

PiCC

# PULSE

October 2025

Newsletter



## Welcome!

Introduction to **Chi Pakarinen**  
PiCC United Board Member

News from our partner



# Welcome to PiCC Pulse

🍂 Autumn is here, and so are busy times at PiCC United!

This month we introduce another of our board members and share updates from our latest activities. With the conference season in full swing, we look forward to bringing you highlights, insights, and new opportunities to get involved.

Thank you for being part of the journey.



## Introducing Chi Pakarinen

Meet Chi Pakarinen, our board member from Finland. In her day job, she is Head of the Programme Management Office at MediPaCe – but her path into patient involvement was, as she puts it, “a very happy coincidence.”

I’m Chi Pakarinen, Board Member at PiCC United and Head of the Programme Management Office at MediPaCe. My journey into patient involvement began by coincidence, but it quickly turned into a passion because of the meaningful and impactful work it creates.



My start in patient involvement was a very happy coincidence and not at all planned. After I graduated my master’s degree, I started working at a small nonprofit organisation in Belgium, as their project manager, not knowing one of their programmes was around patient involvement. I’ve since liked to say that I found my passion because of the meaningful and impactful work that we get to do.



# Introducing Chi Pakarinen

After 5 years, I left this organisation to gain a more rounded experience and worked in the pharmaceutical industry side and while there, got to know Jenny and Sandeep and what MediPaCe does and the rest is kind of history.

An early thinking of PiCC United emerged from various conversations we had within the team in 2022, but thoughts of it have been there even sooner. We could hear industry partners putting “patients at the centre” but in the practical terms, this created immense pressure on the patient community in terms of having to respond to various separate request and have



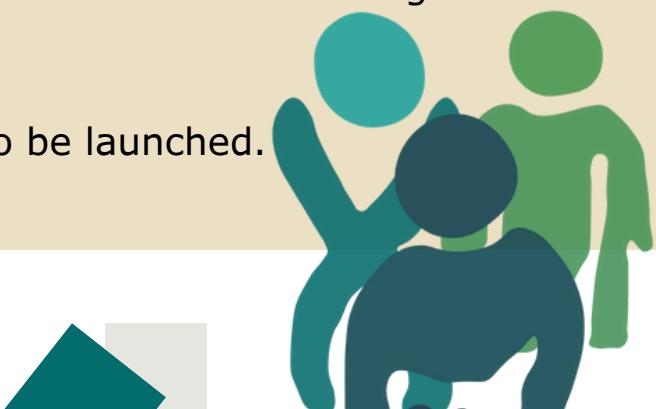
legal and compliance knowledge to go through the industry processes and often times the timeframes of these requests were unreasonably short.

We kept thinking, well, can we do something about this to help foster more collaboration between the patient community and industry?

That's when we decided to test our logic and start creating processes that we thought might help.

Whatever the final structure was going to be, we've always thought that PiCC would need a co-leadership model where the co-lead would represent the patient community. It wasn't until in 2024 when we met Lisbeth Snede, who at the time was leading a patient group called Patients United and was thinking of pivoting somehow, that we found someone with aligned values and that our paths could perhaps merge.

That's when PiCC United was finally ready to be launched.



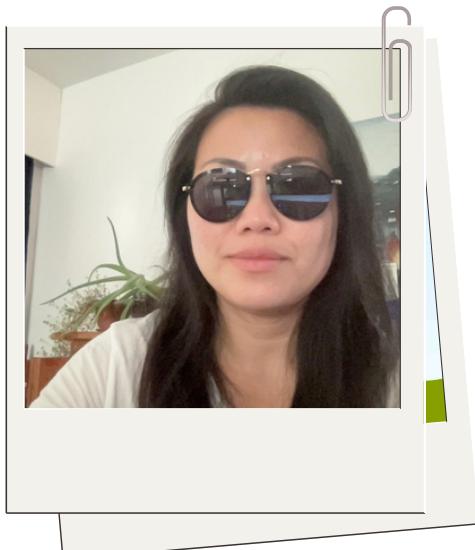
## **"Fun fact: I just became a certified yoga teacher!"**



**Why** I'm uninvolved with PiCC United remains the same as in the early days: to help foster more collaboration between the patient community and industry. I feel like for us to be able to think so much outside the current box of how patient involvement partnerships happen and be able to set up something that could potentially change the way we (as the whole health ecosystem) do it, is huge.

I hope that this kind of practical approach could take on and patients can be more involved in the medicines development and health research, because at the end of the day, it only **improves** health outcomes.

Kind regards,  
Chi



*"What drives me as a board member is the belief that PiCC United can help reshape how patient involvement happens. We are not just talking about including patients – we are working to create a system where their knowledge, values, and lived experiences are recognised as expertise".*



# PiCC News Update

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



## New White Paper: *Mental Health Support in Clinical Trials*

At PiCC United, we believe that patients in clinical trials are more than participants – they are people with lives, emotions, and families. Yet mental health support is still too often overlooked in trial design and delivery.

Our new White Paper – Mental Health Support in Trials: Moving Beyond the Participant Role brings forward the voices of patients and caregivers from across Europe. Through lived experience, they share how uncertainty, lack of information, and absence of follow-up impact not only their willingness to continue in trials, but also their overall wellbeing.

This White Paper is the result of a patient-led dialogue, supported by H. Lundbeck A/S and delivered independently by PiCC United.

We hope this paper sparks discussion and change – and we warmly invite you to read, share, and use it in your own networks. Together, we can make clinical research more ethical, sustainable, and human.

