



**BEATING BLOOD CANCER  
THROUGH RESEARCH**



**LEUKAEMIA  
& LYMPHOMA NI**

**Leukaemia & Lymphoma NI is  
the only charity in NI dedicated to  
research into developing life-saving  
new treatments for Blood Cancers.**

We support the Blood Cancer Research Group which is  
based at Queens University Belfast.



**Leukaemia & Lymphoma NI (LLNI)** is the only local charity in Northern Ireland dedicated to blood cancer research; all funds donated remain in NI to support projects that benefit local patients.

We also work closely with centres throughout the UK, Europe and America to ensure we are funding the most worthwhile research that will have the largest impact on patients both locally and globally.

**“ Ten years ago, my daughter Catherine was diagnosed with a rare form of leukaemia, she died just one week later. I wanted to do something about this disease, I wanted to ensure other families didn’t lose a loved one like we did. The key to improving patient outcomes is research, Leukaemia & Lymphoma NI is the only charity in Northern Ireland that funds the science that aims to deal with these cancers once and for all.”**

Richard Buchanan, LLNI Chairman



**Blood Cancer is the 5th most common cancer in the UK and the 3rd most fatal.**

**BEATING BLOOD CANCER  
THROUGH RESEARCH**



Our founder  
Mrs Olive McDowell.

# Our Story

Since 1964 we have been raising money to support local researchers and the science behind helping improve treatments and outcomes for blood cancer patients in NI. A family from Moira, the McDowells, set up the charity (then called NI Leukaemia Research Fund) after losing their teenage daughter Carole to leukaemia in 1963. Fundraising supported a first research fellow in 1965, followed by a major impetus in 1979 when the charity gave QUB money to establish a Chair of Haematology. Since then the charity's focus has extended to all blood cancers including lymphoma and myeloma, with a focus on funding education, research and clinical support as well as growing public awareness of these diseases and their symptoms.

To continue with this life saving research we need to raise at least **£650K every year.**

'It is thanks to our supporters that we are able to raise the needed funds and continue our work.

Based in Patrick G Johnston Centre for Research, we work closely with Queen's University and the Belfast City Hospital, funding education, research and clinical support for blood cancer.





Blood cancer is:

the **5th most common** cancer

the **most common cancer in children** and the under 30's

the **3rd most fatal** cancer

diagnosed in **3 people every day** in NI

killing **1 out of every 4** people diagnosed

# Blood Cancer

**Blood Cancer** is a type of cancer that affects your blood cells. DNA mutations are the main cause of blood cancers, and as such we are investigating how mutations alter normal blood cell development.

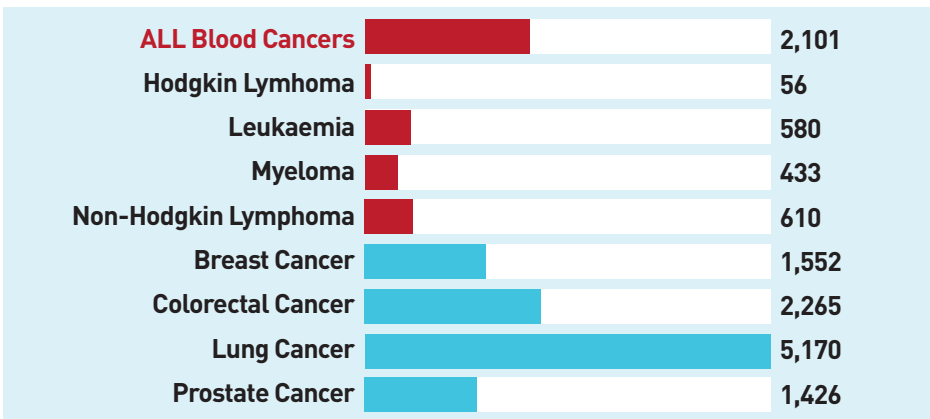
Once we fully understand these molecular changes and what happens when they occur, we can use that knowledge to develop very targeted therapies.

**Blood cancer** is an umbrella term for cancers that affect the blood, bone marrow and lymphatic system.

Blood cancers can be life-threatening, partly because they stop the immune system working properly.

When someone's immune system is badly damaged, they can die from an infection their body could normally fight off.

