

ESID/INGID/IPOPI CONFERENCE 2024 UPDATES



Important dates are:

Early Bird Rate is available until 24 July

[Register Now for ESID 2024, Immunodeficiencies Conference \(esidmeeting.org\)](https://esidmeeting.org)

Hotels

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We are delighted to announce our 2 keynote speakers:

Imelda Coyne: **Shared Decision Making**

Martine Pergent: **IPOPI'S PID LIFE INDEX-The PID Environment Around the Globe**

INGID's 30-year Anniversary

We will be celebrating **INGID's 30-year Anniversary** during the conference with an evening event on Thursday 17th October. We are looking forward to celebrating with you all, another exciting milestone for INGID. More details to follow.

Promoting INGID in Marseille via Social Media

Are you traveling to Marseille in October and are active on **Twitter, Instagram, LinkedIn or Facebook**?

Let us know which platform you prefer?

We are looking for **2 INGID members** who are active on social media and would be willing to actively promote sessions (Adult/Paeds or SCIG or IVIG) during the conference on any of these platforms.

If you can help us- we will pay your registration to attend INGID.

ERN-RITA UPDATE

We are looking for nurses to participate on these topics.

Are you interested, and then please get in touch with us at INGID - ingidboard@ingid.org

- Diagnosis: how to announce diagnosis? Health care providers and patients' perspectives (what can make it better)
- How can patients explain their disease to family, friends, schools & employers and get appropriate support?

Also visit website to visit the latest webinar done on 26.06.2024 available at [Educational webinars organized by ERN-RITA - ERN-RITA](#) on the topic

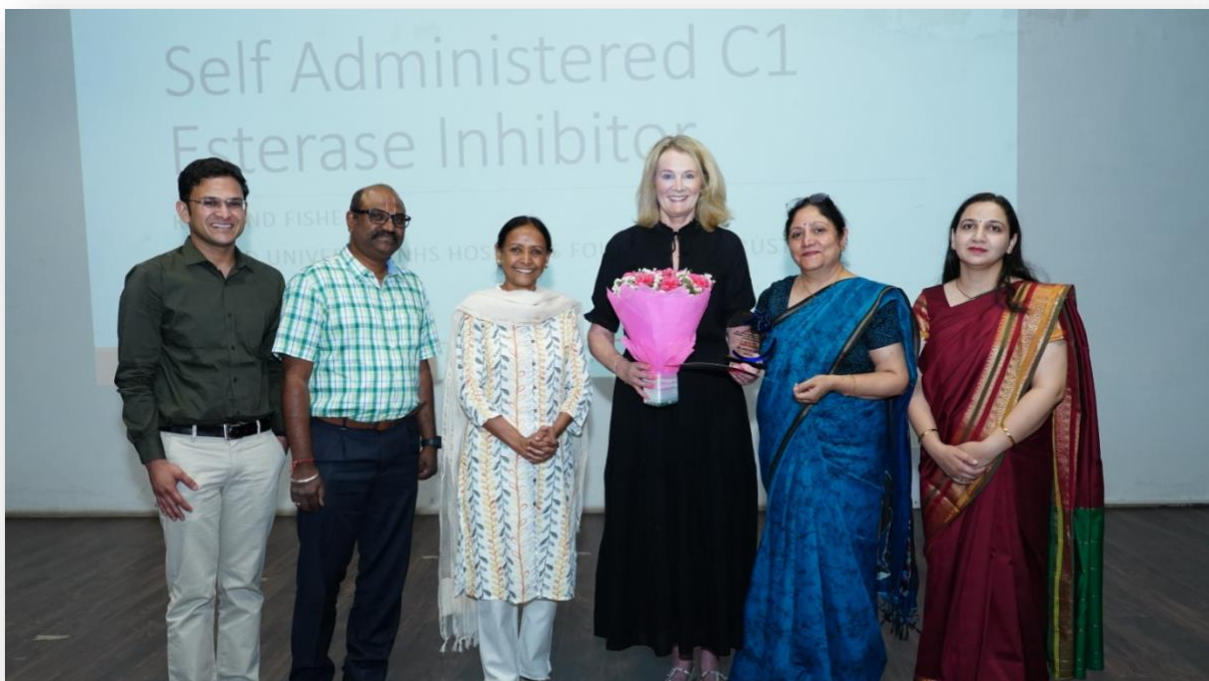
RITA Patient-Centred: Social rights of a person with a rare disease and the patient perspective in advocacy, the case of Malta

What are the rights of a person with a rare disease? Support at European and national level Patient perspective in advocacy of a rare immunological disease: the case of Malta

PIDCAP warning signs Project: Delphi Process for Inborn Errors of Immunity Early Diagnosis

A huge thankyou to all our members who volunteered to participate in the Delphi PIDCAP study. We have forwarded the names of more than 10 experts from INGID to the organizers and their active participation is very much appreciated.

HAE 2024 CONFERENCE AT PGIMER, INDIA





On May 18th 2024 HAESI organized the "CME on – Nursing empowerment in Angioedema Management and Patient Education Programme on Hereditary Angioedema (HAESICON) 2024" at PGIMER institute in India. The CME organisers consisted of Prof . Surjit Singh (Patron), Dr. Sunil Dogra and Dr. Sukhpal Kaur (Organising chairperson) and Organising Secretary **MS. Ruchi Saka (INGID-Director of Communications)**

HAESI invited an INGID representative to support the topic with the nursing perspective. **INGID President Rosalind Fisher** participated and talked about Angioedema management in a Nurse led UK clinic.

The CME focused on Basics of Angioedema for nurses and Hands on workshop for patient groups and workshop was lead by lead **INGID President Rosalind Fisher** along with 6 speakers.

The diverse range of audience gave an overview on different challenges faced in recognising the disease pattern and barriers in the treatment opportunities We from INGID would like to thanks HAESI for their effort on nursing empowerment and patient awareness, in collaboration with our organization .

[World Primary Immunodeficiency Week \(22-29 April\)](#)

Thousands of events happen across the world during World PI Week. Through online/in-person events, public lectures, medical symposia, family activities, runs and walks, media interviews and many other actions, the global primary immunodeficiency community unites to bring about positive changes in healthcare systems and practices, in support of people living with the disease.

This year focus was on:

Access to care for all PID patients, everywhere Let's make early diagnosis & timely access to quality treatment a reality worldwide.

The graphic features a central circular collage of photos showing diverse people celebrating and holding signs. A hand is shown holding the bottom of the collage. The text 'Access to care for all PID patients, everywhere' is prominently displayed in teal. Below it, the slogan 'Let's make early diagnosis & timely access to quality treatment a reality worldwide' is written. A green circular badge in the top right corner contains the World PI Week logo and the dates '22-29 April 2024'. At the bottom, there is a green bar with the website 'www.worldpiweek.org' and social media handles for Instagram (@world_pi_week_), Twitter (@WorldPIWeek), and Facebook (@WorldPIWeekCampaign).

Access to care for all PID patients, everywhere

Let's make early diagnosis & timely access to quality treatment a reality worldwide

Remembering Vicki Modell, global patient advocate, and co-founder of World Primary Immunodeficiency Week.

www.worldpiweek.org @world_pi_week_ @WorldPIWeek @WorldPIWeekCampaign

This year was the first year that a digital comic was produced, please click on the link below to access.

<https://worldpiweek.org/comic-book-v2/>

Please visit the website www.worldpiweek.org there's lots of useful information and next year's campaign will hopefully be coming soon.

With warm wishes to you all

Ruchi Saka and the INGID board