

# lymphoma matters

CONFERENCE SPECIAL  
May 2018



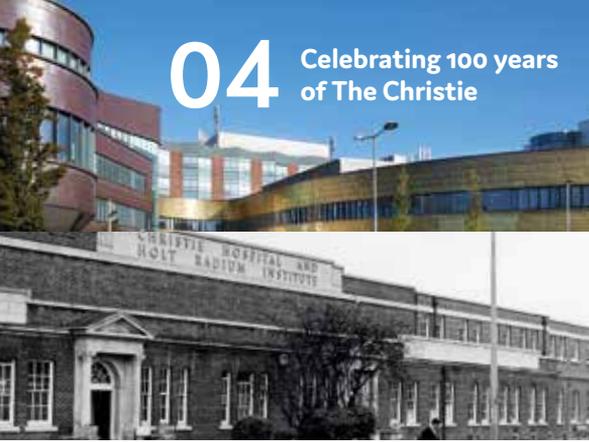
Conference  
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Speaker profiles

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Lymphoma  
action 

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Lymphoma Action is the UK's only charity dedicated to lymphoma, the fifth most common cancer in the UK, and the most common among young people aged 15-24. We've been providing in-depth, expert information and wide-ranging support for over 30 years, helping thousands of people affected by lymphoma. Our work drives improvements in the diagnosis, treatment, and aftercare of lymphoma. We're here for you.

Views expressed are those of the contributors. Lymphoma Action does not necessarily agree with or endorse their comments.

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Read the latest news  
[www.lymphoma-action.org.uk/news](http://www.lymphoma-action.org.uk/news)





Jane Gibson  
Lymphoma Nurse  
Clinician, The Christie  
Hospital

# Welcome to our National Conference

**In this special conference edition of *Lymphoma Matters* you will find the programme for the conference in the centre spread, followed by profiles of your speakers today. You can read about Clare and Neil's experience of lymphoma, as well as find out more about Lymphoma Action's education and training events for people affected by lymphoma.**

**Join us next year**  
Our 2019 National Conference will be held in London. Details to follow in *Lymphoma Matters* magazine.

I am a lymphoma nurse clinician at The Christie in Manchester and was one of the first lymphoma specialist nurses funded by Lymphoma Action (formerly Lymphoma Association) in 2005. I am delighted to be chairing the conference this year. Videos of the talks will be available on the Lymphoma Action YouTube channel after the conference.

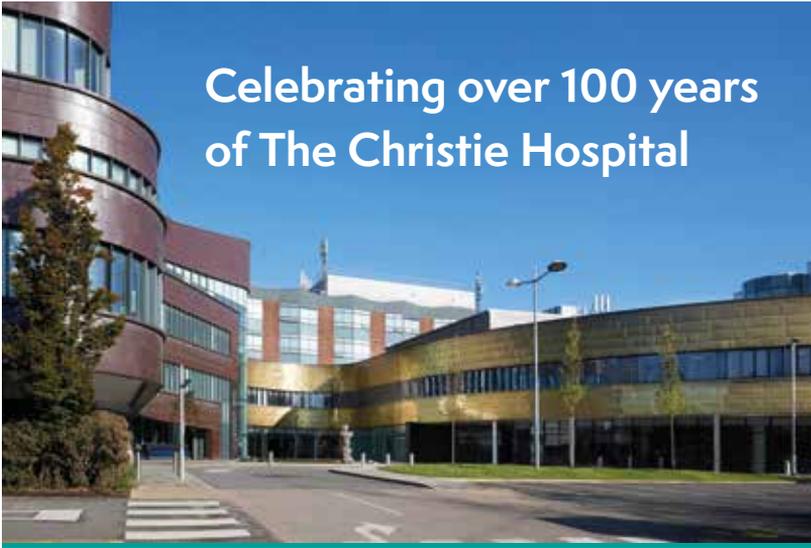


We hope you like this conference edition of *Lymphoma Matters*. You can sign up to regularly receive our magazine at [www.lymphoma-action.org.uk/signup](http://www.lymphoma-action.org.uk/signup)

It's an exciting time for the charity, moving forwards with the new name Lymphoma Action. I have witnessed their continued growth and success over the years, particularly in awareness-raising, support and education, and providing information for the increasing numbers of people affected by lymphoma. I am in no doubt these successes will continue into the future.

