

PiCC

# PULSE

November 2025

Newsletter

## Welcome!

Think big. Act bigger. Patient expertise matters.

News from our partner





# Welcome to PiCC Pulse

🍁 November is here – and PiCC United is moving forward with purpose!

This month, we're delighted to introduce another inspiring board member and share fresh updates from our latest collaborations, workshops and events. With conference season still in full swing, we're gathering new insights, reflections and opportunities for you to engage with our growing community. From international panels to co-designed projects, November is shaping up to be a month of connection, learning and meaningful patient partnership.

Thank you for being part of our shared mission — together, we continue to advance genuine patient involvement across borders and beyond.

Warm regards,  
Team PiCC United



## News from our partner

Mandy C. Daly, Irish Neonatal Health Alliance (INHA) is an internationally recognised patient advocate and patient expert with deep experience across healthcare policy, regulation, research, and academia.

Founded on lived neonatal experience, her work spans national and European initiatives, regulatory authorities, ethics and audit bodies, and over 80 research studies. As founder of the Irish Neonatal Health Alliance and an Embedded Patient Researcher at



University College Cork, she combines real-world insight with scientific, regulatory, and educational expertise—demonstrating how patient advocates can shape systems from within and drive meaningful, lasting change.





# Irish Neonatal Health Alliance

## From Lived Experience to System Change

Patient advocacy often begins with a personal story. In Mandy C. Daly's case, it became the starting point for something far larger: a sustained effort to influence how healthcare systems, research, regulation, and academia are designed and governed.

In this article, Mandy reflects on her journey from lived neonatal experience to becoming a recognised patient expert working alongside clinicians, researchers, regulators, and policymakers.



As founder of the Irish Neonatal Health Alliance (INHA), she shares how patient insights helped identify critical gaps in neonatal care in Ireland—gaps that led to concrete change, including improved national standards, policy reforms, and better support for families.

The article goes beyond awareness-raising and challenges a common misconception: that patient advocates are only storytellers. Mandy shows how lived experience, when combined with knowledge of scientific, regulatory, and ethical frameworks, becomes a powerful form of expertise. One that strengthens research design, clinical guidelines, health technology assessment, digital health initiatives, and national policy-making.

Through examples from regulatory bodies, ethics committees, research governance, academic teaching, and European collaboration, she illustrates how patient advocates can—and should—take part in shaping decisions from within the system.



**“Lived experience is data. Insight is evidence.”**



Her message is clear: patient participation is not symbolic. It directly improves relevance, quality, trust, and outcomes.

The article also serves as a call to action for current and emerging patient advocates. Mandy encourages others to start where it matters most to them, to seek out the tables where decisions are made, and to recognise that their perspective is not optional. Advocacy today is about co-production, shared leadership, and the confidence to act as a strategic partner in change.

👉 Read the full article in our News section on the [PiCC United website](#), and explore how patient expertise can move from lived experience to lasting system impact.



## Tell us what you think...

Since we launched PiCC United we have consistently been reflecting, rebuilding and developing our approach, to provide a better service to you, the community. However to help us develop further we would love to have your input.

If you haven't already given your feedback, please add your thoughts by completing our short survey: [PiCC United Pulse check](#).

Your input will really help us!





## New Webinar series

We're delighted to share a powerful and insightful webinar with Dr. Molly Gracey: Why Emotional Communication Matters in Healthcare

### Why Emotion Matters

Dr Molly Gracey

12th November 2025



MediPaCe®  
Making Patient Engagement a Reality



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Dr. Molly Gracey brings together her PhD research on emotion recognition in people with Parkinson's Disease and her extensive experience-based learning to shed light on a topic that affects every patient interaction: emotional communication.

In this session, Dr. Gracey explores:

- How emotional cues influence patient-clinician relationships
- Why recognising emotions accurately can improve trust and shared decision-making
- The real-life impact of emotional communication on patient experience
- Practical insights for professionals and patient advocates alike

Her combination of scientific research and real-world understanding makes this webinar both thought-provoking and deeply relevant for anyone working with — or supporting — patients.

👉 Watch the full webinar on YouTube here: [Why Emotional Communication Matters in Healthcare](#)

## Never stop collaborating

Sometimes the best ideas and strongest connections are born over a cup of coffee ☕

Because sometimes, the simplest conversations make the biggest difference.



SCIENCE for ALL

# PiCC News Update

PiCC United participated in the Ministry of Foreign Affairs' dialogue on human rights in AI and healthcare in Clinical Innovation Summit 2025.



