immunotherapy
- Managing breathlessness
- Minimally invasive treatments for lung cancer patients. i.e. Radio frequency ablation and endobronchial cryotherapy.
- Surgical pathway
- Survivorship
- Nurse led clinics and virtual clinics
- Palliative care

**The full results of the survey will be available at the NLCFN Conference in November.**



## Members Survey – Highlights

Thanks to all 105 members who took part in our members' survey. Your input is vital to us and allows us to ensure we are relevant to the membership. The preliminary results of the survey show:-

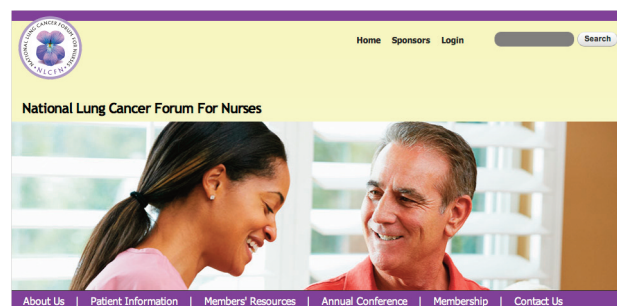
Reasons for joining/renewing membership (delegates were asked to select as many of the following options as applied)



Of the new email service and revamped newsletter service in 2014 more than 90% of participants agreed that the emails and newsletters are either extremely valuable or of some value.

	Extremely valuable	Some value	Little value	No value
Emails	63%	37%	0%	0%
Newsletter	68%	32%	0%	0%

## Website



Whilst 62% of participants use the website regularly or frequently, regretfully 37% of participants use the website only to renew their membership, register for events or do not access it at all. We are interested to hear from those who do not access the website why they don't and any feedback from members on how we can improve the site to make it more attractive to members

Making the site more interactive was suggested by some members as a potential improvement including more information on current breaking news and research results as well as an opportunity for members to interact more with each other.

More than 80% of those who use the website to renew their membership and/or register for events find the system easy to use.



**If you experience problems trying to register or renew your membership try doing so from a home computer. Some NHS networks include stringent software to stop users being able to purchase online services.**

## Feedback on The National Cancer Intelligence Network, Cancer Outcomes Conference 2015: United against cancer. Belfast 8th-10th June



*I attended this conference as the representative for the National Lung Cancer Forum for Nurses.*

*The NCIN conference had a number of presentations including one from a lung cancer survivor as well as clinicians including Mick Peake, Dr Peter Murchie and Sir Richard Peto. There was a questions and answer session at the end of the conference and I was lucky enough to have my question accepted for discussion. For my detailed report on the conference and information on the Q&A session please visit the website at <http://www.nlcfn.org.uk/NCINFeedback>.*

*The NCIN has driven the immense development of knowledge and brought together information intelligence. The conference highlighted that data drives change and improvement in services although there is an ongoing challenge around capacity with ever increasing numbers of*

*patients, more advanced treatments, patients living longer, greater demand on services but with the same or not great increases in resources. The conference also valued the importance of the patient voice, listening to those who have experienced care good and bad to make sure that services are the best possible for those living with cancer.*

*A worthwhile experience? To be honest only partly - the programme was very statistically orientated. Would I change my practice based on what I had learnt? - No. Looking through the delegate list I was the only nurse listed and I only knew two other delegates!!!*

*For a full report on the meeting visit [www.nlcfn.org.uk/NCINFeedback](http://www.nlcfn.org.uk/NCINFeedback)*

**Jeanette Draffan, Committee Member NLCFN**

## NICE scoping workshop

*I recently attended a NICE scoping workshop as the NLCFN representative. It is essential that NICE have representation and opinion from the NLCFN and other professional agencies, we are experts in Lung cancer treatments and also well placed patient advocates. The workshop looks to assess accuracy of information and ensure appropriate information is not missed.*

*On this occasion several potential future treatments were discussed. It is far too early to know if these treatments will be beneficial or potentially become recommended by NICE. But the workshop gave me some insight into the complexities of the scoping process.*

*Several targeted treatments were discussed, all of which have been used in early clinical trials. All identified the possibility of a potential benefit in symptom management and life expectancy. I must emphasise it is far too*

*early to speculate as to whether any of these treatments will prove advantageous.*

*What I did find encouraging is that there is excitement among lung cancer experts. It would appear that pharmaceutical are investing in potential lung cancer treatments. Targeted therapies are identifying potential benefits; this can only be a positive step forward for our lung cancer patients.*