**The total European-age standardised rate (EASR) incidence of haematological, breast, colorectal, lung and prostate cancers in Northern Ireland 2015 - 2019.**



Data provided by the Northern Ireland Cancer Registry.



**Blood cancer is an umbrella term for around 140 different haematological disorders.**



The 3 main types of blood cancer are **leukaemia**, **Lymphoma** and **myeloma**. They can affect anyone, anywhere, at any age, although over **60 years is most common**.

## BLOOD CANCER TREATMENT

There's a range of different treatments for blood cancer. You might have one type of treatment or a number of them, depending on the type of blood cancer you have.

**Common blood cancer treatments include:**

- Chemotherapy
- Targeted therapies
- Immunotherapy
- Radiotherapy
- Stem cell transplants.

**If you have a slow-growing blood cancer, you may not need treatment straight away, and some people never need it.**

**LLNI** funds research to understand how blood cancer develops and to improve treatments and side effects for patients, with a focus on precision medicine for better outcomes.

**Research is vital:**

Since 1949, the survival rate for many blood cancer patients has **doubled or tripled**, and in some cases **quadrupled**

Sixty years ago, a child's chance of **surviving leukemia was three percent**; today, **9 out of 10 are alive** thanks to research

**Hodgkin lymphoma** patient survival rates have more than doubled to **88%** since the 1960s

Survival rate for **myeloma patients** have **tripled in past decade**

# Leukaemia

occurs when white blood cells (leukocytes) become cancerous.

This means they are **unable to fight off infections**. It also affects the **bone marrow and its ability to produce red blood cells and platelets**.

## Types of leukaemia include:

### AML

Acute Myeloid Leukaemia

### APL

Acute Promyelocytic Leukaemia

### CLL

Chronic Lymphocytic Leukaemia

### ALL

Acute Lymphoblastic Leukaemia

### CML

Chronic Myeloid Leukaemia

Symptoms in adults and children are very similar, however, **symptoms in children can develop more quickly**.



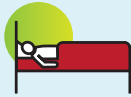
In the UK, **1 in 63 men** and **1 in 94 women** will be diagnosed with **leukaemia** in their lifetime.



## SYMPTOMS



Recurring infections



Extreme Fatigue



Unexplained weight loss



Unusual Bruising

Can be **acute** (fast growing)

**OR**

**chronic** (slower growing)

The National Institute for Health and Care Excellence (NICE) recommends children be offered a very urgent blood count due to the acute nature of leukaemia in children.

## RESEARCH

**LLNI** is currently funding a PHD investigating immune activation in AML to identify new treatment strategies, a PHD on understanding primary chemotherapy resistance in childhood AML, a PHD on genetic dependencies of AML, and research on how we can exploit the immune system to target leukaemic cells, as well as the **CURED** project on therapeutic resistance in paediatric AML. We are funding 2 new PHDs on Azitidine-treated AML and ALL starting September 2024.





# Lymphoma

occurs when white blood cells become abnormal and start to divide and grow uncontrollably.

There are many types of **Lymphoma**.

## Two main types of lymphoma are:



### Hodgkin Lymphoma

Non-Hodgkin lymphomas that are fast-growing:

- Diffuse large B cell lymphoma
- Burkitt lymphoma
- Most T-cell lymphomas



### Non-Hodgkin Lymphoma

Non-Hodgkin lymphomas that are slow-growing:

- Follicular lymphoma
- Waldenström macroglobulinaemia



Over **14,000** people

Symptoms can vary and may include:

## SYMPTOMS

Painless swelling of lymph nodes in the belly, neck, armpits or groin.

Pain in chest, abdomen or bones.



Unexplained itching



Night sweats



Unexplained weight loss



High temperature - no obvious infection

are diagnosed with **lymphoma** each year in the UK, making it the most common blood cancer.

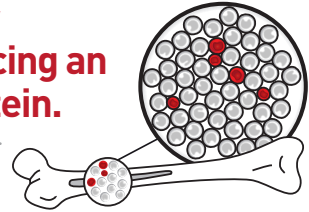
## RESEARCH

There are many challenges and complications with lymphomas. Immune system problems are a key feature of HL, and patients can become resistant to treatment in NHL. **LLNI** funds ongoing research into Non-Hodgkin Lymphomas to investigate alternative treatment strategies for patients who relapse and go on to develop resistance to the drugs they have been treated with. **LLNI** is funding a new Fellowship to recruit a future leader of lymphoma research from September 2024.