## The Danish Ministry of Foreign Affairs — Human Rights & Health Dialogue

We are proud to have participated in the Ministry of Foreign Affairs' dialogue on human rights, health, and the role of civil society, held in Copenhagen. The event brought together diverse perspectives from policymakers, experts, and organisations working to strengthen rights-based approaches in healthcare.

Having our President contribute to the discussions and represent the patient advocacy perspective was a strong reminder of why PiCC United exists:

- to ensure that patient voices are heard — not only in clinical settings, but also in the policies that shape healthcare systems.

It was a meaningful opportunity for PiCC United to highlight how patient experience, equity, and lived insights must be embedded in national and international decision-making related to health.

The dialogue created an important space to emphasise why patient involvement is a human rights issue, touching on transparency, access to care, inclusion, and the right to participate in decisions that affect one's health.

We extend our sincere thanks to the Ministry for the invitation and for creating a forum marked by openness, thoughtful exchange, and shared commitment. We look forward to contributing to future dialogues.





# PiCC News Update

Here we highlight the latest news from the PiCC Community, including new events, webinars, developments and improvements.



## Partner with PiCC United – together we can move mountains (continuation)

As our partner, you will have access to exactly this type of learning and inspiration.

As a **partner of PiCC United**, you get:

- A strong network of like-minded organisations and companies working for patient involvement at the highest level.
- The opportunity to share your expertise – and access that of others – so that together you can create smarter processes, better collaborations and stronger results.
- Visibility for your organisation as a frontrunner in patient involvement and affiliation with an international community with this ambition.
- Concrete contributions to projects, events, webinars and knowledge sharing, where your input can be turned into action.

When we enter into a partnership, we don't go it alone – we work together towards the goal: more meaningful patient involvement, better collaboration between sectors, and stronger results in clinical studies and health research. Because we know that when more of us work together, we can move mountains.



**Want to feature  
on our next cover?**

Contact: [nsw@piccunited.org](mailto:nsw@piccunited.org)

# PiCC News Update

We are excited to share the recording of our latest PiCC Knowledge Partners Webinar, created in collaboration with PAN Canada and featuring the inspiring patient advocate Alies Maybee.



## New Knowledge Partner Webinar

We are excited to share the recording of our latest PiCC Knowledge Partners Webinar, created in collaboration with PAN Canada and featuring the inspiring patient advocate Alies Maybee.

In this session, Alies takes us beyond the idea of “consultation” and into what it truly means for patients to be partners in research, policy development, and system improvement. With her many years of experience, she offers clear, practical insights that both organisations and individual advocates can use immediately.

In this recording, you’ll learn:

- What meaningful patient partnership looks like in real practice
- How to recognise and avoid tokenism
- Examples of co-design and co-delivery from real-world projects
- Practical advice for new patient advocates beginning their journey

 Watch the webinar here: [PiCC Knowledge Partners PAN Canada presentation](#)



### About the collaboration

This webinar is part of PiCC United’s ongoing mission to lower the threshold for patient involvement, build confidence, and make knowledge accessible for patients, carers, and advocates worldwide. By sharing best practices from partners like PAN Canada, we strengthen our global community and help create more meaningful patient partnerships across systems.



# Never stop collaborating

Sometimes the best ideas and strongest connections are born over a cup of coffee ☕. Because sometimes, the simplest conversations make the biggest difference.



## Do you have something to share?



We would love to help share your ideas, experiences or opinions. No matter how you like to share, we can find the perfect platform to help get your voice heard.

Talk to us: [hello@piccunited.org](mailto:hello@piccunited.org) or click here: [Tell us more](#)

## SEARCHING for PiCC Lounge.....

Find the PiCC Lounge Podcast on your normal podcast provider and sign up, follow and get the latest episodes delivered right into your ears!

We are now on most platforms, including [Apple](#), [Spotify](#), [Amazon](#), [PlayerFM](#), and [Podchaser](#)!

If you have an idea for a topic or want to share your story with the community, [email us](#) or [follow this link](#).



### Good input for us?

PiCC United is here for everyone, whether you are a patient, advocate, carer, healthcare or Pharma professional or anyone with a role in this field.

Contact: [hello@piccunited.org](mailto:hello@piccunited.org)





# Trust, inclusion, and action

We make it easier for people to engage, share their voices, and help shape better, more inclusive healthcare.



**PiCC United**

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