

ISSUE 28, SPRING 2019

NLCFN Newsletter

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MESSAGE FROM THE EDITOR



Welcome to the spring newsletter. How lovely to enjoy some sunshine and longer days.

2019 has brought with it change within the Research Interest Group (RIG). We bid a fond farewell to Prof Angela Tod as Chair, and thank her for all her leadership and inspiration. Welcome to Prof Janelle Yorke as RIG Chair. We are delighted to have Janelle on board and look forward to the ongoing growth of RIG.

We are looking forward very much to NLCFN 20th anniversary celebrations this year including launch of our new website. Programme structure and content for the annual conference $14^{th} - 15^{th}$ November is well underway – see page 2 for more information.

For those of you with service development, audit or research projects in mind and looking for funding sources, there are numerous available. Links below will direct you to further information regarding a selection of grants available for lung cancer and mesothelioma:

https://www.nlcfn.org.uk/smallgrants https://www.nlcfn.org.uk/content/AnnualAward https://www.nlcfn.org.uk/MesoUKGrant https://www.roycastle.org/how-we-help/research/research-grants/what-we-fund

Should you require any advice or assistance with NLCFN small grant application do contact us via the website. If you are planning to attend World Conference on Lung Cancer (WCLC) September $7^{th} - 10^{th}$, Barcelona, the deadline for abstract submission is April 10^{th} . Assistance with poster production for successful abstracts and travel bursaries are available. UK nurses and their work have developed a great reputation at WCLC.

We will continue to keep you up to date with regular emails. Do share with us changes and innovations in your area. Articles for the newsletter are welcome. Don't forget if you introduce 2 new members to NLCFN you will receive complimentary membership for one year. We look forward to seeing you in November, if not before.

With best wishes

Lavinia Magee, Co-editor and committee member NLCFN



The National Lung Cancer Forum for Nurses



Direct NLCFN Telephone: 01675 477607 Email: <u>info@nlcfn.net</u> Address: NLCFN, Miria House, 1683B High Street, Knowle, Solihull, B93 OLL



This year's conference is the go-to event for any nurse working in lung cancer providing plenty of highly relevant information and training for your professional portfolio as well as offering a chance to relax and share with your friends, colleagues and peers. We have fantastic and inspiring speakers lined up for this must-attend event as well as some extra special surprises and treats for delegates to help share in our twentieth anniversary year.

As part of our celebratory 20th year we will be taking the opportunity not only to look at current best practice and evidence based care but to look forward to what the future holds in the diagnosis and management of lung cancer and caring for people with lung cancer and mesothelioma.

From screening to surgery and symptom management to end-of-life care we will bring you practical advice, knowledge and personal inspiring stories to illustrate learning. Speakers include Professor Rob George (BBC Horizon – We need to talk about death), Dr Matthew Evison, Dr Neil Bayman, surgeon Doug West and many more.

We will also bring you the latest in lung cancer research and development and facilitate the sharing of best practice and original research by members.

The conference is renowned for being embedded in day-to-day nursing practice and for welcoming delegates with its reinvigorating and friendly atmosphere. It offers busy nurses the chance to recharge their batteries, network and interact with like-minded colleagues and learn from experts about the latest developments and treatments specific to the profession. Book now for best rates and to secure your place. - https://www.nlcfn.org.uk/annual-conference/

Submit an Abstract

Members are invited to submit an abstract of no more than 250 words for presentation (oral or poster) at the conference. Abstracts can be on any subject of relevant to lung cancer nurse specialists working in the lung cancer/ mesothelioma field.

Abstracts can be on a clinical area or based on a project affecting service delivery, LCNS education or palliative care. Abstracts may be based on academic research, audit results or best practice. Submission is via a simple online form https://www.nlcfn.org.uk/annualconference/submitabstract

For support with abstracts please contact info@nlcfn.net and we will support you

Travel bursaries available

The NLCFN committee are delighted to offer up to 10 travel bursaries of up to £250 each to members who have registered and attend the conference. The 10 bursaries will be allocated on a first come, first served basis though preference is given to those who have not previously received a conference travel bursary.

The successful applicants will be provided with an expense claim form which must be completed (and receipts attached) and returned to the operations team within two weeks of the conference taking place.