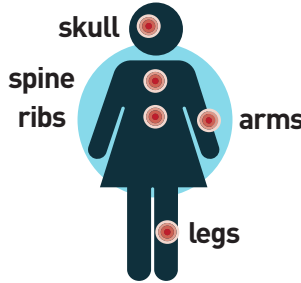
# Myeloma

When the cells responsible for antibody production (plasma cells) undergo malignant change during development.

The damaged cells **multiply and grow within the bone marrow, often producing an abnormal protein, known as paraprotein.**



Can affect multiple locations in the body - sometimes referred to as **multiple myeloma.**

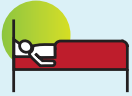


## Myeloma

affects older people over the age of

**65** years old.

## SYMPTOMS



Overwhelming tiredness



Kidney damage



Recurring infections



Bone or joint pain

## RESEARCH

LLNI funds a project **MyMatters** studying metabolic changes in drug resistant myeloma cell lines which has identified a number of drugs that seem to be particularly effective against resistant myeloma cells. LLNI also funds a PhD and postdoctoral fellow investigating a novel therapeutic target for myeloma and a PhD exploring the role of exosomes, a type of small vesicle that cells use for communication, in promoting drug resistance in myeloma.



There are around

**17,500**

patients diagnosed and living with myeloma in the UK.



# Know the symptoms

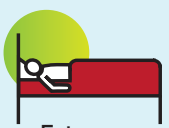







Early diagnosis improves outcomes, if you are concerned about symptoms, see your GP.

Blood cancers like **leukaemia**, **lymphoma** and **myeloma** have numerous signs and symptoms.

Not everyone will experience the same symptoms and in some cases no symptoms will be evident.

Many of the symptoms of **blood cancers** are associated with other illnesses like colds and flu.

### KNOW THE SYMPTOMS

 <p>Extreme Fatigue</p>	 <p>Unusual Bruising and/or Bleeding</p>	 <p>Extreme Sweating, particularly at night</p>
 <p>Recurring infections</p>		 <p>Shortness of breath</p>
 <p>Pain in bones and joints</p>	 <p>Lumps</p>	 <p>Unexplained fever</p>

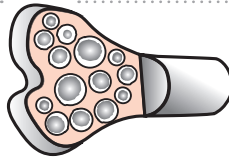
Early diagnosis improves outcomes, so if you are concerned about symptoms, see your GP.

A range of tests can help to diagnose blood cancers, such as: Blood tests, Bone marrow biopsy, Lymph node biopsy, Scans, Genetic tests, Immunophenotyping.

# Myelodysplastic Syndromes (MDS)

A **rare** type of **blood cancer** where the bone marrow doesn't make enough healthy blood cells.

Bone marrow is gradually taken over by immature blood cells.



Can progress **slowly** or **aggressively**

Can develop into **Acute Myeloid Leukaemia**

**MDS** can affect any age but most common in those aged

**70**

**TO**

**80** years old.

## SYMPTOMS



Unusual Bruising and/or Bleeding



Weakness



Recurring infections



Shortness of breath

## RESEARCH

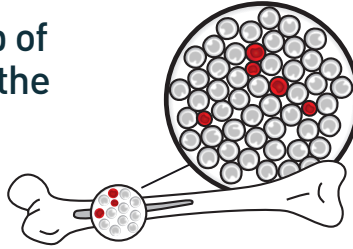
**LLNI** is funding a research project known as **MyBlock** which is focused on myeloid malignancies including **MDS** as well as **AML** and **MPN**.

It aims to understand the genetic mutations in myeloid malignancies at diagnosis and during disease and to identify targeted combination therapies to inhibit these mutations and more effectively treat the cancer. Now in Phase 2, we plan to investigate further by expanding the cohort of patients studied and improving the panel so that it can be used to identify combinations for other blood cancers such as **myeloma**.



# Myeloproliferative Neoplasms (MPNs)

**MPNs** are a group of rare disorders of the bone marrow.









**MPNs** mainly affect people who are

over **60** years old.

Develops

**slowly**

Progresses **slowly**

SYMPTOMS		
 <p>Blurred vision</p>	 <p>Ringing in ears</p>	 <p>Unusual bruising/bleeding</p>
 <p>Tiredness</p>	 <p>Recurring infections</p>	 <p>Frequent Headaches</p>

## RESEARCH

LLNI has awarded a grant to the **MOSAICC Study** which aims to piece together the causes of **MPNs**.

