



# XVIII IPOPI GLOBAL PATIENTS' MEETING

an **IPOPI** event

16-19 OCTOBER 2024  
MARSEILLE, FRANCE

#GPM2024

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# WORDLY

## REAL TIME TRANSLATION



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# SESSION 1 – WELCOME SESSION

Moderator: Martine Pergent

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# IPOPI Team Welcome - Icebreaker

Whitney Goulstone, Otilia Stanga & Miriam Ferreira

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## LET'S PLAY BINGO!!!!

1. Find another participant who has the **same envelope number** as you.
2. Each BINGO card has **two colours**:
  - **White** – find a person who matches a “statement”
  - **Orange** – discuss a “topic” with someone
3. The first team to **complete a line (vertical, horizontal and diagonal)**, call out "**line**".
4. The first team to **complete the card**, call out "**BINGO**".





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# Chair's Welcome

Martine Pergent



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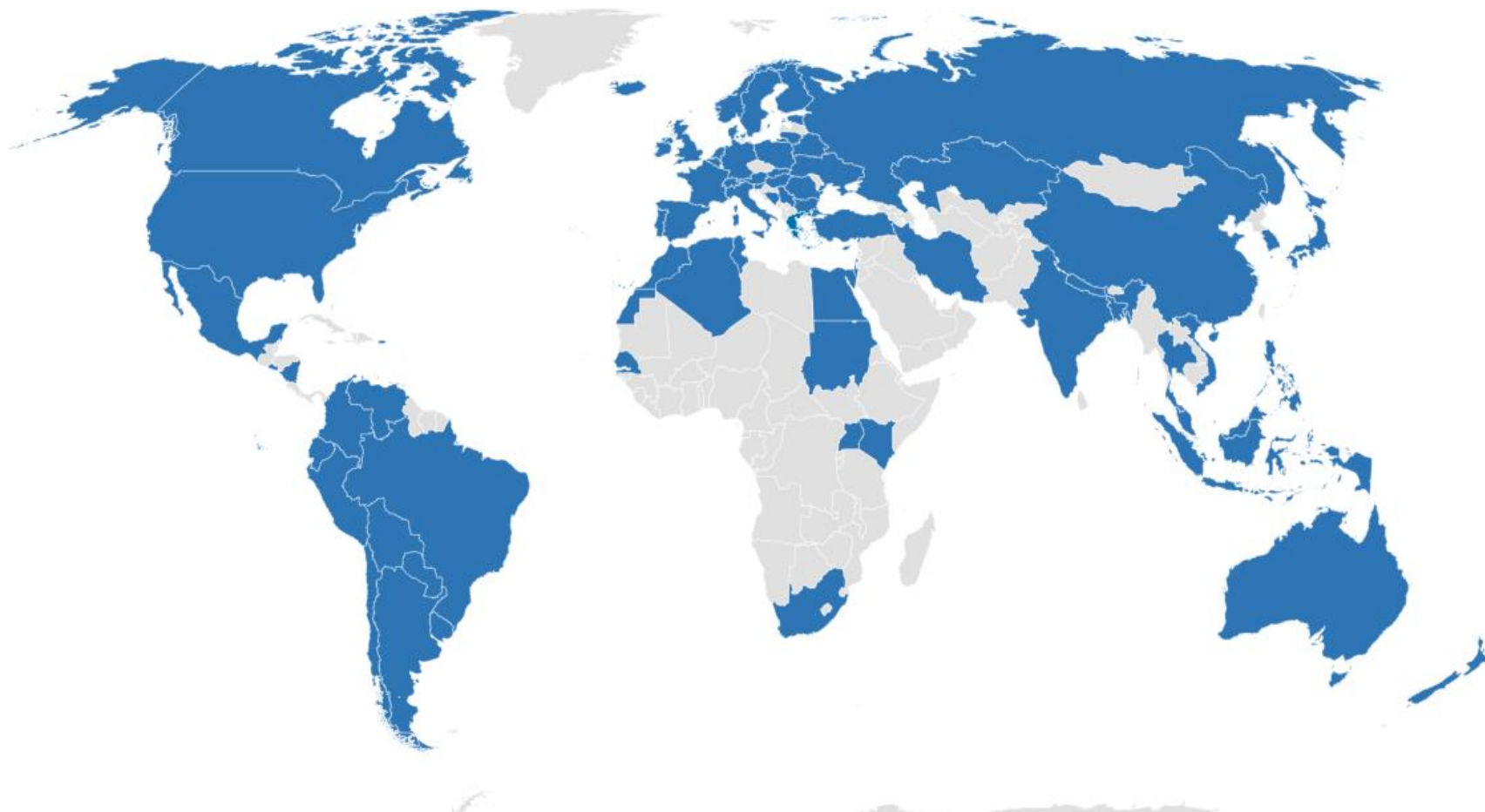
# Welcome

