



# ECLLA European Policy Roundtable 2026

“Pathways to Equitable CLL Care Across Europe”

Dublin, Ireland | 9 May 2026

## SUMMARY REPORT

✉ [info@eclla.org](mailto:info@eclla.org)

🌐 [www.eclla.org](http://www.eclla.org)

The first **ECLLA European Policy Roundtable 2026**, held in **Dublin**, Ireland on **9 May 2026**, brought together a diverse group of patient advocates, clinicians, healthcare professionals, researchers, policymakers, and industry representatives from across Europe to discuss inequalities, unmet needs, and future priorities in Chronic Lymphocytic Leukemia (CLL) care.

Hosted under the theme **“Pathways to Equitable CLL Care Across Europe”**, the Roundtable created a collaborative European platform to explore differences in diagnosis pathways, access to innovative therapies and clinical trials, psychosocial support, immune health, and broader patient experience across healthcare systems. Participants represented a broad range of national perspectives from Western, Northern, Southern, and Eastern Europe, highlighting both shared challenges and important examples of progress and good practice.

The discussions reinforced that despite major advances in CLL treatment and outcomes in recent years, significant inequalities remain across Europe in access to diagnostics, molecular testing, innovative therapies, supportive care services, and psychosocial support. Participants also highlighted persistent differences in healthcare infrastructure, reimbursement systems, awareness, and patient involvement in decision-making.

Particular attention was given to the emotional and psychosocial burden of living with CLL, the importance of immune health and infection management, and the growing need for more holistic and patient-centred care models. Discussions also emphasised the importance of improving collaboration between patient organisations, clinicians, policymakers, researchers, and industry partners to support more equitable outcomes across Europe.

The Roundtable served as the foundation for several strategic ECLLA initiatives planned for 2026–2027, including the development of the ECLLA Policy Brief 2026, the European CLL Equity Declaration, and the future ECLLA CLL Access Observatory project. Together, these initiatives aim to strengthen evidence-based advocacy, improve visibility of CLL within European health policy discussions, and support long-term collaboration focused on reducing inequalities in care.

The meeting demonstrated strong engagement from participants and reinforced the shared ambition to work collectively toward more equitable, informed, and patient-centred CLL care across Europe.

The **European CLL Association (ECLLA)** is a European initiative dedicated to improving outcomes for people living with Chronic Lymphocytic Leukemia (CLL) through collaboration, research, advocacy, and education.

ECLLA brings together national patient advocacy groups (PAGs), clinicians, researchers, policymakers, and industry partners to strengthen understanding of CLL, its biology, immune dysfunction, and infection management, while promoting more equitable access to innovative therapies and high-quality care across Europe.

Guided by a shared ethical foundation centred on respect, collaboration, transparency, and integrity, ECLLA works to address persistent inequalities in diagnosis, treatment access, supportive care, and patient experience between Western and Northern Europe and Southern and Eastern European regions.

**ECLLA's activities focus on five core strategic areas:** Policy & Access, Networking & Collaboration, Patient Empowerment & Education, Immunity & Infection Management, and Research & Data Collaboration.

Through these efforts, ECLLA aims to ensure that every person living with CLL in Europe receives equitable, informed, and optimal care.

**Website:** [www.eclla.org](http://www.eclla.org)

## The Roundtable aimed to:

- Explore inequalities in CLL diagnosis, treatment, care, and support across Europe
- Identify national and regional challenges impacting patients and healthcare professionals
- Share examples of good practice and successful initiatives
- Better understand unmet psychosocial and supportive care needs
- Strengthen European collaboration between stakeholders
- Define future advocacy and policy priorities for ECLLA





The main Roundtable discussions explored multiple dimensions of the CLL patient pathway and broader European policy landscape.

**Key discussion themes included:**

1. Timely Diagnosis and Referral
2. Access to Clinical Trials and Innovative Therapies
3. Inequalities Across European Healthcare Systems
4. Infection Management and Immune Health
5. Psychosocial Support and Quality of Life
6. The Role of Patient Advocacy in Policy Change
7. Data, Registries, and Evidence Generation
8. European Collaboration and Future Priorities



## Several themes consistently emerged throughout the discussions:

- Significant inequalities continue to exist across geographic Europe in diagnosis, treatment access, and supportive care
- Collaboration between patient organisations, clinicians, policymakers, and industry partners is essential
- Patient voice and lived experience should remain central to future policy development
- Education and awareness remain major unmet needs across multiple stakeholder groups
- Real-world evidence and data generation are increasingly important to support advocacy and policy engagement
- Mental health and psychosocial wellbeing require greater visibility and integration into routine care
- Cross-country learning and sharing of good practices can accelerate progress toward more equitable CLL care



Industry partners participated as important stakeholders within the broader multi-stakeholder discussions focused on improving equity and outcomes in CLL care.

The Roundtable provided an opportunity for open dialogue around access challenges, innovation, supportive care, patient experience, and future collaboration opportunities.

Participants recognised the importance of continued engagement between patient organisations, healthcare professionals, policymakers, and industry in supporting:

- Improved access to innovation
- Education and awareness initiatives
- Data and evidence generation
- Supportive care and quality-of-life initiatives
- Sustainable European collaboration

The meeting reinforced the value of collaborative and patient-centred approaches to addressing inequalities in CLL care across Europe.