The project, led by researchers from QUB and University of Aberdeen, will see the largest ever case-control study of **MPNs**.

As of 31 July 2024, the MOSAICC study has recruited 583 participants (438 people with MPNs and 145 people without MPNs (controls) across the UK and Ireland. The hope is it will provide much needed information on the risk factors for **MPNs** and the impact that this condition has on patients' quality of life.



## Our work

Based in Patrick G Johnston Centre for Cancer Research, we work closely with Queen's University and the Belfast City Hospital, funding education, research and clinical support for blood cancer. We fund world-class innovative projects here in Belfast that not only have an impact on local patient treatments and outcomes, but are also shared with the global blood cancer community.

Successful new treatments, repurposed drugs or new drug combinations can then be used in clinical trials and ultimately can be offered by Haematology consultants as new, specialised treatments for their patients.

**All funds donated to LLNI remain in Northern Ireland to support our many projects here.**

- The charity has invested more than £14 million in research since its inception.
- This year alone, **LLNI** has committed over £1.5 million to blood cancer research projects.
- The research that **LLNI** support is aimed at improving diagnosis, identifying more effective treatments and improving patient outcomes.

### LLNI CURRENTLY SUPPORT



**1**  
LECTURER AND  
SENIOR RESEARCHER



**1**  
RESEARCH  
FELLOW



**1**  
LABORATORY  
TECHNICIAN



**1**  
POSTDOCTORAL  
RESEARCHER



**8**  
PHD STUDENTS



**1**  
CLINICAL  
TRIALS  
NURSE



**1**  
PATIENT  
SUPPORT  
WORKER



**&**  
A NUMBER  
OF EXTERNAL  
PROJECTS



# Our team



Joanne Badger  
Operations Manager



Claire Gilmore  
Administration Manager



Collette McMorrow  
Donor Relations Manager

## The board



Richard Buchanan  
Chairman



David Montgomery



Brigid Napier



Prof. Terry Lappin



Graham Coulter



Leanne Cascone



Rob Cascone



Prof. Curly Morris



Aisling Kearney



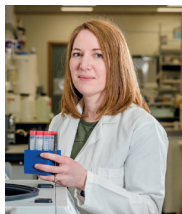
Michael Cafolla

Anna Greenfield and Brendan C. Garland



# LLNI funds

world-class innovative projects led by senior researchers



## **Dr Lisa Crawford**

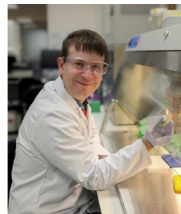
Lecturer and senior principal investigator for the Blood Cancer Research Group.

Pioneering new research into enhancing treatments for myeloma. Dr Crawford and her team investigate how myeloma cells develop resistance to standard therapies and use this information to identify ways to enhance the therapeutic response.



## **Katrina Lappin**

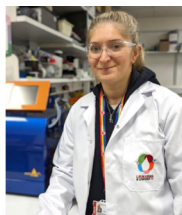
LLNI Fellow exploring immune activation in MDS and AML, and how we can exploit the immune response to target leukaemic cells.



## **Graeme Greenfield**

Academic Clinical Lecturer

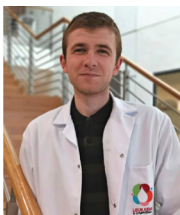
How do individual AML cells adapt to avoid cell death after treatment with azacitidine and venetoclax in individual patients.



## **Hayley McMillan**

Research Assistant

Understanding the genetic mutations in myeloid malignancies at diagnosis and during disease progression, and to also identify specific drug combinations that inhibit these mutations, a project called MyBlock2.



## **Jonathan Morgan**

Post Doc Researcher

Understanding the role of the HUWE1 protein in Multiple Myeloma and to evaluate its potential as a target in the treatment of the disease.



## **Lydia Roets**

PostDoc Researcher

CURED Study  
Characterising drivers of therapeutic Resistance in paediatric AML (CURED study).





# LLNI funds

5 PHD students with 3 more starting in September 2024

**LLNI** is proud to support new PHD students each year, and from September 2024 we will be funding a PHD focused on lymphoma and 2 PHDs focused on AML and ALL.



