PiCC

PULSE

Newsletter

December 2025

Welcome!

A year in the making, our jouney with you.

News from our partner:

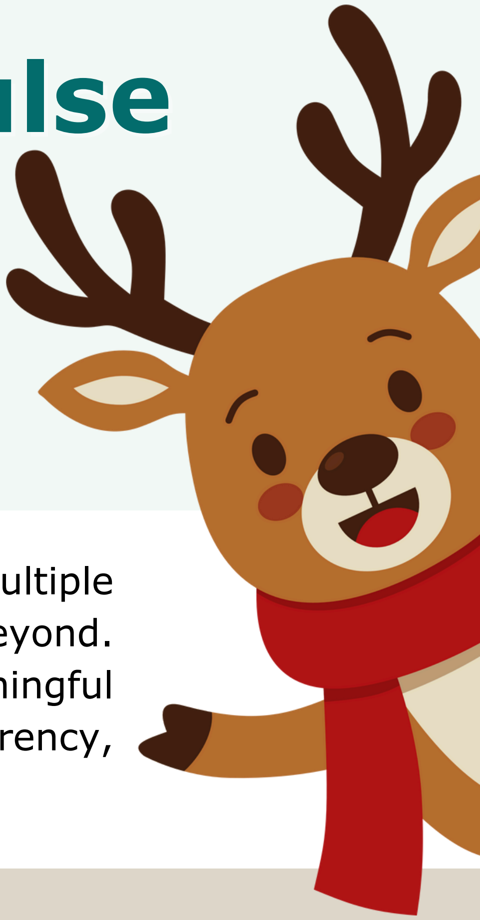
PsorAsia
IFPA Region Asia

International Alliance of
Patients' Organizations
A global voice for patients

PSORIASIS
PHILIPPINES
Voice of Filipinos with Psoriasis

December 2025

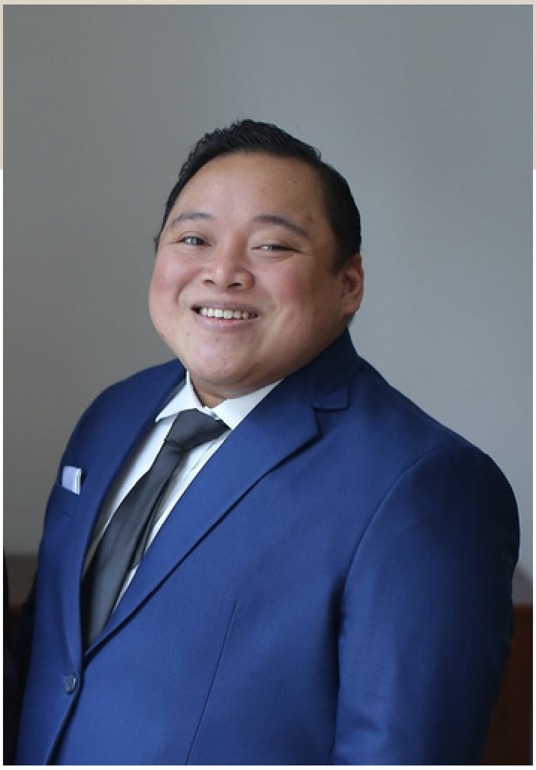
Welcome to PiCC Pulse



December is often a time for summaries and statistics. At PiCC United, we see it as a moment to recognise the people, conversations, and collaborations that have helped move patient involvement forward, sometimes in visible ways, sometimes more quietly. Always with intention.

Over the past months, PiCC United has been part of multiple projects, networks, and dialogues across Europe and beyond. What connects all of them is a shared belief: that meaningful patient involvement requires trust, structure, transparency, and space for learning — not just good intentions.

News from our partner



Paul Mendoza is one of Asia's most influential patient leaders and a strong global voice for patient rights.

As President of Psoriasis Philippines and PsorAsia+Pacific, he leads efforts to improve access to care, strengthen patient communities, and build regional collaboration.

He also serves as Vice Chair of IAPO, advocating for patient voices in global health decision-making.

Paul is known for his empathy, strategic vision, and ability to build meaningful partnerships, always putting people at the center of his work.