## Johnson & Johnson

**We would like to thank the following ECLLA foundational funders for their support and for making this important European dialogue possible.**

This meeting and associated activities were supported by industry partners. Supporting partners had no influence over the content, discussions, conclusions, or recommendations contained within this report.



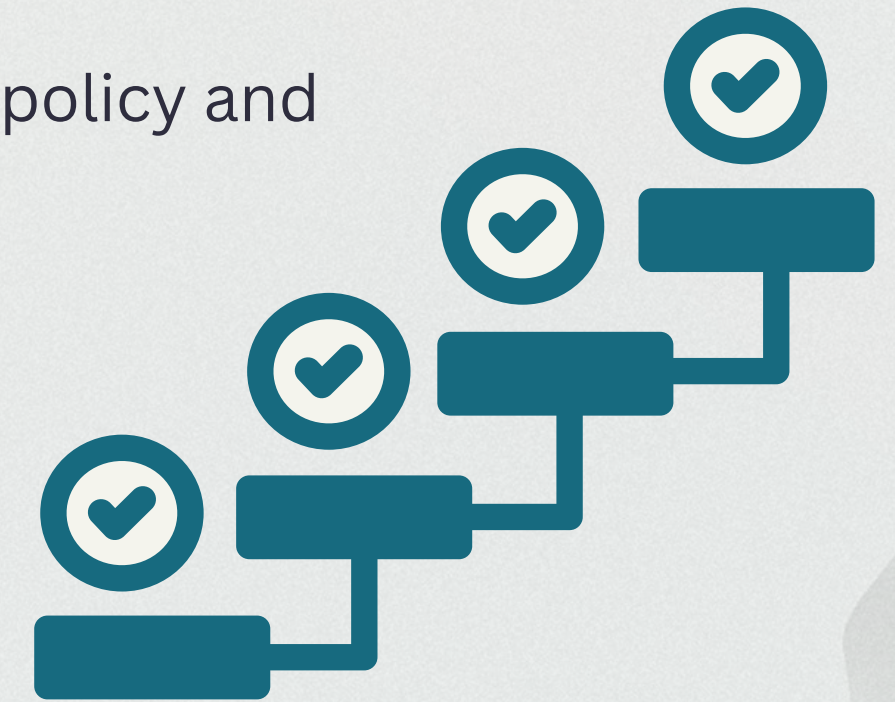
Following the Roundtable, ECLLA will continue work on the next phase of its European policy and advocacy activities.

### Planned next steps include:

- Development of the ECLLA Policy Brief 2026
- Drafting and refinement of the European CLL Equity Declaration
- Further development of the ECLLA CLL Access Observatory concept
- Continued engagement with European stakeholders and partners
- Expansion of awareness, education, and advocacy initiatives
- Identification of future collaboration opportunities across research, policy, and supportive care

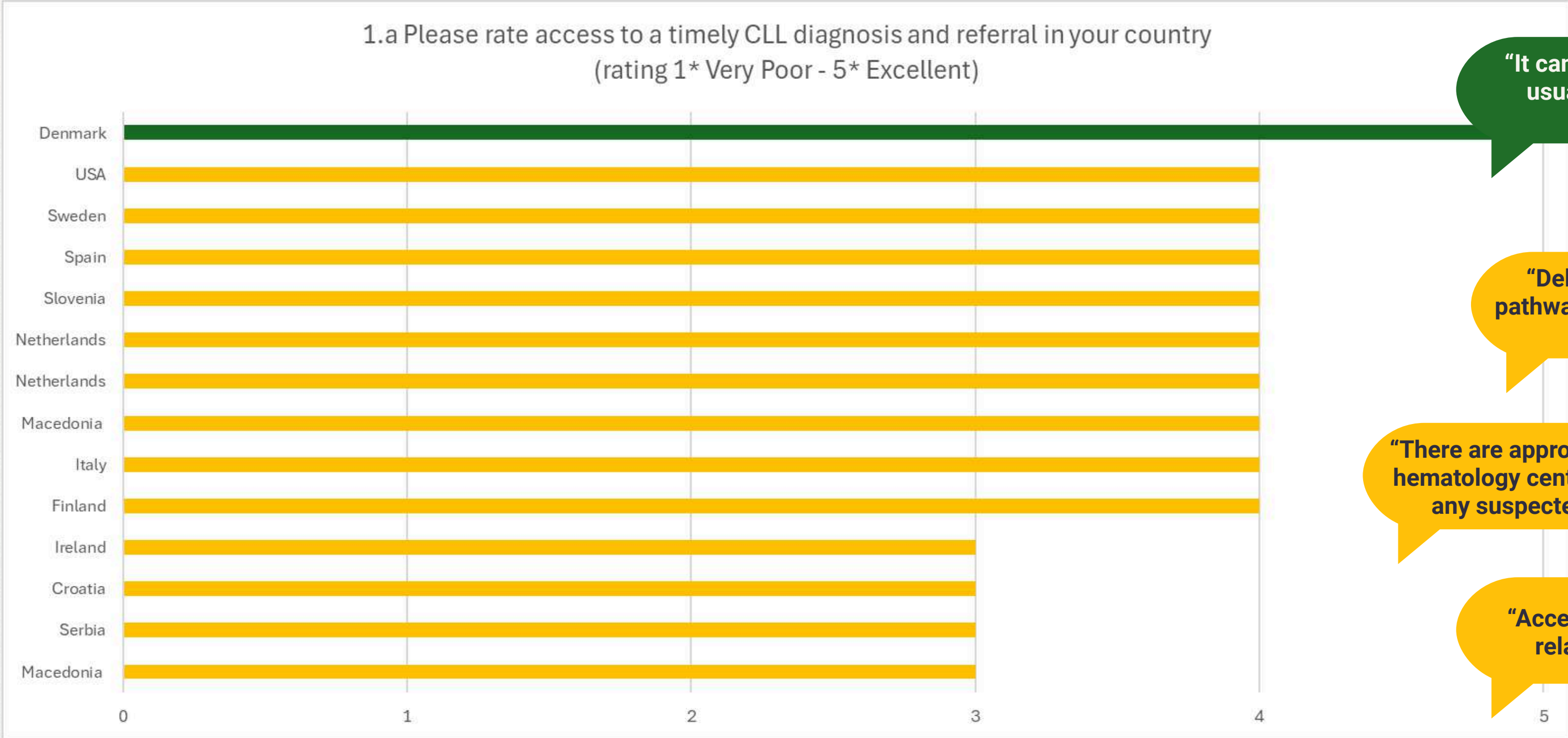
Insights and recommendations gathered during the Roundtable will contribute directly to ECLLA's broader 2026–2027 strategic activities.