Terms and conditions apply. For more information visit https://www.nlcfn.org.uk/annualconference/bursary



Annual Workshop 11/12 February 2019 Birmingham



The NLCFN Annual Workshop 2019 commenced on the 11th February 2019. The group discussed what the term 'Meet the Lung CNS' means within the National Optimal Lung Cancer Pathway. We discussed what happens when the patient/carers meet the lung CNS and how we can evidence how valuable interactions are, ensuring patient compliance to investigations and making sure of a quality experience at a very stressful time.

The group have decided to complete auto-ethnographic study of the interactions between the lung CNS and patient. The results will be presented at NLCFN Annual Conference in London on 14th/15th November 2019. Hopefully many will attend and hear the outcome of this exciting project

Karen Clayton, Macmillan LCNS, Macclesfield

Oncology Nursing in Practice – digital learning platform

The Oncology Nursing in Practice (ONiP) eLearning platform launched in late 2018. Creating independent, accredited and engaging online courses, ONiP upholds the mission of supporting oncology nurses within the multi-disciplinary environment through impactful, needs-driven education.



Understanding that accessibility and flexibility are important factors when it comes to learning, all modules are free-to-access and with a personal log-in, so your progress is saved while you dip in and out at your leisure. With different learning levels available, the content is relevant whether you are entirely new to the subject or a specialist in the area.

Initial topics in lung cancer

The first four modules cover topics within the area of lung cancer: biomarkers and immunotherapy, with foundation and advanced levels in each. The emerging role of biomarkers in non-small cell lung cancer and their implications for clinical treatment is covered, and the role of immunotherapy to empower nurses with knowledge to manage the unique considerations this presents in their clinical practice. With special thanks to our expert faculty of the NLCFN, Jackie Fenemore, Sandra Wakelin, Rachael Thomas and Josie Roberts, for helping develop these modules.

EONS endorsement and new modules

We are delighted to announce endorsement of the platform by the European Society of Oncology Nursing (EONS) at the start of this year and are excited to be readily expanding the online content. Five modules are currently in development for release this Spring (by end of April):

Palliative care; Smoking cessation in those diagnosed with lung cancer; Building a business case for nurseled clinics; and Living with and beyond lung cancer; Self-perceptions following treatment for head and neck cancer;

Please visit the website to access the eLearning for free and to keep up to date with new modules: <u>www.oncologynursinginpractice.com</u>





Oncology Nursing in Practice (ONiP)

OncologyNursinginPractice.com

Contact ONIP: contact@oncologynursinginpractice.com



NEWS, FEEDBACK AND PUBLICATIONS

An overview of BTOG Mesothelioma Essential Update 2019.

The 11th March 2019 saw a large gathering of healthcare professionals in Birmingham to attend the BTOG Mesothelioma Update. The day was co-chaired by Professor James Spicer (Guy's and St Thomas' NHS Trust) and Liz Darlison (CEO and founder of Mesothelioma UK). The day was divided into two parts with the morning session looking at scientific and research advances and the afternoon looking at support and care of Mesothelioma patients. Dr Mick Peake gave an insightful overview of the National Mesothelioma Audit 2014-2016. The audit recommends the following:

- Pathological confirmation should be over 95%
- Data completeness for the performance status field should exceed 90%.
- 90% of patients should be seen by a specialist CNS and signposted to Meso UK resources.

The audit reported that only 64% of patients actually had a pathological subtype recorded. Considering the variance in prognosis for each subtype and the psychological impact of diagnosis on patients I found this result quite shocking. Mesothelioma should not be lumped under one diagnosis but must be split into the three subtypes to ensure patients have access to clinical trials and a true understanding of their prognosis. Considering some trials are only available for Epithelioid or Biphasic/Sarcomatoid Mesothelioma an accurate pathological subtype at diagnosis is crucial and could impact on patient's treatment plan and overall survival.

There was an overview of the main clinical trials in Mesothelioma including MARS2 which is recruiting well and is likely to recruit to full numbers early. There was an insightful account of the interim quality of life outcomes for patients enrolled into MARS2. It was encouraging to hear about a number of clinical trials either closed to recruitment, such as PROMISE, or continuing to recruit, such as SYSTEMS 2. We are now seeing more trials open for patients with the hope being that in the near future we will see more treatment options for Mesothelioma patients. The Mesothelioma UK website lists a full overview of all clinical trials across the UK and is a useful source of information to pass onto patients.