PSORIASIS PHILIPPINES
Voice of Filipinos with Psoriasis

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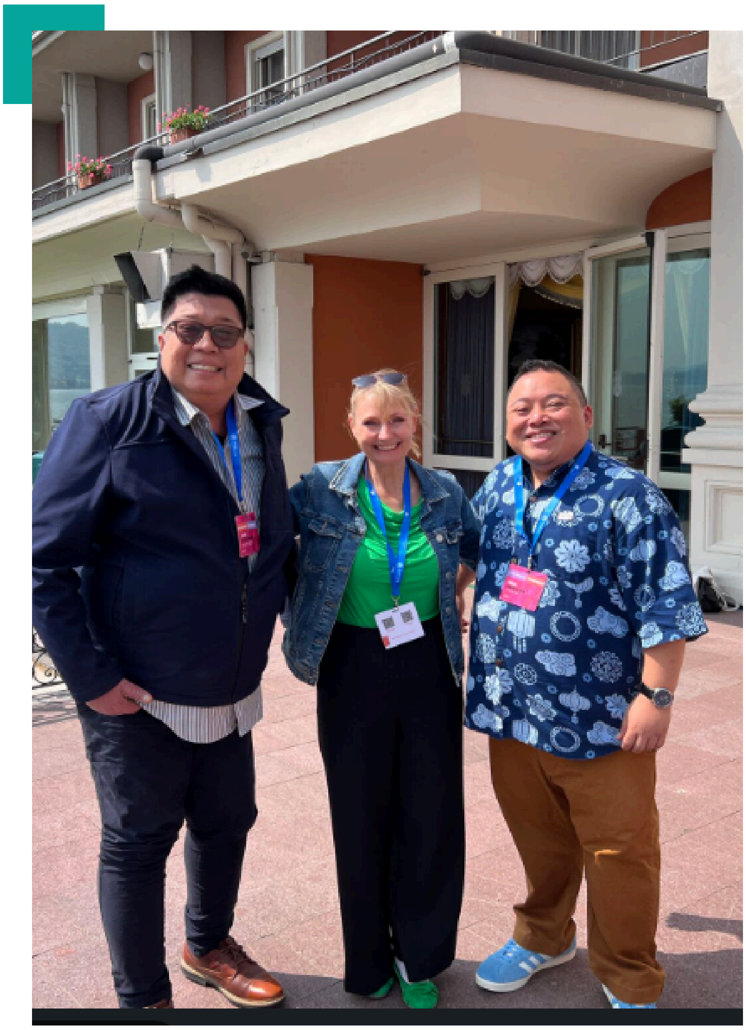
The Power of Working Together

In the Asia-Pacific region, living with psoriasis is not just a medical challenge, it is a daily journey shaped by limited access to care, cultural stigma, and healthcare systems that often overlook the needs of people with chronic conditions. For many, treatment is too expensive, support networks are fragile, and reliable data simply does not exist.

These challenges are deeply personal. They affect families, livelihoods, and the sense of dignity that every person deserves.

It was within this reality that Psoriasis Philippines, led by Josef De Guzman and Paul Mendoza, reached across borders to build something bigger than any single organisation could achieve alone.

With a shared belief that collaboration has the power to transform lives, they brought patient groups together. They listened to one another's stories and helped new communities find their voice. This is how PsorAsia+Pacific was born.



For more than a decade, leaders across the region dreamed of creating a project that would represent the lived experiences of people with psoriasis. This became a reality in 2024 when, with the commitment of 12 member organisations, they launched the Psoriasis Asia Pacific Survey. The results of this survey provides a data-driven collective portrait of what it means to live with psoriasis here.

The Power of Working Together

Together, patients, doctors, researchers, and advocates shaped a project that captures:

- The real burdens patients carry
- What treatments are available, and where gaps remain
- How healthcare professionals understand and support the condition
- Which policies help, and which ones fall short

The outcome will be the region's first Psoriasis Scorecard: a tool each country can use to push for better care, stronger policies, and greater awareness. But beyond the data, this project represents something even more powerful: **the belief that every voice matters, and that shared stories can drive regional change**.

It reflects the passion of patient leaders who work late into the night, the courage of communities who speak up for the first time, and the shared hope that the next generation will face fewer obstacles than we did. The road ahead will require continued advocacy, education, and determination.

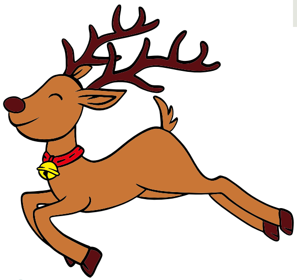
But the foundation is strong.