*On another note I'm honoured (and terrified) to have had a poster abstract accepted for an oral presentation for 2015 World Conference on Lung Cancer. It is the patient story of a Mesothelioma patient. I feel very proud to be able to tell of his experience at such a prestigious event.*

**Carol Davies, Macmillan Lung Cancer Nurse Specialist, Wales**

## TOOLS AND INFORMATION FOR PATIENTS

### Patient support groups

Patient support groups are an invaluable resource for patients, carers and professionals but often the thought of trying to set up and facilitate them is overwhelming. Please consider using the health professional resources available to us on the Roy Castle website. <http://www.roycastle.org/>



#### How we can help in setting up a support group

If setting up a support group is something that you have thought of doing but weren't quite sure where to start, we can offer practical advice and administrative support to help you run your group.

We can help with the following:

- Performing a patient/carer needs assessment
- Finding an appropriate venue
- Providing publicity posters and flyers
- Providing funding of up to £30 per month towards venue and/or refreshments
- Providing a comprehensive facilitator pack

In addition we can put you in touch with any of the facilitators who currently run support groups, who will be able to help answer your questions. You can find out about our existing support groups here

#### Facilitator training

We run a fully funded two day accredited training programme which is open to all our support group facilitators. The training will help to equip you with expert skills to facilitate your group and also provides a fantastic opportunity for you to network with nurse facilitators from throughout the UK.

**For more information about setting up a support group, or for facilitator training, please contact [lorraine.dallas@roycastle.org](mailto:lorraine.dallas@roycastle.org)**

## The 1st Annual Macmillan Lung Cancer Charity Ball

Live music, auction, spot prizes, raffle

**6.30pm, Saturday 14th November 2015**  
Hardwick Hall Hotel, Sedgfield, Co. Durham, TS21 2EH

Tables of 10 or 12 are available

**For tickets contact 01642 624106 or 0789 996 1437**

*All proceeds to Macmillan Cancer Support and  
North Tees Lung Cancer Trust Fund*

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CANCER SUPPORT**

North Tees and Hartlepool

NHS Foundation Trust



## DATES FOR THE DIARY



**11th September 2015** **BTOG Study Day**  
**The Burden of Bone Disease in Lung Cancer**  
 Hotel Russell, London  
 Visit <http://www.BTOG.org> for more information

**14th September 2015** **Management and Treatments for Lung Cancer**  
 Education Centre (Dept 17) The Christie, Manchester, M20 4BX  
 A study day has been designed to provide an update on the evolving treatments of lung cancer  
 Course Fee: £90.00. For more information visit <http://www.christie.nhs.uk/school-of-oncology/education-and-training/education-events/150914-lung-cancer-study-day.aspx>

**18th and 19th September 2015** **Scottish Lung Cancer Forum 10th Biennial Meeting**  
 Central Hotel, Glasgow  
<https://www.eventsforce.net/slc2015>

**2nd October 2015** **Mesothelioma UK 10th Patient & Carer Day 2015**  
 Macdonald Alveston Manor, Clopton Bridge, Stratford-upon-Avon  
 Further information and registration visit <http://www.mesothelioma.uk.com>

**14th October 2015** **Royal Marsden NHS Foundation Trust Palliative Care Update**  
 One day workshop on end of life care.  
 Online booking at <http://www.royal-marsden.nhs.uk/palliativeupdate>  
 Course fee £120

**19th-20th November 2015** **NLCFN National Conference**  
 Windsor, UK  
[www.nlcf.org.uk/2015-annual-conference](http://www.nlcf.org.uk/2015-annual-conference)

**13th-15th December 2015** **The 2015 Cancer Research UK (CRUK) Lung Cancer Centre of Excellence Conference**  
 Manchester  
<http://www.cancerresearchuk.org/support-us/find-an-event/the-lung-cancer-centre-of-excellence-conference-2015>

**27th-29th January 2016** **BTOG 2016 - 14th Annual BTOG Conference**  
 Dublin  
<http://www.btog.org/annual-conference.htm>



### National Lung Cancer Forum for Nurses

Address: Unit 2, Warwick House, Kingsbury Road, Curdworth, Warwicks, B76 9EE  
 Telephone: 01675 477607 Website: <http://www.nlcf.org.uk> Email: [info@nlcf.net](mailto:info@nlcf.net)

The National Lung Cancer Forum for Nurses is grateful to its corporate sponsor Lilly Oncology for the provision of an educational grant to support the activities of the organisation. Lilly Oncology have had no input to the production of this newsletter. Click <http://www.nlcf.org.uk/content/sponsorship-opportunities> for the NLCFN information on sponsorship including our statement on funding