**ECLLA would like to sincerely thank all speakers, facilitator, attendees, patient advocates, healthcare professionals, and partners who contributed to the success of the first ECLLA European Policy Roundtable.**



8:45-8:55	Welcome and Brief Introductions
8:55-9:10	Introduction of ECLLA ( <b>Jan Rynne and Mirna Tomasevic</b> ) Purpose of this roundtable and expected outcomes ( <b>Vicki Hedley, Facilitator</b> )
9:10-9:20	Overview of the CLL landscape in 2026 ( <b>Michael Rynne</b> )
9:20-9:40	Overview of your perspectives on diagnosis, treatment, care and social support for people with CLL: key messages from our pre-roundtable survey ( <b>Vicki Hedley</b> )
9:40-11:00	<b>Interactive Discussion 1: Diagnosis and Referral</b> Roundtable Discussion with expert introduction from <b>Dr Ben Kennedy</b> <ul style="list-style-type: none"> <li>• What is the reality?</li> <li>• How much variation do we see from country to country?</li> <li>• Where are the barriers?</li> <li>• Where are things working better?</li> <li>• <b>How can we improve? What do we want to recommend</b></li> </ul>
11:00-11:20	Break
11:20-12:30	<b>Interactive Discussion 2: Access to Treatment and Innovation</b> Smaller Group Breakout Discussions, with expert introduction from <b>Prof Oliver Karanfilski</b> (Facilitators <b>Lidija Pecova</b> and <b>Jan Rynne</b> ) <ul style="list-style-type: none"> <li>• Are all available treatments actually accessible by all people who need them in your country?</li> <li>• Can people access clinical trials in this space? If not, why?</li> <li>• Can people think of any good practices deployed in other countries, or indeed other conditions, that we might try to replicate?</li> <li>• <b>What would we want to recommend here?</b></li> </ul>
12:30-13:30	Lunch

13:30-14:30	Groups provide feedback in plenary / All-Group Discussion
14:30-16:00 (including short break)	<b>Interactive Session 3: Mental Health, Wellbeing and Psychosocial Support in CLL</b> Introduction by expert <b>Dr Amanda Kracen</b> , followed by independent brainstorming and roundtable discussions Gaps and Challenges: <ul style="list-style-type: none"> <li>• How can CLL impact on mental health?</li> <li>• What is the daily burden of dealing with this condition (for patients and families, carers, wider society?)</li> <li>• Are needs being met? If not, why not?</li> <li>• <b>What do we want to advocate for here? What should our key 'asks' be?</b></li> </ul>
16.15	Final plenary discussion – what have we missed? What are the absolute key points we should be including in a policy brief and the equity declaration?
16.35	Closing comments, next steps and group photo
16.45	Roundtable ends: free time ahead of evening social event



