



# XVIII IPOPI GLOBAL PATIENTS' MEETING

an **IPOPI** event

16-19 OCTOBER 2024  
MARSEILLE, FRANCE

#GPM2024

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# SESSION 8 – DIY: introduction to IPOPI toolkit

Moderators: Otilia Stanga, Rafael Graca & Miriam Ferreira

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# Launch the IPOPI Toolkit

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Miriam Ferreira, IPOPI NMO Programmes  
Officer

# Launch of IPOPI's New Toolkit

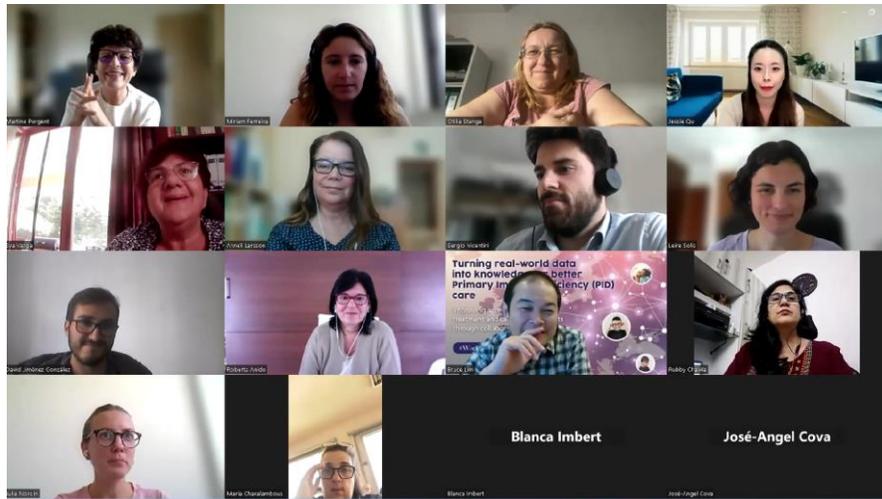
Empowering new and seasoned NMOs with essential tools and resources!



TOOLKIT

# We started this journey by listening to you...

In May 2023, we asked you what they needed via a form in Newsbites and an NMO Webchat. Your feedback guided the development of this toolkit.



**IPOPI's New NMO Toolbox - Feedback**

Country/NMO

Delegate Name

First

Email

What are your TOP 3 priorities? \*

- Fundraising - How to do a proposal to raise funds?
- Advocacy - How to request something from authorities?
- Communication and media - How to write a social media post?
- Patient support - How have the most out of your doctors visit?
- Community building - How to build a strong membership?
- Research and Data collection - How to set up a questionnaire?
- Communication and media - How to pitch your patient organization to stakeholders?
- Awareness - How to raise awareness on a topic?
- Advocacy - How to use the PID Life Index to advocate for improved PID care?

Want to develop a specific tool with IPOPI?

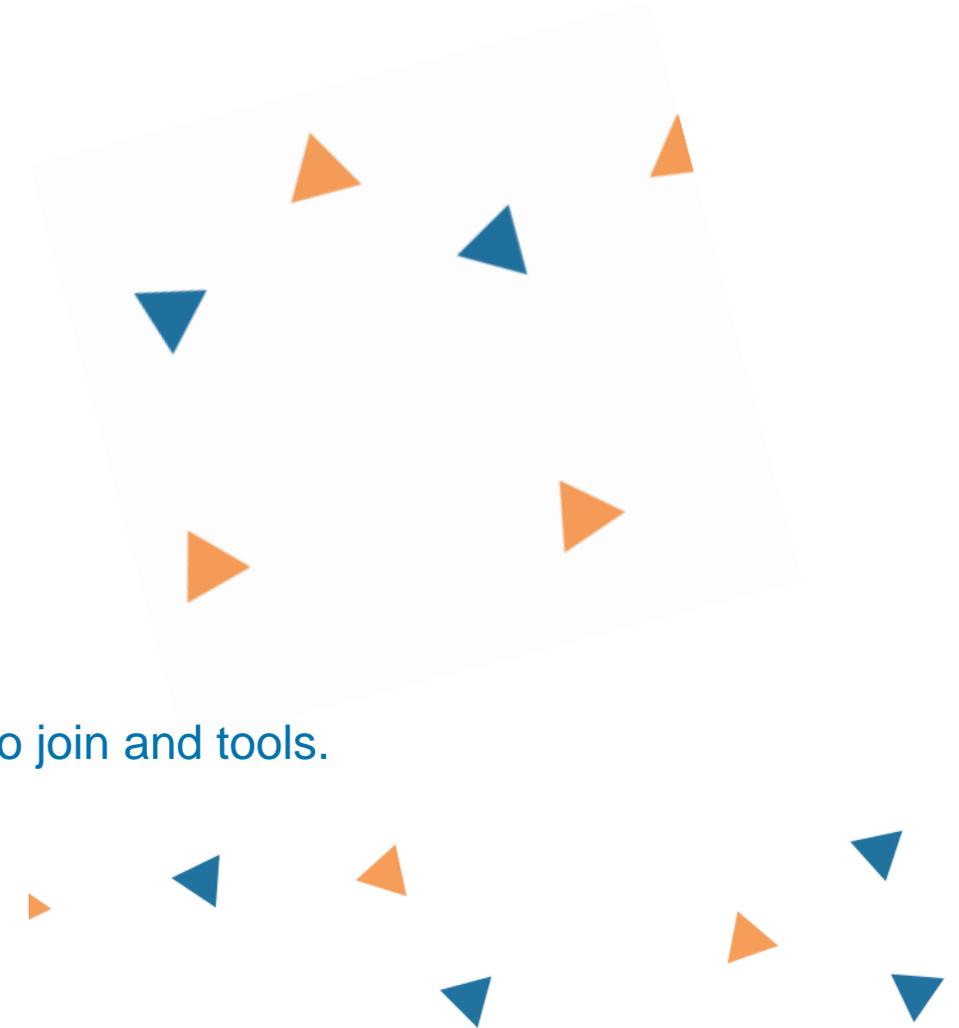
We would like to extend an invitation to NMOs to join forces with IPOPI in creating new tools. If you are interested in collaborating with IPOPI to develop a tool, please let us know by filling out this form and indicating your