The afternoon saw the focus on support and care of Mesothelioma patients including benefits and compensation, a very thorough presentation by Lynne Squibb (HASAG) explained the range of benefits available to Mesothelioma patients. Another two excellent presentations looked at managing pain in Mesothelioma, focusing on percutaneous cordotomy and radiotherapy. It was pointed out that patients are often referred for percutaneous cordotomy too late and the difficulty for healthcare professionals to know when to refer for these forms of pain management.

The day ended with patient case studies and discussions by a multi-disciplinary team of healthcare professionals which brought together all the experts that had presented to give views on patients care and treatment options. An interesting and informative day.

Rachel Thomas, Mesothelioma LCNS, Guys and St Thomas' London

Seeking evidence in support of LCNS local services

In Manchester there has been a great deal of work trying to improve the service given to lung cancer patients from a local CNS. This has involved a Macmillan sponsored project at The Christie which is a tertiary treatment centre. Macmillan have recruited a senior project manager and service user co-ordinator who have been mapping out local support services for all people with lung cancer. Two service users attended BTOG 2019 advocates meeting from The Christie, where they heard Natalie Doyle and Chris Draft talk passionately about patient advocacy in lung cancer.

The project is nearing its completion to try to prove the additional 2 temporary Lung CNS's in post in are essential to providing a comprehensive service based around the 4 sector MDT's in Manchester. An answer is expected in May when the business case goes to the board at The Christie.



NEWS, FEEDBACK AND PUBLICATIONS

Insights into NICE Appraisals

What an exciting time to be working within the lung cancer field. There is a marked increase in the number of lung cancer clinical trials being undertaken; within the UK, within Europe and further afield. Pharmaceutical companies appear to be heavily investing in lung cancer treatment research.

I think you will all agree the priority for lung cancer patients is to improve outcomes. Higher cure rates, early presentation, early diagnosis and more tolerable treatments are all a priority. However, for the majority of lung cancer patients cure is not possible. Most present at either a late stage, with limited performance status (PS2 or PS3) and/or with multiple co morbidities; all of which impact on treatment options.

Evidence from previous clinic trials has enabled the emergence of 2nd and 3rd generation TKIs to be used in clinic practice. This has positive impact for EGFR-positive NSCLC patients. ALK positive and ROS1 positive treatments show a similar picture for this specific patient group. Immunotherapy has certainly been beneficial for many (but not all) NSCLC patients. Both single agent and combination treatments have changed clinical pathways and practice. Such patients are frequently treated for longer; (to time of progression with targeted treatments, up to 2 years with immune therapy) and provided performance status is maintained many go on to 2nd, 3rd and sometimes further lines of treatment.

When new trail data emerges, pharmaceutical companies submit data to NICE requesting a NICE drug appraisal. (Full details of the NICE appraisal process is available on the NICE website). For a variety of reasons not all submissions result in a full appraisal. However, the number of NICE lung cancer drug appraisals have increased.



I thought for this edition of the newsletter it may be helpful to provide you with a brief insight into the NLCFN input into a NICE drug appraisal. The NICE appraisal is a robust process. The NLCFN (along with many other specialist groups) are invited by NICE to take part an appraisal as a consultee. If we agree to be a consultee documentation is sent by NICE; this needs to be completed and returned.

Consultees are asked to comment on draft remits and draft scopes. The documentation is extensive and detailed. Information provided in the pharmaceutical company submission is reviewed by the ERG, (this is an independent academic group) who help prepare additional analysis on the submitted data.

Experts are invited to help clarify certain issues raised in the submitted evidence. They can be invited to attend committee meeting.

The NLCFN attend as a patient expert; key questions are what do patients think about the technology, how will they cope with treatment side effects, discussions regarding tolerability of treatment etc.

Clinical experts, representatives for the submitting pharmaceutical organisation, representatives of the ERG, NICE appraisal staff and NICE committee members all attend the appraisal meetings.

Members of the public are able to apply to attend some of the meetings as an observer, but are unable to ask questions. A decision is never made at these meetings. All information remains confidential until published on the NICE website.

The final appraisal document is published on the NICE website in due course; this forms guidance to the NHS.

