



INGID NEWS - December 2024

We had an amazing time at the ESID/INGID/IPOPI meeting in Marseilles. A huge thank you to everyone who made this event possible, the speakers, the organisers, the INGID Board and all of the attendees. We have received overwhelmingly positive feedback, it was really great to welcome so many international immunology nursing colleagues to France and a joy to welcome our speakers in person after all of the months of planning.

INGID was able to fully sponsor 11 nurses to attend the conference and support the registration of an additional 16 international nurses, this is a record level of funding that we are proud to have secured. We thank all of the pharmaceutical companies whose contributions were very generous.

There were record numbers of participants enjoying opportunities to learn, collaborate, and network during a very interactive and thought provoking programme which covered cutting edge topics such as artificial intelligence, genetics, shared decision making and fascinating case studies from all over the world.

There were many highlights, an excellent educational afternoon, many interesting and insightful talks on a huge range of subjects related to immunodeficiency and inborn errors of immunity, research developments and an educational market-place session introduced by our Director of Education Karlien Claus. We had our first live debate which was very well attended and there was a constant buzz in our INGID room.

Special thanks must go to our 2 keynote speakers, Professor Imelda Coyne who presented Shared Decision Making which was extremely well received and very topical. Also to Martine Pergent President of IPOPI who presented IPOPI's PID Life Index tool, this received excellent feedback.

An AI translation tool was used for the first time which was hugely successful and encouraged inclusivity.

It was a very special conference for INGID as we celebrated our 30 year anniversary in style at a networking party in a lively bar in Marseilles. A huge thank you to Professor Ann Gardulf who gave a celebratory speech and showed many fascinating photographs from the early days of INGID.

Dutch Nursing Group

Some news below from, Lucy Gossens and Linda van der Knaap, on behalf of LW-VID (Dutch Nursing Group for Immune Deficiencies) and partners.

The excellent immunoglobulin therapy videos that were presented at the ESID/INGID/IPOPI meeting are now available on You Tube.

Lucy and Linda want to let you know that they do have a 'naked' version without voice overs, so INGID members (non profit) that want to make their own translation, according to our script, are welcome to send their request to us at kinderinfectieziekten@erasmusmc.nl.

Our British colleagues are already working on an English translation.

Because we've made this video in PROSA language (Procedural Comfort Care) we want translations also according to this method, so colleagues will receive a brochure with an explanation about specific PROSA language.

If you want to, you are welcome to share the link on the INGID website with the above explanation.

[LW-VID - YouTube](#)

All of the talks were recorded at the conference and are available on the ESID web-site for 3 months <https://esidmeeting.org/> You will need to enter your registration number to access these.

We are looking forward to receiving the official photographs which will go up on the web-site, but in the meantime there are a few highlights below.

European Parliament PID Forum

In other news It was a great pleasure for INGID to be invited to the PID Forum at the European Parliament in Brussels in November. Karlien Claes, Director of Education at INGID and Nurse Specialist at University Hospital Ghent represented INGID and shared her front-line experience on the critical effects of Ig therapy shortages on patients with primary immunodeficiencies (PIDs) and healthcare professionals.

Karlien highlighted:

- **Lack of Timely Communication** 📢: Patients first identified the shortage, leaving healthcare providers unprepared to respond or inform patients, pharmacists, and home care teams.
- **Increased Burden on Nurses** 🧑‍⚕️: In the acute phase, shortage management became so demanding that essential nursing tasks were set aside.
- **Challenges to Medication Adherence** 💊: Adjustments in dose intervals disrupted patients' routines, making it hard to restore adherence after the shortage.
- **New Patients Left Without Treatment** ❌: Newly diagnosed patients couldn't access necessary Ig therapy.

Karlien's message was clear: **Improved support and proactive communication from authorities is urgently needed to manage—and ideally prevent—future shortages.** Let's work together to secure stable treatment access for all patients with PIDs in the world! 🌍💙

Festive greetings

The INGID Board would like to take this opportunity to thank all our members for your involvement in and contributions to INGID throughout 2024.

Wherever you are in the world we wish you a healthy, restful and peaceful holiday season.

We are very much looking forward to engaging with you and working alongside you again in 2025.

The members of the INGID Board

Rosalind, Patricia, Ruchi, Julia, Sary, Lisa and Mary-Louise