The Power of Working Together

Trust has been built.

The movement that began with a dream is now shaping a legacy for millions across the Asia-Pacific. When we stand together, listen to each other, and lift one another up, extraordinary things become possible.

Read the full story here: The Power of Working together



🎥 New Knowledge Partner Webinar

We are excited to share the recording from our PiCC Knowledge Partners Webinar on 10 December, created together with PRxEngage and Fight2Breathe, and featuring two powerful voices in patient advocacy: Keith Berelowitz and Caleigh Sarah Haber.

Keith and Caleigh share honest, experience-based insights on how patient perspectives can strengthen research, digital innovation, clinical operations, and long-term system change. In this recording, you'll gain:

- Real examples of how lived experience improves trial design and patient retention
- How digital health, community-building and patient voice intersect in 2025
- Practical strategies for turning engagement into genuine partnership
- Inspiration for both new and experienced patient advocates

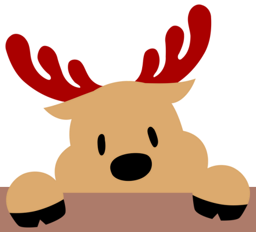
Watch the webinar here: **PiCC Knowledge Partners video**

pRxEngage FIGHT 2 BREATHE PiCC® UNITED

News Update

PiCC United at the EPF Congress 2025 – More voices, fewer resources?

At the end of November 2025, PiCC United sent two representatives to the European Patients' Forum (EPF) Congress 2025 in Brussels — one of Europe's most important gatherings for patient organisations, decision-makers, professionals and industry representatives focusing on patient involvement and the future of the healthcare system.



The EPF Congress 2025 brought together over 200 participants from across Europe with the overall aim of setting the course for the future of healthcare: towards more robust, inclusive and patient-centred systems.

For PiCC United, it was an obvious opportunity to bring our experience with patient involvement, diversity and co-design directly into a broad European context.

We heard about current trends and challenges. For example, how digitalisation and AI can be developed with patients' needs at the centre, or how to ensure equitable access for marginalised or under-represented patient groups.

We met other patient organisations, decision-makers and experts. Gained inspiration, networks and concrete ideas on how we can strengthen our own efforts: from communication, member involvement and social media plans to strategic collaborations and advisory content.

At the same time, the congress confirmed the message that has been central to our work: that patients are not just 'stakeholders' or 'target groups' — they must be equal partners in the development of health, medicines, care and policy.

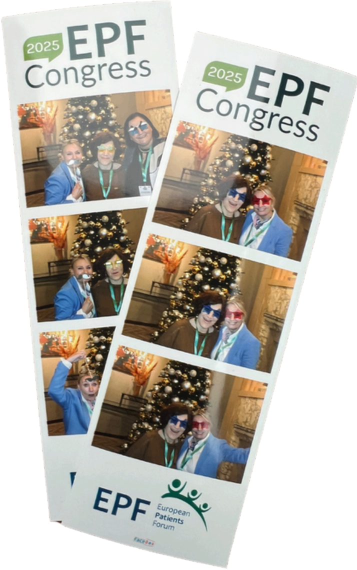
We took home with us

A clear confirmation that digital health and AI only make sense with a human foundation, a focus on ethics, inclusion and patient rights.

The importance of mental health and holistic care, an area we at PiCC United are already working on (an example of which is our ‘Mental Health Support in Clinical Trials’).

New knowledge, new contacts and new ideas on how patient involvement can be stronger at EU level, which we can draw on in our future collaborations and projects.

For PiCC United, the EPF Congress 2025 marks not just one event — but a clear direction: a more patient-led, more humane and more equitable healthcare systems.



We look forward to sharing, implementing and translating what we have learned — for the benefit of members, partners and patients across Europe.

Your voice. Your impact. Your community.

It's easy to become part of PiCC United.

All you need is your email address to sign up – and membership is free. It costs you **nothing**, but gives you access to all our resources: knowledge, webinars, materials, networks and opportunities to get involved in patient involvement on your own terms.

At PiCC United, it doesn't take much to get started, so whether you are curious, new to the role of patient advocate, or already active and experienced. Your experience is enough.