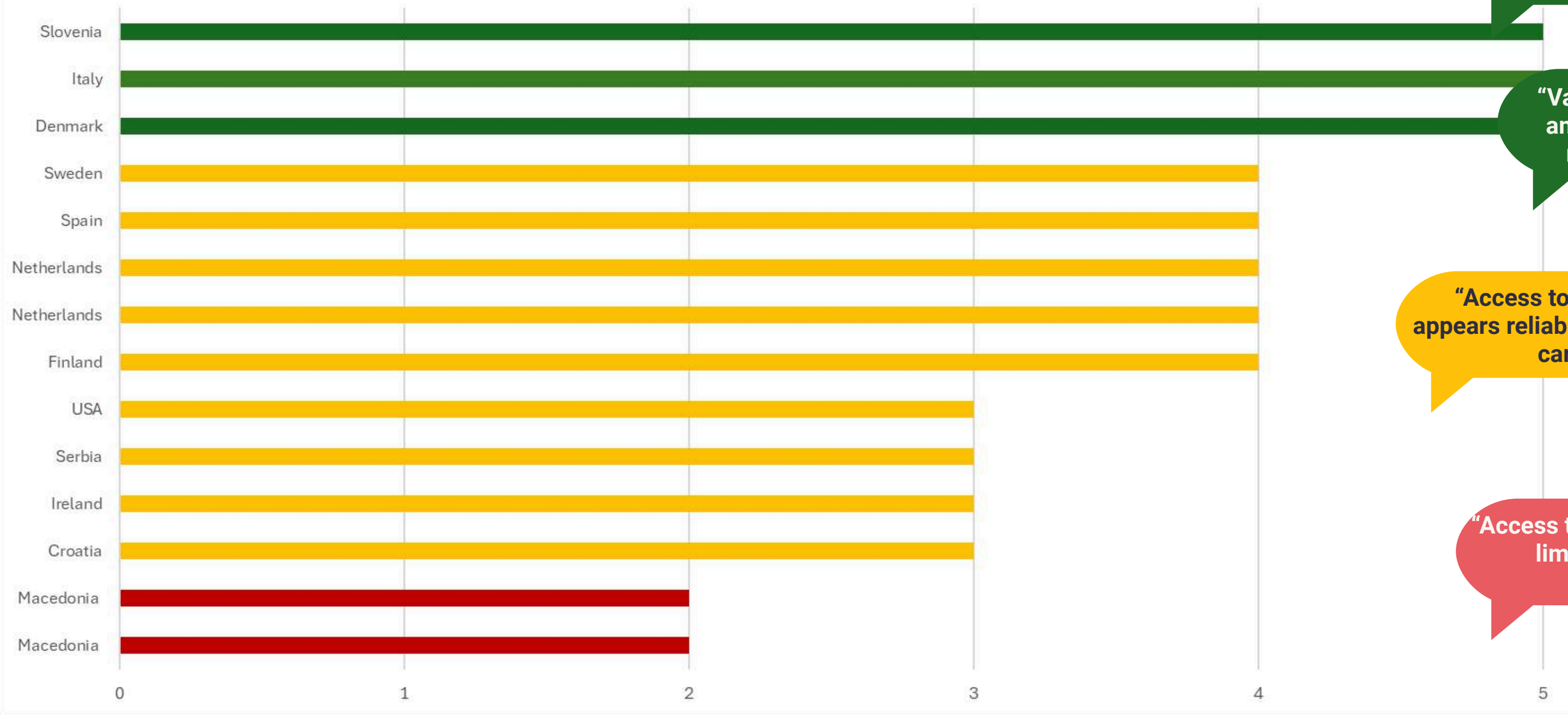
**"It can sometimes take time and usually you will go on W&W"  
(Denmark)**

**"Delays can occur earlier in the pathway during referral from primary care."  
(Serbia)**

**"There are approximately 150 public hematology centers... GPs can refer any suspected cases."  
(Italy)**

**"Access to timely diagnostics is relatively good."  
(Slovenia)**

2.a Please rate access to CLL treatments and innovation in your country in terms of approved therapies/medicines (rating 1\* Very Poor - 5\* Excellent)



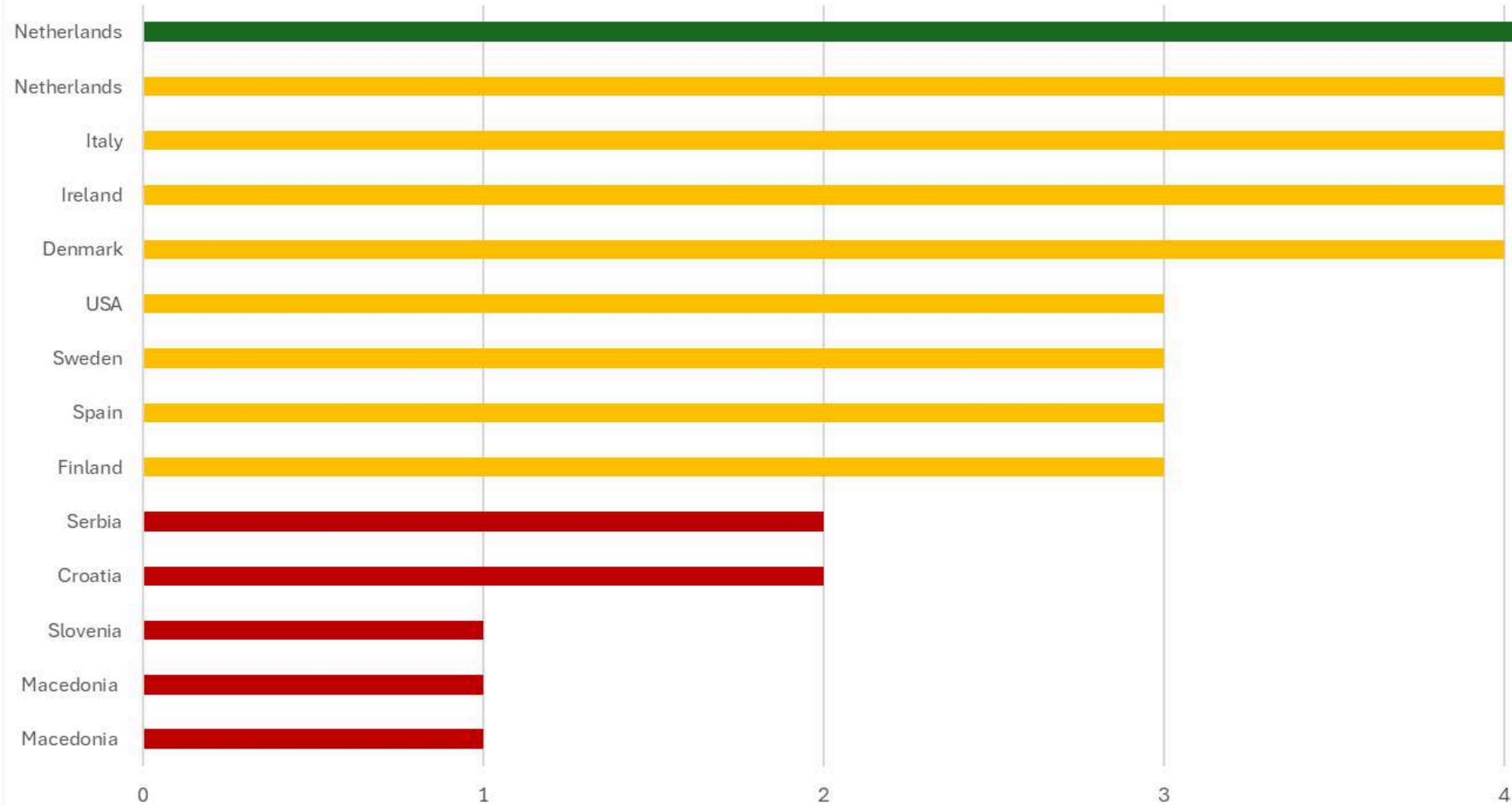
**“The national health system guarantees free access to lifesaving therapies.” (Italy)**