Carol Davies, Macmillan Lung Cancer Specialist Nurse, Nevill Hall Hospital South Wales



NEWS, FEEDBACK AND PUBLICATIONS



I would like to thank the NLCFN for giving me the opportunity to attend the recent BTOG conference 2019 in Dublin. I am currently a Candidate Advanced Nurse Practitioner Oncology Rapid Access Lung working in one of the eight designated cancer centres in Ireland. My focus, once registered as an Advanced Nurse Practitioner, will be on follow up of post-surgical essential elements of the prevention and treatment of patients with lung cancer, post stereotactic radiotherapy and similarly patients with pulmonary nodules identified on CT thorax.

For this reason, I was particularly interested in the diagnostic section of the BTOG conference. I attended the conference on Wednesday and Thursday. There were many interesting and thought provoking sessions. approach for lung cancer cachexia. I will give a brief outline of some of the presentations that I attended and the main learning points which I picked up.

I enjoyed the presentation on 'Nodule Management: BTS versus Fleischner and role of Volumetry, CAD and Al' for the follow up of pulmonary nodules. There were patients with lung cancer are approached. many similarities in the protocols and it provides some The posters on display at the conference provide a interesting discussion in my hospital as to which guidelines will be used. Currently, depending, on Radiologist preference and training some will refer to Fleischner and some to BTS guidelines. However, the of streamlining this and will in the future refer to one set of guidelines.

As part of my role within the lung cancer service, there attending on an annual basis. is a focus on survivorship for patients who are postsurgical resection for lung cancer.

The presentation on 'Managing Tobacco Addiction in the Optimal Pathway' was a very clear and concise

review of the evidence on the various smoking cessation aids available to patients. As a nurse prescriber, I felt that this presentation dispelled some of the myths surrounding Varenicline.

Furthermore, there was clear evidence from the speaker about the superiority of Varenicline over other products. It provides me with increased confidence as to whether Varenicline or Nicotine Replacement Therapy would be more appropriate and in which circumstances you would use one product over the other.

I found the presentation on 'Getting Ready for Treatment- Supportive Care Perspective' a very enlightening talk. It provided a clear outline of the lung cancer cachexia. It requires a multimodality approach and this was very clearly highlighted and supported during this presentation. The three key elements for the treatment of lung cancer cachexia are exercise, anti-inflammatories, and a dietician review. This gives a clear starting point for health care professionals when considering the best management

This conference was a great opportunity to meet with nursing colleagues from the various centres in Ireland to discuss the challenges and opportunities available. It was also a forum to meet colleagues from the UK to discuss how different issues relating to nursing care of

clear overview of the fantastic work that is being done in different centres in the UK and I certainly picked up some ideas that would be very relevant to my practice. This conference was very beneficial to my work within Radiology Department in my hospital are in the process the lung cancer service here in Ireland. I have not been to the conference for a couple of years but it is definitely something that I am going to consider

> Rosie Murphy, Candidate Advanced Nurse Practitioner Oncology Rapid Access Lung, UL Hospitals Group, Limerick

Foreign Language Information sheets on lung cancer

A members has contacted us to ask us if any members have patient information on Mesothelioma in Farsi. If you have any information leaflets you are willing to share in foreign languages please let us know via info@nlcfn.net so that we can share them via the NLCFN website



NEWS, FEEDBACK AND PUBLICATIONS

DVLA Update

The DVLA's fitness to drive guidelines has been updated. The section on 'Brain Metastases' now provides guidance for those with metastatic brain disease treated by immunotherapy or other targeted therapies. The general guidance for lung cancer section continues to advise that any patient with lung cancer can no longer hold a Group 2 license (bus, lorry, etc) regardless of whether they have brain metastases or not, with the exception of stage T1 N0 M0 NSCLC. You can read more about this via the following links:

https://bit.ly/2uusmIn https://bit.ly/2FxBDEN

Pamela Rose, LCNS Glasgow

Scottish Government consultation: definition of terminal illness

The Scottish Government has opened a consultation <u>http://www.lungcancercoalition.org/e-atlas</u> on their draft guidance for doctors completing Benefits Assessments Under Special Rules in Scotland (BASRiS) form for terminal illness.

The BASRiS will replace the DS 1500 for benefits devolved to Scotland. Devolved benefits include Attendance Allowance (AA), Disability Living Allowance (DLA), and Personal Independence Payments (PIP). Some benefits however, including Employment and Support Allowance (ESA), remain DS 1500 will still be required.