Practical support

If you are new to patient involvement, short, easy to read/watch online help is there to give you relevant information about patient involvement and research so, especially if you're new to the field, sign up and give it a go!

Tell us what you think...

Since we launched PiCC United we have consistently been listening and improving our ways of providing a better service for yourselves as the PiCC United 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!

PiCC Knowledge Partners

A collaborative approach

At PiCC United, we believe in strong partnerships. We collaborate with patient groups, healthcare professionals, researchers, and industry leaders to create patient-focused solutions. Knowledge Partners contribute expertise that supports our mission, strengthening patient engagement and healthcare outcomes.

ICHOM

The International Consortium for Health Outcomes Measurement (ICHOM) is a non-profit organization dedicated to transforming healthcare systems worldwide by focusing on what matters most to patients—health outcomes.

The Patient Partner Alliance

The PPA was established as part of ICHOM's commitment to ensuring that patient perspectives are central to the development and implementation of health outcome measurement. The alliance brings together patients, caregivers, and advocates to contribute their lived experiences, insights, and priorities to ICHOM's work. By integrating patient voices, the PPA aims to enhance the relevance, usability, and impact of ICHOM's Sets of Patient-Centered Outcome Measures, ultimately driving the global adoption of value-based healthcare. This collaboration seeks to empower patients as active stakeholders in shaping healthcare decisions, fostering transparency, and advancing the delivery of high-quality, patient-centered care worldwide.

For more information visit www.ichom.or

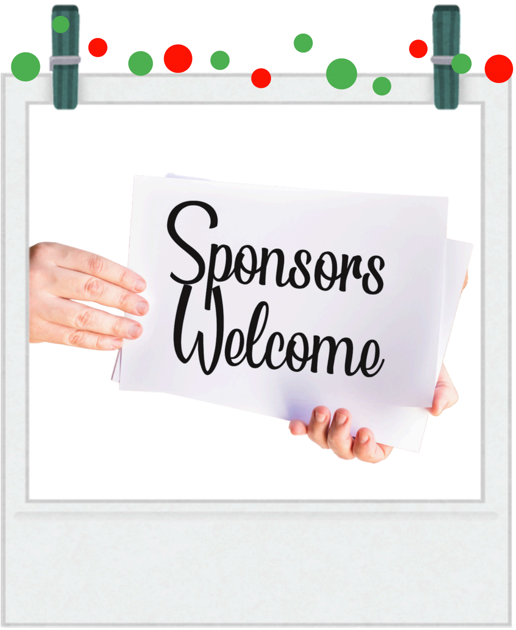
ICHOM

PiCC United takes the next step

A new chapter for patient involvement in 2026. At PiCC United, we are now in the midst of an important development.

At PiCC United, we are now in the midst of an important development. 2025 marks a year in which our capacity, network, and collaborations are growing significantly, from WHO collaborations to partnerships and sharing learnings with international patient organisations and public structures. And at the beginning of 2026, we will take the next big step:

PiCC United will be established as a fully independent non-profit NGO.



Although our structure is changing, our goals and values remain the same:

- To increase the diversity of voices that are heard
- To make patient involvement much more accessible in practice
- To give people who have never been involved before the support and reassurance they need
- To ensure that patient and family perspectives become a natural part of research, system improvement, and health policy

This new chapter gives us the opportunity to strengthen key aspects thatt many in small associations/groups are calling for: Patient-driven, peer-supported engagement environment, and a legal proxy and patient engagement lifeline for small and ultra-rare patient groups.

When we are an NGO sponsorship aligned with these goals and values will be possible and brings additional chance for identifying gaps, needs, and new challenges where patient involvement can be strengthened. All collaborations adhere to clear rules and ethical boundaries.

Buddy up

We “buddy up” with small patient organizations

Small associations and groups can continue their core tasks—such as patient support or political advocacy—while PiCC United helps them to:

- raise awareness of patient involvement
- provide their members with an easy and safe way to get involved
- handle the administration involved in involvement

This means that more patients will have the opportunity to participate without small associations burning out on the task.

A lifeline for small and ultra-rare patient groups

Some patient communities are just a small Facebook group or a network of parents.

For them, PiCC United offers:

- legal proxy function
- administrative support
- ethical framework for collaboration with healthcare and industry

In this way, even the smallest groups can be heard in the development of healthcare.