*Jane Gibson*  
Conference Chair

## Celebrating over 100 years of The Christie Hospital



We are enormously grateful to our speakers, many of whom are from The Christie. As we are here in Manchester, it seems fitting to look back at a hospital that has played such a crucial role in the advancement of cancer treatment and care.

### Did you know?

The Christie Hospital was founded in 1901 as a 30 bed hospital treating less than 500 people annually. In 1948, The Christie became part of the newly created National Health Service (NHS).

The Christie has one of the largest trials portfolios in the UK, with over 550 active clinical trials over all cancers and is a leading centre for lymphoma research.

Today, The Christie is the largest single site cancer centre in Europe, treating more than 44,000 patients each year.



### Firsts

- 1991** World's first single harvest blood stem-cell transplant performed at The Christie
- 2002** World's first clinical use of image guided radiotherapy on a radiotherapy machine.
- 2009** First trials in Europe undertaking pioneering radioimmunotherapy cancer treatment
- 2010** Patient treatment centre opens housing the world's largest single site early phase clinical trials unit and largest chemotherapy facility in the UK

### Coming soon –

A proton beam therapy centre will open later this year



# Lymphoma Action

New name and a fresher look, but it's still us. And we're here for you.



As the UK's only lymphoma-specific charity, we've been providing in-depth, expert information and wide-ranging support for over 30 years, helping thousands of people affected by lymphoma.



On 18 April 2018 we launched our new name, Lymphoma Action, with a fresh look and a new website.

## Why Lymphoma Action?

Lymphoma Action feels like a positive and inspirational name that reflects our progress as an organisation, our energy and initiative. We wanted a name that inspires hope and conveys our aspiration and ambition. It encompasses all that we

do to take action on behalf of people affected by lymphoma and empower them to take action themselves. It is also short and helps to differentiate us within a busy charity marketplace.

We're looking forward to the next 30 years - and beyond. Together we can

make sure that no one has to face lymphoma alone.

- Our new name Lymphoma Action gives us a louder voice and increases our reach.
- Our fresher look reflects our progress as a charity.
- Our new website makes it easier to find the information you need.

To find out more, please visit [www.lymphoma-action.org.uk](http://www.lymphoma-action.org.uk)





# With or without follicular lymphoma, I won't just wait for life to come to me

Clare



**'In 2010 I noticed a swelling in my abdomen. Because I have fibroids I just thought it was them. But I found I was uncomfortable, particularly around my waist and it hurt when I sat up. I mentioned this to my neighbour and we agreed I should visit my doctor.**

My GP arranged for me to have a colonoscopy which was inconclusive, so an ultrasound scan was planned, followed by a CT-guided biopsy.

Then it was a waiting game while the slides were sent off for an accurate diagnosis. After around two weeks, I was told I had follicular lymphoma.

I was to have treatment straightaway in the form of R-CHOP chemotherapy followed by two years of maintenance rituximab.

My life started to revolve around three week cycles. Week one I felt really terrible, week two was a bit easier and week three felt like party time.

I avoided planning anything for week one as I felt incredibly tired. I avoided sleeping in the day because I didn't want to ruin my sleep pattern, but I couldn't have coped with doing very much.

My hair started to come out in handfuls, so my neighbour came over and shaved my



Meet others,  
feel heard and share  
experiences at  
Lymphoma Action  
support groups

head. I would have found it more distressing seeing it disappear in handfuls than taking control myself and removing it. In fact, although I always covered my head, usually with a beret, I wasn't devastated about losing my hair.

**I had a PET scan before treatment started and then CT scans to ascertain how the lymphoma was responding. I was thrilled to hear the lymphoma was responding to the treatment and the scan at the end showed that the tumour had shrunk by 95%.**

I decided to try out a support group. Although I went along with some trepidation, from that first visit I have found the group really supportive and have made many new friends.

Having lymphoma has totally changed my life. I'm a great believer that you can't wait for life to come to you. You have to go out and make new friends and do the things you want to do. I get involved in volunteering at the Macmillan Information Centre at a local hospital and am a buddy for Lymphoma Action. I have also spoken at one of these conferences.

I was delighted to be awarded a Beacons of Hope Award last year for my work as a buddy, volunteer ambassador and my work for the support group.