👉 Read the White Paper [here](#)



**Want to feature  
on our next cover?  
Contact: [nsw@piccunited.org](mailto:nsw@piccunited.org)**

# PiCC Partners

Here we highlight the latest news from the PiCC United's partners



## ELPA European Liver Screening Week 2025

The European Liver Patients' Association (ELPA) launched the third edition of the European Liver Screening Week initiative under the Patronage of the European Parliament. The primary goal was to raise awareness about liver health and the importance of early detection of liver disease through simple, non-invasive methods.

This initiative is driven by a strong commitment to patient-centred care and active engagement. ELPA member organisations, including Liver4Life (UK) and SOS Hépatite (France), play a pivotal role in the design and execution of the program.

The project's central feature is the deployment of liver health testing vans to the pedestrianised area outside the European Parliament. Over five days each October, these vans offer free liver health assessments using portable transient elastography (TE) devices, a non-invasive method to measure liver stiffness and fat levels. Hundreds of individuals, including Parliament staff and the general public, participate in the screenings, many unaware of potential risks to their liver health. The inclusion of a questionnaire in 2024 also provided valuable insights into participants' perceptions of liver health and common risk factors, including concerns about obesity, alcohol consumption, and stress.

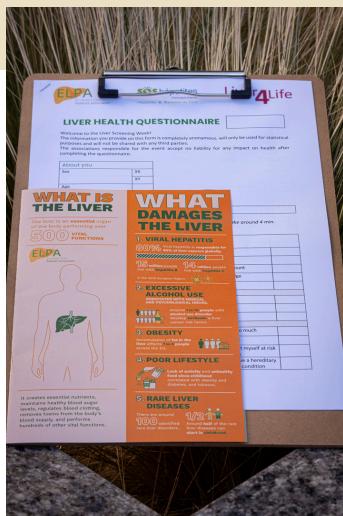
The ELPA team and trained healthcare professionals provide participants with immediate feedback on their results and deliver tailored lifestyle advice when needed. For individuals with concerning results, self-referral letters are issued, enabling them to seek further medical consultation. Beyond direct engagement with participants, ELPA also works to amplify the initiative's reach by connecting with Members of the European Parliament (MEPs). ELPA representatives hold discussions with policymakers to highlight the significance of liver health and advocate for preventive healthcare policies at the EU level. The initiative also features targeted messaging and visual campaigns on the vans, which help draw attention to liver health and its link to risk factors.

**Read more on the following page....**

# ELPA European Liver Screening Week 2025



Early detection of liver disease is crucial because many liver conditions can progress without symptoms until the later stages. Diagnosing early allows treatment, better outcomes, and reduced complications. Europe has a high burden of liver disease: rates of metabolic dysfunction-associated steatotic liver disease - MASLD (aka fatty liver), viral hepatitis, and alcohol-related liver disease are significant. Many liver diseases are preventable or treatable if caught early, which reduces healthcare costs, improves quality of life, and reduces mortality.



Raising public and policy awareness can encourage more screening programmes, policy support, funding, and equitable access.

This initiative demonstrates the power of grassroots-level health campaigns in driving awareness and promoting early detection. In addition, this initiative exemplifies pure patient engagement at its core. It created a platform for meaningful interaction between the general public, patient advocates, healthcare professionals, and policymakers. By meeting people in their community and providing practical, actionable insights into their liver health, ELPA demonstrates how

accessible and effective health interventions can lead to early detection and preventive action. Moreover, the collaboration of ELPA member organisations across different countries highlights the strength of patient networks in addressing public health challenges. By engaging with policymakers, this project raised awareness and laid the groundwork for future initiatives that could lead to policy change.



## News to share?

We will also publish your post – because we believe that together we can create greater visibility and stronger voices.

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



# ICHOM conference

Once again this year, PiCC United was present at the ICHOM conference!

This year, we had the great pleasure of having our president, Lisbeth Snede, serve as an abstract judge at the conference. We participated in exciting discussions about PROMs (Patient-Reported Outcomes), value-based healthcare, and much more. We came home with many new ideas, potential collaboration opportunities and, not least, a strengthened network with patients, healthcare professionals and partners from all over the world. Thank you to **ICHOM** for another meaningful conference where the voice of patients continues to be at the centre.



## We are part of Project COMFORT – your voice makes a difference! ❤️



PiCC United is proud to be part of IHI Project COMFORT – an international initiative working to improve support for patients and their families during clinical trials.

To create solutions that truly reflect patients' needs and experiences, we need your voice and your experiences. We therefore hope that you will participate in our questionnaire, which will help the project gather valuable knowledge:

[Participate in the questionnaire here](#)

Your feedback can help shape the clinical trials of the future, making them more humane, supportive and inclusive.

Together we can bring about change – one voice at a time.

A graphic for the 'Project COMFORT Perception Survey'. It features a large hand holding a red blood test tube against a teal background. The text 'WHAT ARE YOUR THOUGHTS ON BLOOD TESTS? PERCEPTION SURVEY' is at the top, and the 'PROJECT COMFORT' logo is in the bottom left. A smaller version of the same graphic is shown in the bottom right corner.

# 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.



## New at PiCC United: Our Online Café ☕

At PiCC United we believe in one thing: Never stop collaborating. True change in healthcare happens when patients, professionals, and partners come together, share knowledge, and co-create solutions.

Our community is built on dialogue, trust, and the belief that every voice matters. That's why we're have PiCC United's Forum.

Join the conversation, grab your virtual coffee ☕ in our Forum, and connect with colleagues across the patient engagement world.



## 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)





**PiCC**<sup>®</sup>  
UNITED

## **Trust, inclusion, and action**

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



**PiCC United**

*Initiative of MediPaCe Ltd.*  
Suomen Sivuliike/Finland Branch  
PL 15  
00811 Helsinki  
Finland  
Email: [Hello@piccunited.org](mailto:Hello@piccunited.org)