**“Various therapies are accessible, and new treatments are adopted relatively quickly.” (Slovenia)**

**“Access to approved therapies appears reliable once part of standard care.” (Finland)**

**“Access to newer targeted therapies is limited and often delayed.” (Macedonia)**

2.b Please rate access to CLL treatments and innovation in your country in terms of access to clinical trials (rating 1\* Very Poor - 5\* Excellent)



**“Exceptionally strong hematology network... high patient enrollment rates.” (Netherlands)**

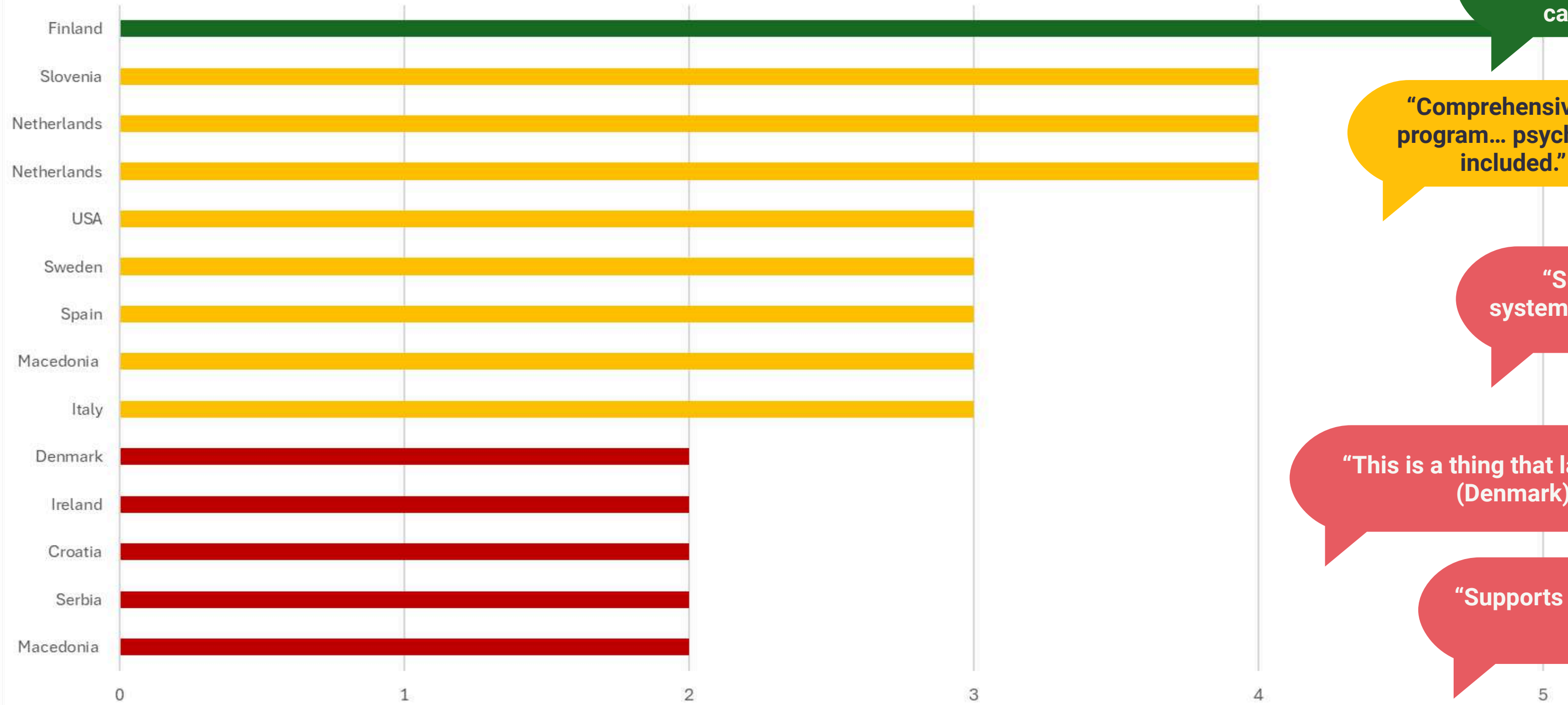
**“Generally good... but varies depending on location.” (Spain)**