I would like to thank my medical team for the wonderful treatment I have received, which has meant that I am here today to enjoy life with my sons and to watch my three amazing grandchildren growing up.'

*Clare*



## Did you know?

Follicular lymphoma is the most common single type of low-grade non-Hodgkin lymphoma.



**Would I take the winnings from the Euro millions or a clear PET scan?**

**A clear PET scan any day!**



## Neil talks about his diagnosis of grey zone lymphoma

**At the end of 2015 I noticed a minor cough, which wasn't troubling me and wasn't interfering with my running or cycling. By April my cough was getting worse and I noticed that I needed to cough at the end of every sentence.**

I went to see my GP who arranged for me to have an X-ray as a precaution. The X-ray showed a 5cm mass above my right lung, which was likely to be cancer. In truth, I was not surprised, as I was gradually coming to this conclusion.

A CT scan was arranged and an appointment with the consultant planned for the following day. By the end of the first week, I was having a CT-guided needle lung biopsy. Everything seemed to be moving along. Then

everything went quiet and there was the waiting.

I saw a consultant haematologist who explained that I had lymphoma, but that it was complicated. While most of the cells coming back from the biopsy were diffuse large B-cell like, in the middle there were also Reed-Sternberg like cells that are present in Hodgkin lymphoma.

My diagnosis was grey zone lymphoma, stage 2E. I had features of diffuse large B-cell lymphoma and classical Hodgkin lymphoma. My treatment would be six cycles of R-CHOP chemotherapy, probably followed by radiotherapy.

I decided to throw myself into sport. I wanted to be as fit as I could to manage the treatment and as robust as possible to give myself the best chance. I also tried to mentally prepare myself for the biggest challenge of my life. I had started out feeling shocked and at times a little angry. I had kept myself fit and had never smoked. But understanding that nothing I or anyone else had done had caused this and that it was random luck, helped.

**My diagnosis was grey zone lymphoma, stage 2E**

## I felt nervous about my first chemotherapy

and as a chemist I understood the potential side effects. On arrival, I found it reassuring to see people sitting around, reading magazines and behaving perfectly normally. In fact, the treatment wasn't nearly as bad as I feared, with no dramas.

We had arranged a family holiday in the Lake District just after my first cycle of chemotherapy. I had my reservations about going; I imagined lying on the floor being sick all the time. But we decided to go anyway. I hoped to be able to do some low level walking, but found I was managing well; so much so, we actually got to the top. I felt so emotional, as I hadn't expected to be able to do that. The next day I felt tired out, but I realised that even while undergoing treatment, I could still manage to have some lovely days. It was great to still do normal stuff together.

Suddenly I was on high alert about things being said or minor twinges that I would previously have ignored. My throat felt bad on one occasion and I started to think the lymphoma was spreading, and that the treatment wasn't working. It was only a mouth ulcer!

Because I had a lump behind my sternum bone, I could not

Grey zone is a rare type of high-grade B-cell lymphoma that is difficult to classify

see or feel it. So I couldn't judge whether the lump was going down. After the first round of chemotherapy, my cough vanished, which I took as a good sign that the treatment was working.

Ten days after the fourth cycle of chemotherapy, I was given a CT scan to see how the treatment was going. This was the first measurement and an important moment. About five days after the scan, I was told I was responding well and they would therefore carry on with the planned chemotherapy, followed by radiotherapy.

Because the tumour had reduced so much with treatment and was now relatively small, they could target it with radiation. At first I could not really tell that anything was happening. It didn't hurt and I felt fine. By the eighth or ninth session I

noticed I was feeling very tired and my throat was getting a bit tight. I was also starting to get cramps in my calves. The radiotherapy was taking its toll and I was relieved when it finished.

After treatment I needed to build up my muscles, especially in my legs, but didn't want to overdo it. I was shocked at how much slower I was than I had been before treatment, but I have gradually built it up and have a lot of plans for cycling, walking and climbing. At the end of April 2017, I had a three month post-treatment scan which showed I was in complete remission.

## How bad can a bad day get?

I think my perspective on life has changed. I used to take things very much more seriously, but a cancer diagnosis puts things into perspective. And if someone offered me the Euromillions or a clear scan, I know which one I would choose.'



Neil's full story will appear in a future issue of *Lymphoma Matters* magazine.