Further suggestions? Share them here

# What you asked for...

## Your Voice, Our Toolkit:

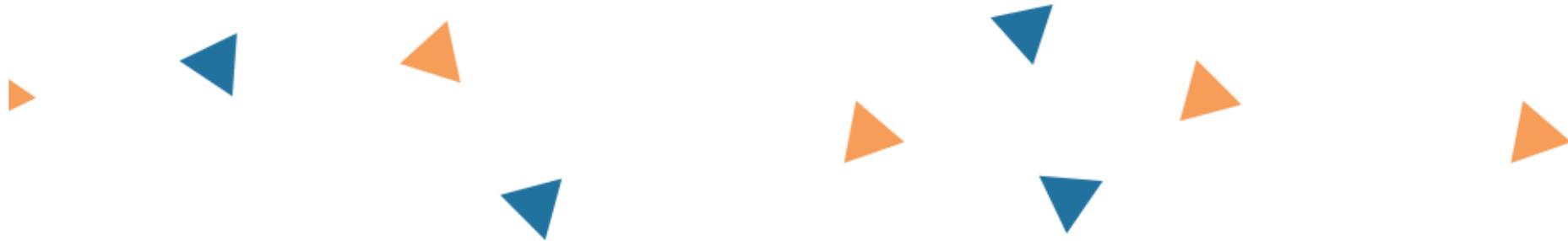
- Create a forum for NMOs to connect and share ideas.
- Provide communication tips for social media impact.
- Practical “How to” guidelines.
- Have tools from the basic to more complex ones.
- Guidance on most important international campaigns for members to join and tools.
- Ready-made event templates for big events like WPIW.
- Harmonised platform with all educational tools.



## Toolkit overview

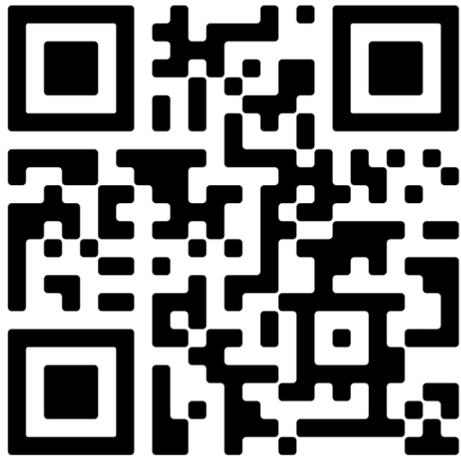
**An essential resource pack to help our members reach the next level!**

-  **Explore a treasure of resources, templates, and best practices.**
-  **Divided into nine exciting categories** for easy navigation.
-  **Empowers both new and seasoned NMOs** with adaptable tools.



# Toolkit overview

An essential resource pack to help our members reach the next level!



STRATEGY AND GOVERNANCE

AWARENESS

ADVOCACY

EDUCATION

COMMUNICATIONS AND MEDIA

COMMUNITY BUILDING

PATIENT SUPPORT

FUNDRAISING

RESEARCH AND DATA COLLECTION

# Moving forward

**WE WANT TO HEAR FROM YOU!** 🗣️

Are there any other tools you need? Let us know here:

Country of organisation (NMO) \*

Your Name

E-Mail \*

Tool suggestions: What other tools would help you achieve your goals? Any other feedback or ideas? \*

Submit

Our toolkit is a living resource designed to grow with our community.

We're excited to see how you use it!