**“This is one of the weakest areas of our system.” (Macedonia)**

**“Trials concentrated in a small number of urban centres.” (Croatia)**

**“Poorly accessible because Slovenia is a very small country with a unique language and a relatively small clinical team.” (Slovenia)**

3.a Please rate the quality/availability of mental health and social support for people with CLL in your country  
(rating 1\* Very Poor - 5\* Excellent)



**"Mental health and social support... is accessible and embedded in standard care pathways." (Finland)**

**"Comprehensive rehabilitation program... psychosocial support included." (Slovenia)**

**"Support exists but is not systematically integrated." (Serbia)**

**"This is a thing that lacks here." (Denmark)**

**"Supports were not spoken about." (Ireland)**

Tier	Countries	Treatment & innovation	Clinical trials	Psychosocial support	Key pattern
● High equity	Germany, Denmark, Netherlands, France	Fast access to modern therapies	Strong access	Moderate–high (but not perfect)	Strong systems, but psychosocial care still lags behind treatment
● Moderate equity	UK, Sweden, Italy, Spain, Finland	Good access with delays/variation	Good but uneven	Moderate	Good clinical care, but gaps in system efficiency and support
● Emerging gap	Ireland, Slovenia, Croatia	Slower or delayed access	Limited outside centres	Low–moderate	Treatment available, but system fragmentation and weak support
● High inequality	Serbia, Macedonia	Limited access to innovation	Very limited	Very low	Structural barriers across all areas, especially support services
● Outlier	US	Excellent (insurance-dependent)	Very strong	Unequal	High innovation, but major inequities across populations

**Consistent gap across all countries, even in strong systems:**  
 “Psychosocial and survivorship support is weaker than treatment access”

“While modern CLL treatment is highly effective and widely available in leading European systems, access remains uneven across countries, particularly for newer therapies and clinical trials, highlighting the need for stronger European coordination and equitable access policies.”

“Psychosocial support is the weakest and least developed pillar of CLL care across all countries – even in the strongest health systems!”

## ECLLA NEWS

Welcome to ECLLA News, where we share updates on our work, key activities, and developments across the European CLL community. Stay informed about our initiatives, events, and efforts to strengthen collaboration and improve CLL care across Europe.



### Thank you to everyone who contributed to the first ECLLA European Policy Roundtable

May 11, 2026

Thank you to everyone who contributed to the first ECLLA European Policy Roundtable 2026 – “Pathways to Equitable CLL Care Across Europe.” We are grateful to ECLLA members and patient leaders, clinicians, policy experts and partners who came together in Dublin with a...



### Today is the day! ECLLA European Policy Roundtable 2026 – “Pathways to Equitable CLL Care Across Europe”

May 9, 2026

Today, PAG representatives, clinicians, policy experts and partners from across geographic Europe have gathered in Dublin for the first ECLLA European Policy Roundtable 2026 – “Pathways to Equitable CLL Care Across Europe.” Together, we share one clear ambition: to...



### First ECLLA European Policy Roundtable 2026 – “Pathways to Equitable CLL Care Across Europe” | May 9, Dublin, Ireland

May 6, 2026

On Saturday, May 9, in Dublin, the European CLL Association (ECLLA) will bring together members and patient leaders, alongside clinicians, policy experts and partners from across geographic Europe, for its first ECLLA European Policy Roundtable 2026 – “Pathways to...

### Thank you to everyone who contributed to the first ECLLA European Policy Roundtable

May 11, 2026 | News

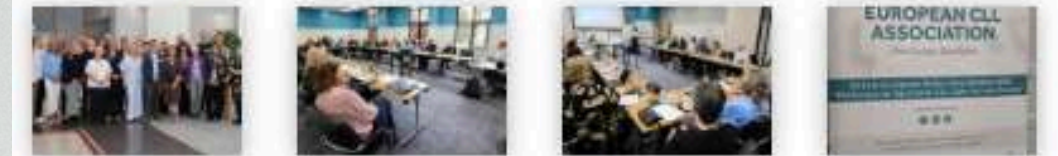


Thank you to everyone who contributed to the first ECLLA European Policy Roundtable 2026 - “Pathways to Equitable CLL Care Across Europe.”

We are grateful to ECLLA members and patient leaders, clinicians, policy experts and partners who came together in Dublin with a shared commitment to improving care for people living with Chronic Lymphocytic Leukemia (CLL).

The discussions throughout the day demonstrated the real strength of European collaboration, the value of shared experience, and the importance of bringing different voices together to address inequalities in diagnosis, treatment access, psychosocial support and wider care services.

This Roundtable marks an important step forward in building a stronger collective voice for fairer CLL care across geographic Europe.