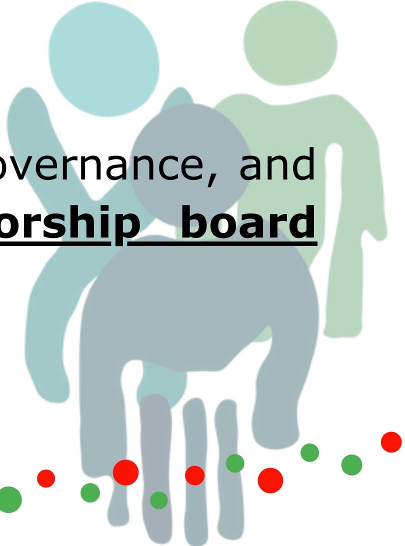
A patient-driven, peer-supported engagement environment

No new patient representative should stand alone.

Through PiCC United, new participants gain access to:

- a safe community
- other patient representatives who can answer questions
- sparring, support, and experience sharing

This lowers barriers and makes the path to engagement clear and realistic.



Read more

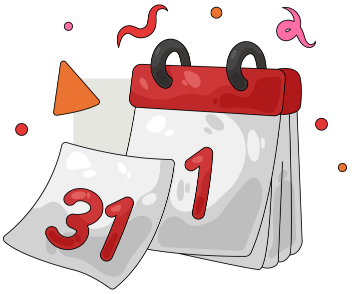
The full description of the Sponsorship Board, governance, and practical details can be found here: **Sponsorship board members**

December 2025

Annual Report 2025

at the start of 2026

We are approaching the end of a year where PiCC United has taken some important and meaningful steps forward — both as an organisation and as part of a growing international patient community. Our full annual report will be published at the start of 2026, but for now we would like to share some of the key initiatives, partnerships, and outcomes that have shaped our work throughout 2025.



In the meantime, we would like to share some of the highlights from the year — including:

- our progress in establishing PiCC United as an NGO
- the growth of our international collaborations and partnerships
- new initiatives focused on capacity building for patients and relatives
- the development of PiCC Knowledge Partners
- and the most important lessons learned, shaping our direction towards 2026
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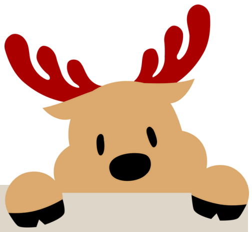
We look forward to sharing the full report at the start of 2026, and to a new year built on even stronger collaboration, more patient voices, and meaningful, lasting impact.

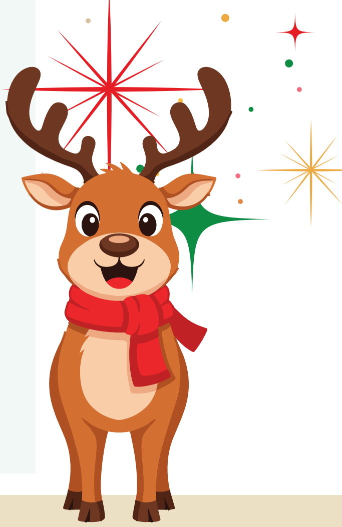


Collaboration opportunities

Our webinar series 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 Psoriasis Philippines and PsorAsia+Pacific, we strengthen our global community and help create more meaningful patient partnerships across systems.

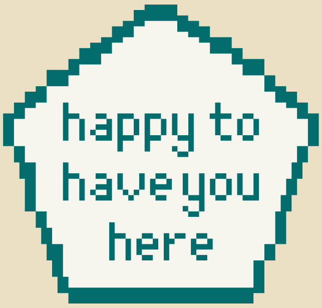
December 2025



Never stop collaborating

Sometimes the best ideas and strongest connections are born over a cup of coffee, when 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 or click here: Tell us more

SEARCHING for PiCC Lounge

Our PiCC Lounge Podcast is on Apple, Spotify, Amazon, PlayerFM, and Podchaser, sign up, follow and get the latest episodes delivered right into your ears!

In our latest episode Susanna Von Tonder, patient expert, psychologist, advocate, and disability rights activist, shares how her own lived experience turned silence and exclusion into a powerful drive for change. She shares an inspiring call for young people with chronic illness or disability to step forward as the next generation of patient experts.

www.piccunited.org

One Shared Mission

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**

SEE YOU IN 2026

PiCC®
UNITED

Trust, inclusion, and action

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

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