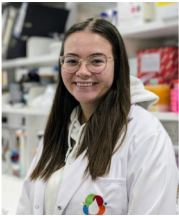
**Alex Mutch, PhD**  
Genetic dependencies of spliceosome mutated myelodysplastic syndromes and acute myeloid leukaemia.



**Chloe Wylie, PhD**  
Exosome-mediated molecular mechanisms in the progression of multiple myeloma.



**Edward Tang, PhD**  
Understanding primary chemotherapy resistance in childhood acute myeloid leukaemia.



**Beth McCrea, PhD**  
Developing small molecule inhibitors to target HUWE1 mutation.



**Rebecca Briggs, PhD**  
Investigating immune activation in myelodysplastic syndromes and acute myeloid leukaemia in the hope of identifying new treatment strategies for patients.



# LLNI funds

**The Scientific and Medical Advisory Committee** is a panel of independent researchers and clinicians who provide recommendations to **LLNI** on decisions relating to the funding and management of research projects.

They ensure that all **LLNI** funding awards support the highest quality research and will consider applications for funding for basic, translational and clinical related research.

## Current Members:

Dr Aaron Niblock, Dr Kathryn Clarke, Dr Lynn McCallum, Dr Bridgin Merron, Dr Glenda Joanne Dickson.



**Laura Croan**  
Clinical Trials Nurse,  
Belfast City Hospital

## Clinical Trials Nurse (2022 - 2027)

This role is co-funded by **LLNI** and the HSC PHA Research and Development Division for the NI Cancer Trials Network.

Involved in screening and recruitment of patients, organising their treatment and ensuring the smooth running of the study supporting the patient for the duration of their study treatment and into the follow up period when treatment is complete.



**Susanne McNeilly**

## Blood Cancer patient supporter (2024 - 2026)

A new role created and co-funded with **Leukaemia Care** to provide blood cancer patients at Belfast City Hospital Bridgewater Suite and Antrim hospital with a listening/signposting holistic support service.





# Raising Awareness

Another key aim of **LLNI** is to raise awareness of blood cancer to the NI public, as well as help to advocate for improvements in care and ensure patients here have the same access to treatments and care as other UK patients.

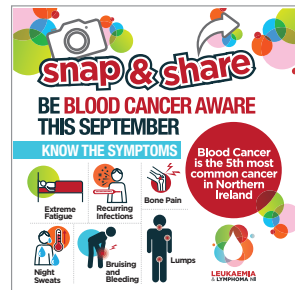
**31% of people** with blood cancer have to visit their GP **three or more times** before being diagnosed.

**76% of people** with blood cancer say they **were not told their condition was a type of blood cancer** when they were diagnosed.

**Blood Cancer Awareness Month** is held every September to raise the profile of blood cancer, which doesn't get the attention of other cancers. **LLNI**, along with other blood cancer charities across the UK, has a program of activities in the month of September, to raise public awareness of blood cancers. This can include civic buildings being lit up red, fundraising activities and events, and information sharing. The month includes specific blood cancer type awareness days to highlight symptoms, treatments and patient stories.

## September 2024 dates are:

- 1st: CLL Awareness Day
- 4th: Leukaemia Awareness Day
- 12th: MPN Awareness Day
- 15th: World Lymphoma Awareness Day
- 20th: World ALL Day
- 22nd: World CML Day
- 27th: European Myeloma Day





NICCC Launch event at Stormont, June 2024



# Advocacy work

## Blood Cancer Alliance

We are a member of the **Blood Cancer Alliance**, a group of UK blood cancer charities. Our vision is to see all people with blood cancer live longer, better lives. Together, we are going to change the conversation around blood cancer in order to improve diagnosis, treatment and care.

### **BCA's goals for blood cancer patients:**

- Diagnosis is improved for all blood cancer patients
- All blood cancer patients have access to kinder, better treatments, trials and care across the UK
- Health inequalities do not influence access to diagnosis, treatment and support.

### **BCA's goals for UK cancer policymaking:**

- Blood cancer is recognised as a common cancer
- Blood cancer is addressed in national cancer strategies, plans and policies.

## Northern Ireland Cancer Charities Coalition

**LLNI** is also a member of the NICCC (Northern Ireland Cancer Charities Coalition) – a group of 34 cancer charities working across all Health Trusts. Formally partnering to establish a local sector voice, the aim of the membership organisation is to strengthen advocacy on cancer issues and facilitate more streamlined and unified engagement with governing officials.