## to IPOPI 18<sup>th</sup> Global Patient meeting to Marseille!

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A round of introduction after the ice breaker

## 75 countries: 75 family members





## Some Key Messages to the Family Members

- 46 countries represented at the Global Patient Meeting, our thoughts go to those who could not make this meeting for different reasons.
- New countries, new people, don't be shy, try to speak with as many people as possible!
- A patient representative is a patient representative
- The Global Patient Meeting is a great opportunity to learn share and network: please raise your questions, cast your ideas! Again, don't be shy 😊
- Board and staff members are all dedicated to you, if any question come, to us.
- We have booth at the exhibition, and good news, the exhibition is open to patient representatives.
- English is IPOPI language, English native speakers think that not everybody is, help each other.

## Join the IPOPI NMO Community on WhatsApp

- A hub for key NMO leaders to receive regular updates from IPOPI and get inspired by the successful initiatives shared by fellow NMOs worldwide. This group is specifically for key leaders, not all members of your organisation.
- Access this QR code to access now (not to be shared externally). Further members reach out to Miriam at [miriam@ipopi.org](mailto:miriam@ipopi.org)



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**Board and Staff,  
we all wish you a wonderful  
Global Patient Meeting!**

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# IRIS Welcome to Marseille

Pierre Aubisse (IRIS, France)

# Help us grow on social media!

## Connect with us!



IRIS on Instagram



IRIS on Facebook





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# Andrea Gressani Keynote Lecture