#ECLLA #CLL #OneEuropeEqualCare

We would like to thank the following ECLLA foundational funders for supporting this important initiative.



**European CLL Association (ECLLA)**  
282 followers  
1w • 🌐

On Saturday in Dublin, the [European CLL Association \(ECLLA\)](#) will bring together members and patient leaders, alongside clinicians, policy experts and partners from across geographic Europe, for its first ECLLA European Policy Roundtable 2026 – “Pathways to Equitable CLL Care Across Europe.”

Across Europe, the experience of living with CLL can still vary greatly depending on where someone lives, from diagnosis pathways and access to therapies, to clinical trials, psychosocial support and wider care services.

The Roundtable will create a space for open discussion, shared learning and practical recommendations for action to support stronger collaboration, stronger patient voice and fairer care across Europe.

One Europe. Equal Care.  
#ECLLA #CLL #OneEuropeEqualCare



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**ECLLA EUROPEAN POLICY ROUNDTABLE 2026**

**“Pathways to Equitable CLL Care Across Europe”**

9 May 2026, Dublin, Ireland

#eclla #cll #OneEuropeEqualCare

Jan Rynne and 21 others • 5 reposts

**European CLL Association (ECLLA)**  
282 followers  
1w • 🌐

**Why It Matters**

People living with CLL should not face very different standards of care depending on where they live. Yet inequalities still remain in diagnosis pathways, access to treatment, psychosocial support and wider care services across Europe. That is why stronger collaboration and coordinated European action matter now more than ever.

In two days, the ECLLA European Policy Roundtable 2026 – “Pathways to Equitable CLL Care Across Europe” will bring voices together to help drive practical solutions and fairer CLL care across geographic Europe.

#ECLLA #CLL #OneEuropeEqualCare



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**ECLLA EUROPEAN POLICY ROUNDTABLE 2026**

**“Pathways to Equitable CLL Care Across Europe”**

9 May 2026, Dublin, Ireland

#eclla #cll #OneEuropeEqualCare

Jan Rynne and 11 others • 4 reposts

**Amanda Kracen, PhD** • 1st  
Professor of Psychology, National College of Ireland / Past President, Irish Psychos...  
1w • 🌐

Honored to be a part of this event tomorrow that is focused on equitable cancer care across Europe. ...more

**European CLL Association (ECLLA)**  
282 followers  
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On Saturday in Dublin, the [European CLL Association \(ECLLA\)](#) will bring together members and patient leaders, alongside clinicians, policy experts and partners from across geographic Europe, for its first ECLLA European ...more



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**ECLLA EUROPEAN POLICY ROUNDTABLE 2026**

**“Pathways to Equitable CLL Care Across Europe”**

9 May 2026, Dublin, Ireland

#eclla #cll #OneEuropeEqualCare

You and 11 others • 1 comment • 2 reposts

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**European CLL Association (ECLLA)**  
282 followers  
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The honor is ours [Amanda Kracen, PhD](#)  
Looking forward to working with you to benefit our patient community across Europe

**Ben Kennedy** • 1st  
Haematology Consultant with interest in CLL, lymphoproliferative disorders, clinica...  
1w • 🌐

Such an important initiative to identify challenges and seek opportunities to improve the wellbeing of people with CLL across Europe. I am looking forward to engaging as a member of the Medical Advisory Board.

**European CLL Association (ECLLA)**  
282 followers  
1w • 🌐

**Why It Matters**

People living with CLL should not face very different standards of care ...more



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**ECLLA EUROPEAN POLICY ROUNDTABLE 2026**

**“Pathways to Equitable CLL Care Across Europe”**

9 May 2026, Dublin, Ireland

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**European CLL Association (ECLLA)**  
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👉 Today is the day.



Today, PAG representatives, clinicians, policy experts and partners from across geographic Europe have gathered in Dublin for the first ECLLA European Policy Roundtable 2026 – “Pathways to Equitable CLL Care Across Europe.”

Together, we share one clear ambition: to advance more equitable care for people living with Chronic Lymphocytic Leukemia (CLL) across Europe.

The Roundtable will create a space for open discussion, shared learning and practical recommendations for action to help address inequalities in diagnosis, access to treatment, psychosocial support and wider care services.

Different countries. Different realities. Shared purpose.

#ECLLA #CLL #OneEuropeEqualCare

Michael Rynne and 25 others  
4 reposts

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**Lidija Pecova** • 1st  
Global Nonprofit Leader | Partnerships, Fundraising, Capacity-Building & Advocacy...  
1w • Edited • 🌐

Today's ECLLA European Policy Roundtable in Dublin was a reminder of how important real discussion and collaboration are if we truly want to improve patient care across Europe.




While the focus was on CLL, many of the conversations were relevant across other Leukemia's too, access to treatment, clinical trials, diagnosis pathways, mental health support and the differences patients still experience depending on where they live. These are challenges many of our communities understand well.

What made today stand out was the format itself. It was not built around long presentations or people simply speaking at an audience. The experts introduced the topics, but most of the day was genuine discussion around the table between patient advocates, clinicians, pharma and policy voices from across geographic Europe. People listened to each other, shared experiences openly and spoke honestly about both the challenges and the possibilities for change.