Where the DS 1500 could be completed by a clinical nurse specialist they will be excluded from completing a BASRiS which can only be completed by a Registered Medical Practitioner.

Will these changes affect the lung cancer patients you

care for? Find out more about these changes and have your say by visiting the following link:

https://bit.ly/2FuVtk2

Pamela Rose, LCNS Glasgow

Lung Cancer Resource: GLCC

The Global Lung Cancer Coalition (GLCC) has recently updated their e-Atlas with new data from GLOBOCAN, the World Health Organisation and national cancer registries. The interactive e-Atlas is publicly accessible and can be used to compare global and national data on lung cancer incidence, mortality and survival by gender and age. It also includes data on whether countries have a cancer registry, a cancer plan or are signatories to the Framework Convention on Tobacco Control.

Users can create and export graphs, charts and infographics to use in presentations or meetings.

You can access the updated version by visiting

Vanessa Beattie, LCNS, Liverpool

Want to write a great paper but need help?

Angela Tod forwarded this career feature article published in Nature on how to write a first-class paper where six experts offer advice on producing a under the UK Government and the completion of the manuscript that will get published and pull in readers. You can view the article at https://go.nature.com/2Tze3fP

Professor Angela Tod, Sheffield

NEWS, FEEDBACK AND PUBLICATIONS

The next meeting of the West Midlands Lung Cancer Nurse Forum will be held on Friday 5th April 2019 09.00-16.00. The venue is courtesy of For further details and copies of the flyer, please Irwin Mitchell- Imperial House, 31 Temple Street, contact Julia.mcadam2@nhs.net or Birmingham B2 5DB. The meeting will have guest Doug Jewell, Project manager at Asbestos speakers and updates from the pharmaceutical industry and also Alida Coates, Partner at Irwin Mitchell. There will be lots of opportunity for networking and Peer support, as well as a lovely The NLCA are planning to publish the latest lunch. For further information and confirm attendance contact Christine.jordan6@nhs.net

The Central England Mesothelioma Support (CEMS) group continues to meet monthly in Birmingham. This is a group for patients and carers and is facilitated by the Lung Cancer CNS teams from across the region, as well as Asbestosso the NLCA are working with them to identify Support (Central England). The CNS team arranges for speakers to come to talk to the group on a range of subjects, which have so far included Pleural effusion management, Breathlessness, Living Well with Mesothelioma, when the report for 2017 is published Clinical Trials update, Palliative symptom

management. The meetings are free to attend and Tea and Coffee are available. Support Central England dougi@wmht.co.uk

report (patients seen in 2017) in March 2019. Preliminary results show an improvement in data collection and provide a good overview of the position on treatments, outcomes and survival across England and Wales. Treatment rates on the whole are improving, but there are still some Hospital Trusts that are outliers in this area, and

the reasons for the differences, to ensure that patients have equal access to services in their locality. New measures will be introduced for subsequent audits and these will be announced

Julia McAdam, LCNS, Shrewsbury

Mesothelioma Masterclass

In 2015 there were 2,697 new cases of Mesothelioma reported and in 2016 there were 2,496 deaths from mesothelioma reported. Overall, in the last decade the incidence of Mesothelioma has increased by 7%. (Cancer Research UK).

Patients who are diagnosed with mesothelioma still have very limited treatment options and there continues to be a variance across the UK on patient experience and access to specialist mesothelioma services. Many patients still continue to experience a poor prognosis. In the healthcare setting many healthcare professionals such as GPs, hospice teams, AOS teams, A&E staff and community nurses may need to provide care for a mesothelioma patient. It is therefore important that all healthcare professionals have a good understanding of this cancer and the often complex symptom burden that these patients will present with.

It is also acknowledged that many health care professionals now struggle to fund study days and so are unable to maintain a good level of knowledge around Mesothelioma.

With this in mind the Mesothelioma UK CNS at Guy's Hospital has linked up with Guy's Cancer Academy to provide a one day Mesothelioma Masterclass. The aim of the masterclass is to bring together a group of experts in the care and treatment of patients with a mesothelioma diagnosis to share best practice. The masterclass is aimed at all healthcare professionals who wish to build on their knowledge and skills around mesothelioma. CPD accreditation is currently being sought to ensure that attending the masterclass will benefit NMC revalidation other professional portfolios.