Multiple myeloma patient and committed supporter Eleanor & husband Sam

# Why Fundraise?

The money you raise will be used to fund research based at the Patrick G. Johnston Centre for Cancer Research (PGJCCR) at Queens University, Belfast.

The **LLNI** scientists are experts in their field and with their research they aim to understand how the disease develops, better methods of treatment and ultimately improve the outcome and quality of life for all patients affected by leukaemia, lymphoma, myeloma and other related conditions.

Why not set up an online giving page to allow people to donate online at: <https://justgiving.com/nlrf> or via our QR code.





# Legacy giving

Making a will can be a daunting thought, but as we all know tomorrow isn't promised.

Making a will ensures that your loved ones are looked after and your wishes are met.

Choosing to leave a gift to **LLNI** is a wonderful gesture to ensure that your legacy lives on through research long after you are gone.

If you would like further information about legacy giving and why leaving a gift in your will can be so meaningful please get in touch.

Our free Will You guide provides information and advice on leaving a gift in your will. Download your copy at <https://llni.co.uk/get-involved/>



# Some useful contacts

## Action Cancer

[www.actioncancer.org/](http://www.actioncancer.org/)

## Blood cancer UK

[www.bloodcancer.org.uk](http://www.bloodcancer.org.uk)

0808 2080 888

[support@bloodcancer.org.uk](mailto:support@bloodcancer.org.uk)

## Cancer Focus NI

[www.cancerfocusni.org/](http://www.cancerfocusni.org/)

Cancer Nurseline: 0800 783 3339

(Mon-Fri 9am -1pm)

Nurseline/Group Work Facilitator:

Valerie Magowan

[valeriemagowan@cancerfocusni.org](mailto:valeriemagowan@cancerfocusni.org)

Direct Line: 028 9066 3281

Mobile: 07769365667

## Cancer Fund for Children

[www.cancerfundforchildren.com/](http://www.cancerfundforchildren.com/)

## Children's Cancer Unit Charity

[www.childrenscancerunit.com/](http://www.childrenscancerunit.com/)

## Friends of the Cancer Centre

[www.friendsofthecancercentre.com/](http://www.friendsofthecancercentre.com/)

## Leukaemia Care

[www.leukaemiacare.org.uk/](http://www.leukaemiacare.org.uk/)

Talk to our Nurse or Support team about yours or a loved one's diagnosis of leukaemia, MDS or MPN

Call our freephone helpline

on 08088 010 444

or chat via WhatsApp on 07500068065

## Leukaemia UK

[www.leukaemiauk.org.uk](http://www.leukaemiauk.org.uk)

## Lymphoma Action

[www.lymphoma-action.org.uk](http://www.lymphoma-action.org.uk)

## Lymphoma out loud

[www.lymphomaoutloud.org/](http://www.lymphomaoutloud.org/)

## Macmillan Cancer Support

[www.macmillan.org.uk](http://www.macmillan.org.uk)

## Marie Curie

[www.mariecurie.org](http://www.mariecurie.org)

## Myeloma UK

[www.myeloma.org.uk](http://www.myeloma.org.uk)

Infoline: 0800 980 3332 for practical advice, emotional support and a listening ear.

## NICan (Northern Ireland Cancer Network)

[www.nican.hscni.net](http://www.nican.hscni.net)

Information about services in NI to support people with cancer and their families.

## MPN Voice

[www.mpnvoice.org.uk/](http://www.mpnvoice.org.uk/)

## MDS UK Patient Support Group

[www.mdspatientsupport.org.uk/](http://www.mdspatientsupport.org.uk/)

## MDS Foundation

[www.mds-foundation.org/](http://www.mds-foundation.org/)

LLNI & Leukaemia Care Patient Supporter: Susanne McNeilly

[Susanne.McNeilly@leukaemiacare.org.uk](mailto:Susanne.McNeilly@leukaemiacare.org.uk)

## Leukaemia & Lymphoma NI

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Sign up to our Newsletter via email or our website [llni.co.uk](http://llni.co.uk)



If you would like further information on LLNI, our events or how you can support our work, please email [info@llni.co.uk](mailto:info@llni.co.uk)

   [www.llni.co.uk](http://www.llni.co.uk)