For organisations like **HEMA-ONKO- Association dedicated to cancer patients and their caregivers** from non-EU countries, it was meaningful to be part of those conversations and to feel included within the wider European effort to improve equity of care.

It felt less like a one-day event and more like the beginning of important conversations that now need to continue beyond Dublin. Proud that **European CLL Association (ECLLA)** created the space for that to happen.




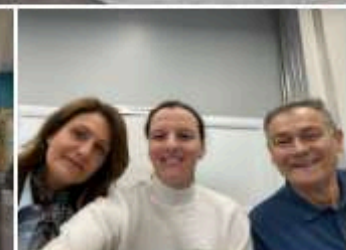
#ECLLA #CLL #OneEuropeEqualCare #HEMAONKO

**Slovensko združenje bolnikov z limfomom in levkemijo, L&L**  
137 followers  
4d • 🌐

Prvo srečanje nove evropske organizacije **European CLL Association (ECLLA)**: skupna prizadevanja za pravičnejšo obravnavo bolnikov s KLL ...more

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**European CLL Association (ECLLA)**  
282 followers    4d ...

We are proud and honoured to have you with us and we looking forward to what we can achieve together for our European region.

Like · 🌐 1 | Reply | 43 impressions

**Ivana Cattaneo** • 1st  
Head of European Government Affairs and Public Policy  
1w • Edited

Behind every policy debate, there are people living with serious, life- altering diseases. And families waiting for answers, options and hopes. ...more

**European CLL Association (ECLLA)**  
282 followers  
1w • Edited

Thank you to everyone who contributed to the first ECLLA European Policy Roundtable 2026 – "Pathways to Equitable CLL Care Across Europe." ...more




You and 52 others

4 reposts



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**Evaristo Martinez** • 2nd  
Global Policy & Market Access Sr Director  
1w • Edited

It was a privilege to participate in the first ECLLA European policy round table that bring together such a diverse range of voices and expertise to share best practices, exchange ideas, and help build a strong voice to drive meaningful progress ...more

**European CLL Association (ECLLA)**  
282 followers  
1w • Edited

Thank you to everyone who contributed to the first ECLLA European Policy Roundtable 2026 – "Pathways to Equitable CLL Care Across Europe." ...more

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Celebrate Comment Repost

Give your good wishes...

Most relevant

**Sandra M. Rivera Mendieta** • 3rd+  
Director Comercial y Co-Founder en CEP/ Coach Ontológica/Mindfulness y c...  
1w

Felicidades Evaristo!

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**European CLL Association (ECLLA)**  
282 followers  
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This Roundtable marks an important step forward in building a stronger collective voice for fairer CLL care across geographic Europe.

THANK YOU 🙌👏

**Ben Kennedy** **Oliver Karanfilski** **Amanda Kracen, PhD** **Brian Koffman** **Jan Rynne** **Mirna Tomasevic** **Michael Rynne** **Victoria Hedley** **Lidija Pecova** **LYLE Patientforeningen**, **AIL Ravenna – Associazione Italiana contro Leucemie Sezione Ravenna**, **Slovenian lymphoma and leukemia patient association**, **L&L, Blodcancerforum**, **HEMA-ONKO- Association dedicated to cancer patients and their caregivers**, **Croatian Leukemia and Lymphoma Society - HULL**, **CLL Ireland**, **ASPA-LLC Spain**, **LIPA - Lymphoma, CLL, MPN Patient Association Serbia**, **Stichting Hematon**, **Suomen Syöpäpotilaat - Cancerpatienterna i Finland ry**, **CLL Society**, **Rachel Giles**, **Ana Marjanovikj**, **Felice Bombaci**, **Lise-Iott Eriksson**, **Rita O. Christensen**, **Dražen Vincek**, **Fionnuala Clifton**, **Jesús Manuel Pérez Viejo**, **Marianne van Maarschalkwerweerd**, **Birit Keve**, **Maurice Grehan**, **Ivana Cattaneo**, **Sandra COURBIER**, **Evaristo Martinez**, **Nicola Fullam**

#ECLLA #CLL #OneEuropeEqualCare



Most relevant

**Ben Kennedy** • 1st  
Haematology Consultant with interest in CLL, lymphoproliferative disorders, ...  
1w

So pleased to be part of the Medical Advisory Board for ECLLA and extending every good wish for success in achieving equality of access across Europe, improving the lives of people with CLL.

Like • 5 | Reply

**Amanda Kracen, PhD** • 1st  
Professor of Psychology, National College of Ireland / Past President, Irish Ps...  
1w

Well done **Jan Rynne** **Mirna Tomasevic** and team! Thank you for prioritising the psychosocial aspects of living with CLL. It was an excellent, productive day, Just the start of an important process!

Like • 2 | Reply

**Fionnuala Clifton** • 1st  
Trustee CLL Ireland, Director Empireunlocked Ltd  
1w

So happy to be a part of this first ECLLA Roundtable on behalf of CLL IRELAND..the start of something significant for all patients

Like • 1 | Reply

**Sandra COURBIER** • 2nd  
Global Patient Advocacy Lead  
1w

Thank you for organising the first ECLLA Roundtable. It was essential to bring together such a diverse range of voices and expertise to share best practices, exchange perspectives, and continue building a strong common European voice to move things forward for people living with CLL across Europe.

Like • 4 | Reply

Thank  
you!