The masterclass has been kindly sponsored by Leigh Day, Hodge Jones and Allen and Irwin Mitchell Solicitors and the Mesothelioma Research and Support Group Charitable Fund at Guy's Hospital. Therefore we are delighted to announce that this day will be **free** to anyone who wishes to attend.

The date of the Mesothelioma Masterclass is the 20th May 2019 to be held at Guy's Hospital, London

If you would like submit interest in registering for the Mesothelioma Masterclass please email your name and email address to rachel.c.thomas@gstt.nhs.uk





MESOTHELIOMA NEWS



Women, men and gendered experiences of mesothelioma

On International Women's Day, 8 March 2019, Mesothelioma UK held a 'Ladies' Lunch' centred around the women, men and Gendered Experiences of Mesothelioma (GEM) study. The proposed study will explore men and women's experiences of mesothelioma in order to identify the implications for health, social care and legal practices. Consultation with health and legal professionals indicates that women may have a different experience to men regarding mesothelioma in terms of awareness of the disease, diagnosis, access to treatment and compensation and legal processes.

Later in the year we will be recruiting people to interview them about their mesothelioma experiences. The interviews will be conducted by phone. If you are interested in knowing more about the study – or in taking part – more information will be available from Mesothelioma UK by emailing info@mesothelioma.uk.com or calling 0800 169 2409.

Thanks to HASAG, Irwin Mitchell Solicitors and Papworth Mesothelioma Social Group who have provided funding for this valuable study.

Diary dates

This year's Action Mesothelioma Day will be held on Friday 5 July. Events will be held around the country and Mesothelioma UK's event will be at Leicester Cathedral.

The next Patient & Carer Day will be held on Friday 4 October in Blackpool.

Muffins for Meso fundraising – bake and sell muffins to raise money during May. Contact <u>jill.lemon@mesothelioma.uk.com</u> for a fundraising pack.

Military Mesothelioma Experience Study (MIMES)

The MIMES research study is being conducted as part of the wider Mesothelioma UK - Supporting our Armed Forces initiative which aims to raise awareness of the disease and establish a comprehensive shared approach to provide mesothelioma information and support for armed forces personnel and veterans.

The incidence of mesothelioma amongst UK military personnel is not known. It is important to understand more about the patient experience of mesothelioma amongst British armed forces personnel/veterans. This will help us to understand how to better meet the needs of those at risk of developing the disease, and those newly diagnosed.

The School of Nursing and Midwifery at the University of Sheffield is conducting some research to explore the experiences of British Armed Forces personnel/veterans with mesothelioma and their family members. The research engages with health professionals and support agencies to identify how services can best meet the health and support needs of these patients and their families. The project involves interviewing people with a mesothelioma diagnosis who have also served in the armed forces. Family members are also interviewed.

So far the MIMES has:

- recruited and interviewed six participants
- conducted some initial analysis of these interviews before recruiting additional participants
- welcomed Stephanie Ejegi-Memeh as the new researcher.

Please contact Angela Tod at <u>a.tod@sheffield.ac.uk</u> or call the Mesothelioma UK freephone information line on 0800 169 2409 to register your interest.



INFORMATION FOR PATIENTS



Few patients diagnosed with lung cancer are truly prepared for the impact their condition will have upon their own life and those of their family, friends and colleagues. As lung cancer nurse specialists know well, patients often find it difficult to retain much of the information given to them during consultations. Roy Castle Lung Cancer Foundation produces peer-reviewed information materials and services to support people in this situation. These are regularly updated to reflect advances in available therapies and other changes in circumstances.

The charity offers newly-revised versions of our booklets on 'Living With Lung Cancer', 'Understanding Small Cell Lung Cancer', 'Lung Cancer Facts and Figures' and 'Chemotherapy For Lung Cancer'. We have also updated the 'Travelling, Going On Holiday and Lung Cancer', 'Targeted Therapies and Lung Cancer', 'Immunotherapy and Lung Cancer' and 'Understanding Brain Metastases and Lung Cancer' booklets, as well as our 'Answering Your Questions' pack.

All these resources are available from Roy Castle Lung Cancer Information and Support Services, at the address below.

People may also need help in making a Will. The Foundation offers a suite of estate planning services, including FREE Will-writing, half-price Powers of Attorney provision, and funeral plans.