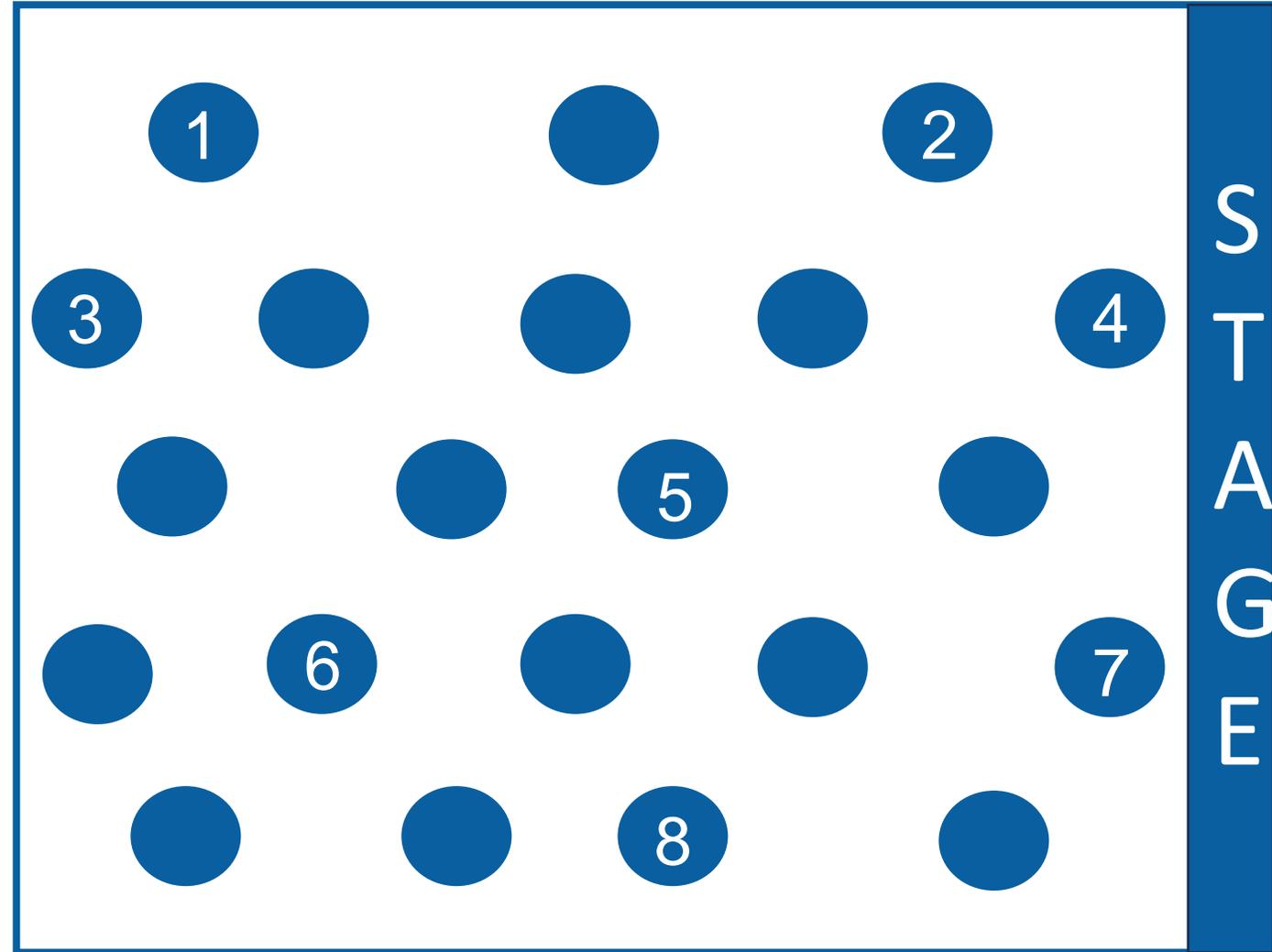


## And now... Let's practice

1. Basic tips for mobile videography - Iqbal Hossain
2. Patient Storytelling – Share Your Story - Carolyn Dews
3. How to talk to media - Blanca Imbert
4. How to pitch your organisation - Jorey Berry
5. How to grow an active membership? Jose Verstegen
6. How to speak to politicians & decision-makers - Leire Solis
7. How to produce and use a white paper - Bruce Lim
8. Mastering fundraising for your organisation - Johan Prévot

## TABLES

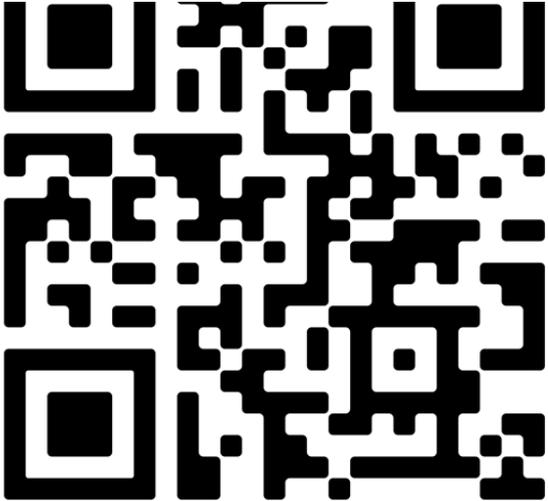
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7. How to produce and use a white paper
8. Mastering fundraising for your organisation



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# Conclusions

TOOLKIT



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# END OF THE DAY

## Thank you!

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