## Chronic Granulomatous disease at 70: Where have we been and Where are we going?

Andrea Gressani



Prof Steve Holland

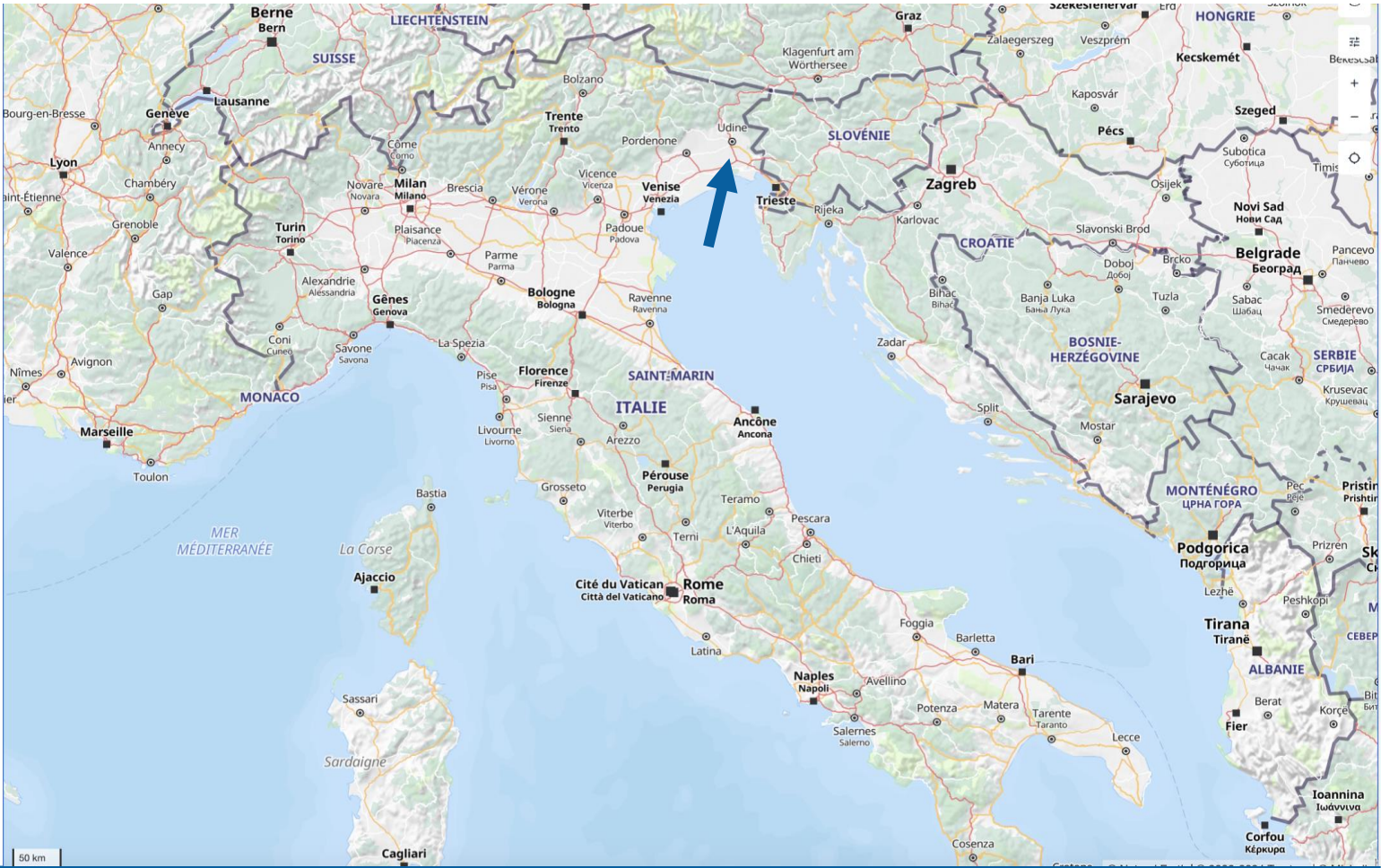


# Andrea was born in Udine, Friuli, Italy

University of Udine



Semplitech





## He became the vice president of AIP



## An IPOPI esteemed board member



**He served on IPOPI Board  
from October 2016  
to April 2023**



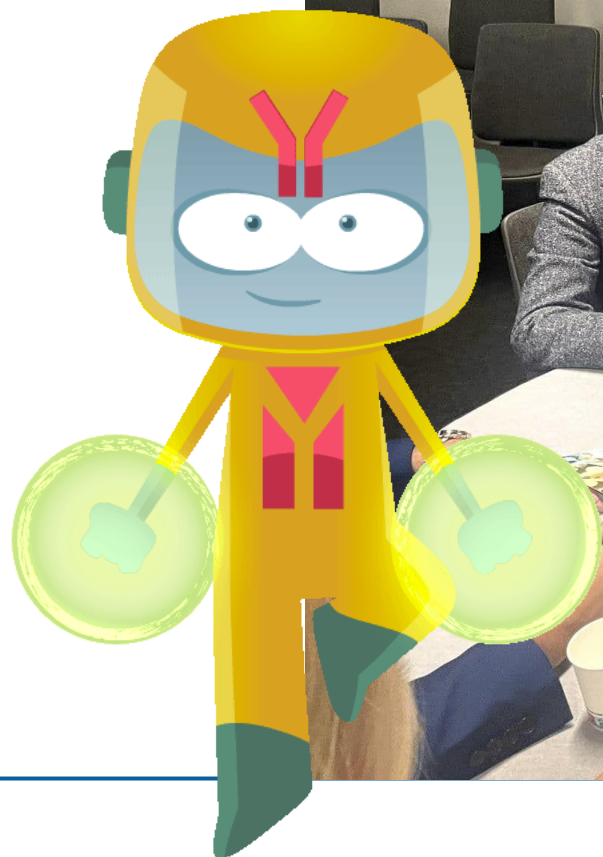
## A Fantastic Patient Advocate

« Once upon a time »





## A great fan and promoter of Lino Globulino



## A hard worker



**Sometimes a bit stuck between his phone, his computer and all of us**



## A dear Friend





# A team player





**Always smart  
in his Italian style suit**





He loved  
Life



... and  
Bros



Loved laughing





Loved wine



Even more when it  
came from Friuli

Sometimes  
also  
...  
water





## A man for networking



## Rare disease connexion

## Italian connexion



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**Also some ...  
dark sides**



**Mafia connexions from  
different continents...**

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We miss our friend,  
but will never forget his legacy

Life is not Perfect,  
but it is Wonderful!



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# CGD at 70: Where Have We Been and Where are We Going

Prof Steven Holland

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# THANK YOU!

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