Details of these information materials and services are available at Roy Castle Lung Cancer Patient Information Day events.

The 2019 schedule of Information Days is currently being finalised, with the aim of covering locations right across the UK. The next event will take place in Stockton on Tees on 1 April.

Should you wish to contribute to the development of any materials or if you identify topics where information is not yet available, please get in touch with our Director of Information, Lorraine Dallas - <u>lorraine.dallas@roycastle.org</u>

We are always looking for patients who are prepared to share their experiences, participate in local awareness activities and feature in our campaigns. If you have any patients or carers who might be interested in taking part in these ways, please let us know.

Lorraine Dallas, Director of Information, Roy Castle Lung Cancer Foundation, 98 Holm Street, Glasgow G2 6SY Lorraine.dallas@roycastle.org





RESEARCH NEWS

The Research Interest Group



A big hello from me - Janelle Yorke, the new National Lung Cancer Forum for Nurses (NLCFN) Research Interest Group (RIG) Chair. I have taken over from Angela Tod. Angela has led the phenomenal development RIG from its very early beginnings. I hope that I am able to further develop the RIG and create a truly vibrant lung cancer nurse research community! This can only be achieved with your support and continued enthusiasm.

A little bit about me...I complete my nurse training and Masters of Nursing Research in Australia whilst holding numerous clinical roles in Intensive Care and Nurse Consultant. I moved to the UK for a one-year teaching post...that was 15 years ago! I completed my PhD which explored the experience of breathlessness in a number of different respiratory and

cardiac conditions and that work led to the development of the Dyspnoea-12 questionnaire which has been validated for use in many conditions including lung cancer.

Since 2015 I have held the joint Professorship in Nursing at the University of Manchester and The Christie Foundation NHS Trust and developed the Christie Patient Centred Research (CPCR) group. The primary objective of my research work has been to improve symptom experience and quality of life for people living with a long term illness, through the development of measurement tools, better understanding of the illness experience and palliative care needs of patients and their families, and the testing of multifaceted non-pharmacological interventions. I currently lead a programme of work (funded by Marie Curie and NIHR) to evaluate the effectiveness of a non-pharmacological intervention to manage the symptom cluster of breathlessness-cough-fatigue in people with lung cancer. I am passionate about the development of research and clinical academic careers in nursing and allied health professions; which is a key part of my role at the Christie. I am very much looking forward to working with NLCFN to further build on the Forum's research success.

The 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 the 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 NLCFN 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 NLCFN member. If you would like to join the RIG or would like more information please contact <u>info@nlcfn.net</u> The RIG meet four times a year and would love to hear from interested NLCFN members who would like to come along and share your ideas and research activities.

NLCFN Research database

The NLCFN Research Interest Group 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.

All you need to do is login (<u>https://www.nlcfn.org.uk/user/login</u>) to the NLCFN website and then go to <u>https://www.nlcfn.org.uk/research-projects</u> to add the details of your research project



RESEARCH NEWS

Call for Abstracts – NLCFN 20th Anniversary Conference 14/15 November 2019 - London

Members are invited to submit an abstract of no more than 250 words for presentation (oral or poster) at the conference. Abstracts can be on any subject of relevant to lung cancer nurse specialists working in the lung cancer/mesothelioma field. Abstracts can be on a clinical area or based on a project affecting service delivery, LCNS education or palliative care. Abstracts can be based on academic research, audit results or best practice.

Accepted abstracts meeting the criteria for publication will be published on the website, the conference app and in the conference handbook. All abstracts submitted will be reviewed by the committee. The abstract achieving the highest reviewer score will be invited to be presented in the main conference plenary session. **The deadline for submissions is 13 September**.

FOR THE STUDY OF

IASL

See https://www.nlcfn.org.uk/annual-conference/submitabstract

NLCFN Small Grants 2019

The NLCFN offers funding for one-two small projects per year up to a total value of £5000 per project. Projects should generate research, evaluation or audit data that inform the practice of forum members.

Applicants should demonstrate that their project meets some or all of the following criteria. Good scientific quality and rigour.

Terms and conditions apply. Deadline for applications 7 September 2019 More information and apply online via <u>https://www.nlcfn.org.uk/sm</u> <u>allgrants</u>

Call for Abstracts From Nurses and Allied Healthcare Professionals

As the world's largest meeting dedicated to lung cancer and other thoracic malignancies, IASLC WCLC 2019 will include specific tracks and workshops designed to meet the educational needs of nurses and healthcare professionals who treat patients with lung cancer.