Make sure you have opted in to receive your free copy at [www.lymphoma-action.org.uk/signup](http://www.lymphoma-action.org.uk/signup)

# Programme

9:30

**Registration**

Meet the Lymphoma Action team and browse the information stands

10:20

**Introduction and welcome from Lymphoma Action**

Helen Mee, Education and Training Manager, Lymphoma Action, Jane Gibson, Lymphoma Nurse Clinician, The Christie



11:05

**Clinical trials**

Professor John Radford, Consultant Medical Oncologist, The Christie

11:35

Coffee break



12:20

**New approaches to living with and beyond cancer**

Ben Heyworth, Macmillan Survivorship Network Manager, The Christie

12:50

**Personal experience**

Hannah's experience of Hodgkin lymphoma

13:05

Lunch



14:40

**Managing the late effects of lymphoma**

Dr Laura Cove-Smith, Consultant Medical Oncologist, The Christie

15:10

Coffee break



15:20

**New and future developments in the treatment and management of lymphoma**

Dr Adam Gibb, Clinical Research Fellow, Lymphoma Research Team, The Christie

-  Refreshments
-  Manchester Suite
-  Optional parallel session in the Vienna or Milano Suite

**'I went home with a deeper understanding of lymphoma and very positive feelings'**



**10:35**

**Understanding your diagnosis: Advances in lymphoma diagnostics**

Dr Cathy Burton,  
Consultant Haematologist,  
Leeds Teaching Hospitals



**11:55**

**Coping with the emotional impact**

Dr Anna Ridding,  
Specialist Clinical  
Psychologist, Blackpool  
Victoria Hospital

**11:55-13:10**

**Working with and after lymphoma (Vienna Suite)**  
Barbara Wilson,  
Working after Cancer

*OPTIONAL*

**11:55-13:10**

**Cutaneous lymphoma (Milano Suite)**  
Dr Eileen Parry,  
UK Cutaneous  
Lymphoma Group

*OPTIONAL*



**14:10**

**The role of radiotherapy in lymphoma**

Dr Maggie Harris,  
Consultant Clinical  
Oncologist, The Christie

**14:10-15:15**

**Waldenström's macroglobulinaemia (Vienna Suite)**  
Dr Joshua Bomsztyk,  
UCLH and WMUK

*OPTIONAL*

**14:10-15:15**

**Chronic lymphocytic leukaemia (CLL) (Milano Suite)**  
Dr Elaine Vickers, Science  
Communicated Ltd

*OPTIONAL*

**16:00**

**Ask the expert:  
Put your questions  
to our team  
of experts**

**16:30**

**Closing remarks**  
Jane Gibson,  
Lymphoma Nurse  
Clinician,  
The Christie

**16:45**

Depart



# Biographies of the speakers

At this year's conference, we're fortunate to have a truly multidisciplinary team of speakers from across the UK, all experts in their field.



Dr Cathy Burton

**Dr Cathy Burton** studied medicine at the University of Cambridge. After haematology training in London, she moved to Leeds, completing a MD in Hodgkin lymphoma and then becoming an Academic Clinical Lecturer. In 2009, Dr Burton was appointed as a Consultant Haematologist at St James's University Hospital, Leeds, specialising in lymphoma and diagnostics. In 2014, she also became Clinical Lead of the Haematological Malignancy Diagnostic Service in Leeds. She is a member of the NCRI Lymphoma Clinical Studies Group and Hodgkin lymphoma subgroup. She has recently become a member of the Lunenberg Lymphoma Biomarker Consortium, which is an international collaboration studying the application of biomarker analyses to clinical practice in lymphoma. Dr Burton has recently become a trustee of Lymphoma Action.



Professor John Radford

**Professor John Radford** is Professor of Medical Oncology based at The Christie, Director of Research and clinical lead for the Manchester Cancer Research Centre (MCRC). His research interests are focused on developing and testing new ways of treating lymphoma and monitoring the effectiveness of these treatments using novel biomarkers. He is studying the late effects of chemotherapy on fertility, heart function and the risk of second cancers and is investigating how best to prevent or minimise the impact of these in people cured of lymphoma. He is an advocate of patient choice in healthcare systems and believes that patient organisations have an important role in terms of providing information and support and influencing the development of national policy. He is a member of the Lymphoma Action Medical Advisory Panel.



Dr Anna Ridding

**Dr Anna Ridding** is a Specialist Clinical Psychologist working in oncology at Blackpool Victoria Hospital. Dr Ridding received a BSc in Psychology at the University of Bath and went on to complete her Doctorate in Clinical Psychology more locally at the University of Liverpool. Her professional career has seen her work with patients experiencing psychological difficulties related to their physical health within the NHS for almost 10 years. Dr Ridding loves to travel and learn about the lived experiences of others!



Ben Heyworth

**Ben Heyworth** is the Macmillan Survivorship Network Manager and the LGBT and Cancer Strategy Manager at The Christie. Throughout his career, Ben has supported a number of successful transformation and service improvement projects, education and training initiatives, new research, the creation of patient information resources, and effective communication strategy for living with and beyond cancer.



Hannah

I'm **Hannah** and I am delighted to be here at the lymphoma patient conference in my home city of Manchester. I was diagnosed in July 2014 with grade 2 Hodgkin lymphoma aged 33, following a small swelling developing in my neck. I have travelled a complicated and challenging journey over the last four years. During this time I have received fantastic care, support and treatment at both Salford Royal and The Christie. I look forward to sharing details of my journey with you.



Dr Maggie Harris

**Dr Maggie Harris** graduated from Nottingham University in 1994 and trained in general medicine and oncology in Derby, London and Leeds before completing her training in Clinical Oncology at The Christie. She has been a consultant at the Christie since 2003 and gives both chemotherapy and radiotherapy. She specialises in lymphoma and lung cancer and is also heavily involved in medical education. Outside of medicine she is a keen runner and cyclist and loves crime fiction!



Dr Laura Cove-Smith

**Dr Laura Cove-Smith** gained her medical degree at Sheffield University before moving to Manchester to pursue a career in Medical Oncology at The Christie. She developed an interest in living with and beyond cancer during her speciality registrar training and gained a PhD exploring circulating and imaging biomarkers of cardiotoxicity in cancer survivors at the University of Manchester. Dr Cove-Smith is currently completing her registrar training and is a Consultant in early lung cancer at the University Hospital of South Manchester/The Christie.

## Biographies of the speakers *continued*



Dr Adam Gibb

**Dr Adam Gibb** trained in Newcastle-Upon-Tyne in the 1990s and has been working as a Clinical Research Fellow in Lymphoma at The Christie, Manchester, since 2009. As a part of a busy clinical research team seeing over 100 patients per week, he is a sub-investigator in a portfolio of over 30 clinical trials, the majority of which are early phase with novel agents. Dr Gibb has multiple publications in the field of lymphoma including first author of the BREVITY study in older/frailer Hodgkin patients.



Jane Gibson

**Jane Gibson** has been a nurse since 1989 and has specialised in haematology/oncology nursing for the past 20 years. She has worked in Belfast, London, and for the past 15 years, at The Christie in Manchester. In 2005 she was appointed as the second Lymphoma Action funded Lymphoma Clinical Nurse Specialist and maintains close links with the charity to date. Most recently, after completing an MSc in Advanced Practice, she works as a Lymphoma Nurse Clinician. She has a particular interest in the care of older people and those undergoing stem cell transplantation.



“  
An absolutely fantastic day. I left with more knowledge and felt more reassured.

# Breakout session biographies



**Barbara Wilson**

**Barbara Wilson** founded Working With Cancer in April 2013. Barbara is a senior HR professional with almost 40 years' experience following her degree in history at Cambridge. Nine years ago, after being diagnosed with breast cancer and based on her professional and personal experience, Barbara set up a group with the aim of helping those of working age affected by cancer to return successfully to work. In 2014, after attending the School for Social Entrepreneurs, Barbara re-launched Working With Cancer as a Social Enterprise providing coaching, training and consultancy services to employers, employees, carers and health professionals.



**Dr Eileen Parry**

**Dr Eileen Parry** is a Dermatologist in Manchester. She developed an interest in cutaneous (skin) lymphoma while training, and spent a year in Cleveland, USA to gain further experience. She set up the Manchester Cutaneous Lymphoma service in conjunction with colleagues at Salford Royal and The Christie. She has contributed to Lymphoma Action patient information leaflets, the UK clinical guidelines for management of cutaneous lymphoma from the British Association of Dermatologists and is secretary of the United Kingdom Cutaneous Lymphoma Group.