🔐 TRAVEL AWARD

IASLE is othering Nurses or Alled Health Professionals presenting an accepted abstract the opportunity to apply for a Travel Award that will come with a complimentary conference registration, 4 nights' accommodation and 1,000 USD to help offset travel expenses. Important dates

January 8, 2019 Abstract Submission Opens

IASLC

20th World Conference on Lung Cancer

BER 7-10, 2019 BARCELONA, SPA

April 10 2019 (23:59 PST) Abstract Submission Deadline

For more information Please visit wclc2019.iaslc.org or email membership@iaslc.org with any questions

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MEMBER NEWS

Meet the committee – Introducing Pamela



I currently work as an advanced lung cancer clinical nurse specialist at the Beatson West of Scotland Cancer Centre in Glasgow. My role involves delivering systemic anti cancer therapy and radiotherapy pre assessment, follow up and supportive care to lung cancer patients from the West of Scotland. As part of a multidisciplinary team I will also be involved in trialling a prehabilitation clinic to improve the outcomes of those undergoing radical radiotherapy.

Holding a BSc Nursing Palliative Care and MSc Nursing Cancer Care I have quite varied experience in delivering cancer care across various settings including the NHS, private sector, local hospices (both in-patient and community), a national cancer charity and a local authority.

I am passionate about generating evidence to support practice development and have participated in two of the Lily workshops. As a lung cancer nurse specialist I have a special interest in the use of patient reported outcome measure to deliver patient focused care, the use of technology to improve the patient's experience and care pathway, prehabilitation and rehabilitation to improve patient outcomes. These interests have led to me delivering oral presentations, both nationally and internationally, including at the NLCFN, BTOG and ISLAC conferences.

At the heart of the National Lung Cancer Forum for Nurses is the commitment and drive to improve the quality of care that lung cancer patients receive. The forum gives us as nurses, and as advocates for our patients, a voice. It is with this voice that we can inspire a change in practice to set and improve the standards of care for lung cancer patients. As a committee member I hope to use my experience and passion to give lung cancer patients a voice, to be their advocate and to continue to raise the stand of care they receive.

Pamela Rose, LCNS Glasgow

Outstanding achievement Award

Calls for nominations for our prestigious Award for Outstanding Achievement are now being invited. This exclusive award, offered once every five years is open to any NLCFN member. Do you know someone you think deserves the award? Find out more about the award and how to apply at https://www.plofp.org.uk/plofp.award

https://www.nlcfn.org.uk/nlcfn-awardoutstanding-achievement

Annual Award 2019

The NLCFN invites applications for the 2019 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. Find out more at

https://www.nlcfn.org.uk/content/AnnualA ward



Social media

Are you following NLCFN on Twitter? You can follow us at <u>nlcfntweet</u>. We post regular messages and retweets and help keep you up to date with current news and information.

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



EVENTS



DATES FOR THE DIARY

10-13 April, Geneva Switzerland

European Lung Cancer Conference (ELCC)

https://www.esmo.org/Conferences/ELCC-2019-European-Lung-Cancer-Congress

28th April 2019, London

Nurse Prescribing in Cancer Care

https://www.healthcareconferencesuk.co.uk/nurse-prescribing-cancer

10th May 2019, America Square, London NCRI Lung Cancer CSG Annual Trials Meeting https://csg.ncri.org.uk/events/lung-cancer-csg-trials-meeting/

20th May 2019, Guys Hospital London Mesothelioma Masterclass Contact <u>rachel.c.thomas@gstt.nhs.uk</u>

28th June 2019, Kings College Strand Campus Pleural Research Day https://www.pleura.org.uk/wp/events/pleural-research-day/

27 Sept – 1St October 2019 European Society for Medical Oncology https://www.esmo.org/Conferences/ESMO-2019-Congress

7-10 September 2019 IASLC World Conference On Lung Cancer https://www.iaslc.org/events/iaslc-20th-world-conference-lung-cancer-wclc19

14 -15 November 2019 National Lung Cancer Forum for Nurses Annual Conference https://www.nlcfn.org.uk/annual-conference

4-6 December 2019 British Thoracic Society, London

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