**Dr Joshua Bomsztyk**

**Dr Joshua Bomsztyk** graduated from the University of Birmingham in 2013 and won the Sally Tweddle award for Oncology. Dr Bomsztyk further completed an academic foundation programme at The Christie studying patient reported outcomes in lymphoma. He is currently a Clinical Fellow at University College London Hospital specialising in Waldenström's macroglobulinaemia. He is leading the Rory Morrison Registry for WM, a national project aimed at capturing the true landscape of WM in the UK.



**Dr Elaine Vickers**

**Dr Elaine Vickers** has a degree in medical science from the University of Birmingham and a PhD in Molecular Biology from the University of Manchester. She also has 15 years experience in communicating science to a wide range of audiences. She is the Founder of Science Communicated Ltd. Dr Vickers delivers energetic, interactive teaching on the biology of cancer and the mechanism of action of cancer treatments. She is passionate about her subject and an expert in creating illustrations and materials that explain complex science in understandable terms. Alongside delivering courses, Dr Vickers is currently writing a book 'A Beginner's Guide to Targeted Cancer Treatments', which is due to be published in 2018.

# Live YOUR life

Our Live your Life health and wellbeing project received Big Lottery Fund funding in January 2017 and since then we have reached over 800 people across the country.

**With a further 30 events planned in 2018, the number is sure to rise, and we are proud that we can support so many people across the UK to live well with and beyond lymphoma.**

Our Live your Life workshops are one-day events aimed at people who have recently finished lymphoma treatment or are on watch and wait. The workshops are free to attend and lunch and refreshments are included.

Each day is run by a facilitator, a volunteer who has personal experience of lymphoma, with the support of a member of the Lymphoma Action project team and a local nurse specialist. The group size is kept small and the day is interactive. Topics include:

- what is lymphoma?
- coping with the emotional aspects
- getting active after diagnosis and treatment
- maintaining a healthy lifestyle.

A highlight of the day for many attendees is the chance to meet and talk to others affected by lymphoma, and share experiences.

We also run Live your Life conferences, which cover similar topics but are delivered by expert speakers in a more formal way.

To find out more about our upcoming events, visit our website [www.lymphoma-action.org.uk/LYL](http://www.lymphoma-action.org.uk/LYL)



# KEY FACTS on Live your Life

We delivered  
**31**  
events  
in 2017

We have over  
  
**54**  
events  
planned in 2018



More than  
**800**  
people affected by  
lymphoma have  
attended a Live your  
Life event to date

This is what people  
say about our events:

**100%**

'I have learnt what I can  
do to live better during  
and after lymphoma'

**94%**

'I feel better able to cope  
with the emotional aspects  
of a lymphoma diagnosis'

**91%**

'I feel more comfortable  
contacting health professionals if I  
have any concerns about my health'

**94%**

'I feel I can better manage  
the physical side effects of my  
treatment'



**99%**

'I feel confident I can maintain a  
healthy, active lifestyle, even in  
times of stress'



The best part of the day  
was realising I'm not alone.  
I learnt loads about what  
lymphoma is and ways  
to cope with negative  
emotions. I left feeling  
inspired to live a more  
healthy, active lifestyle.

Live your Life workshop  
attendee, Bournemouth

It was great to meet  
everyone and have the  
chance to talk about my  
experiences. The facilitator  
was inspiring in the way  
they'd learnt to live their  
life with their lymphoma.

Live your Life workshop  
attendee, Southport

Thank you so much.  
I found the day  
inspirational and felt  
privileged to be present.  
Well run, comfortable,  
and excellent content.  
Please can we do another?

Lymphoma  
Clinical Nurse  
Specialist





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# Join us at Lymphoma TrialsLink Live this September

We're coming to:



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Basingstoke  
Glasgow



Learn more about clinical trials  
and the latest lymphoma  
treatment innovations.

Find out more and book your place:

 [lymphoma-action.org.uk/events](https://lymphoma-action.org.uk/events)

 [conferences@lymphoma-action.org.uk](mailto:conferences@lymphoma-action.org.uk)

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Check out the Lymphoma Action YouTube channel to watch a range of personal experience and medical information videos.



Conference presentations will be available by the end of June.



To make a comment, to sign up, or to unsubscribe to the magazine, email [publications@lymphoma-action.org.uk](mailto:publications@lymphoma-action.org.uk) or telephone 01296 619400.

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