



NM WEBCHAT

NEWBORN SCREENING

MAY 9, 3 PM CEST - ON ZOOM

On the agenda

- Newborn Screening for PIDs – How to advocate?
- Presentation of World Blood and Plasma Donor Day and International Neonatal Screening Day campaigns
- IPIC2023 NMO Travel Grants
- NMO Toolbox relaunch – Share with us your insights



Moderated by Martine Pergent

In Andrea's Memory



POSTCARD

*Pensieri di Francia
In ricordo
d'Andrea*



Anna Marcotti
Via Manzini 9
33100 Udine
Italy

Newborn screening for PIDs & advocacy

Leire Solis

IPOPI Health Policy and Advocacy Senior Manager



Why we advocate?



Apparently healthy baby at birth

“Joy of having a healthy baby”



Repeated hospitalisations due to pneumonia, diarrhoea, repeated infections

“He was just 2 months old and he was transferred to our local hospital for 5 months”

“despite treatment, not getting better”

“it was hard breaking to see him surrounded by these machines”



If untreated, most babies die within the 1st year of life

“Nothing could be done – he died one month later”

“We lost our baby girl when she was 11 months”

Why we advocate?

WHAT DOES NEONATAL SCREENING MEAN FOR PATIENTS?

Timely access to diagnosis, treatment and care!



Whilst some conditions, such as phenylketonuria (PKU) or congenital hypothyroidism (CH) have long been implemented in many national neonatal screening programmes, others such as severe combined immunodeficiencies (SCID) or spinal muscular atrophy (SMA), have been gaining growing attention in the past decade, with new advanced therapies becoming available.

Why we advocate?



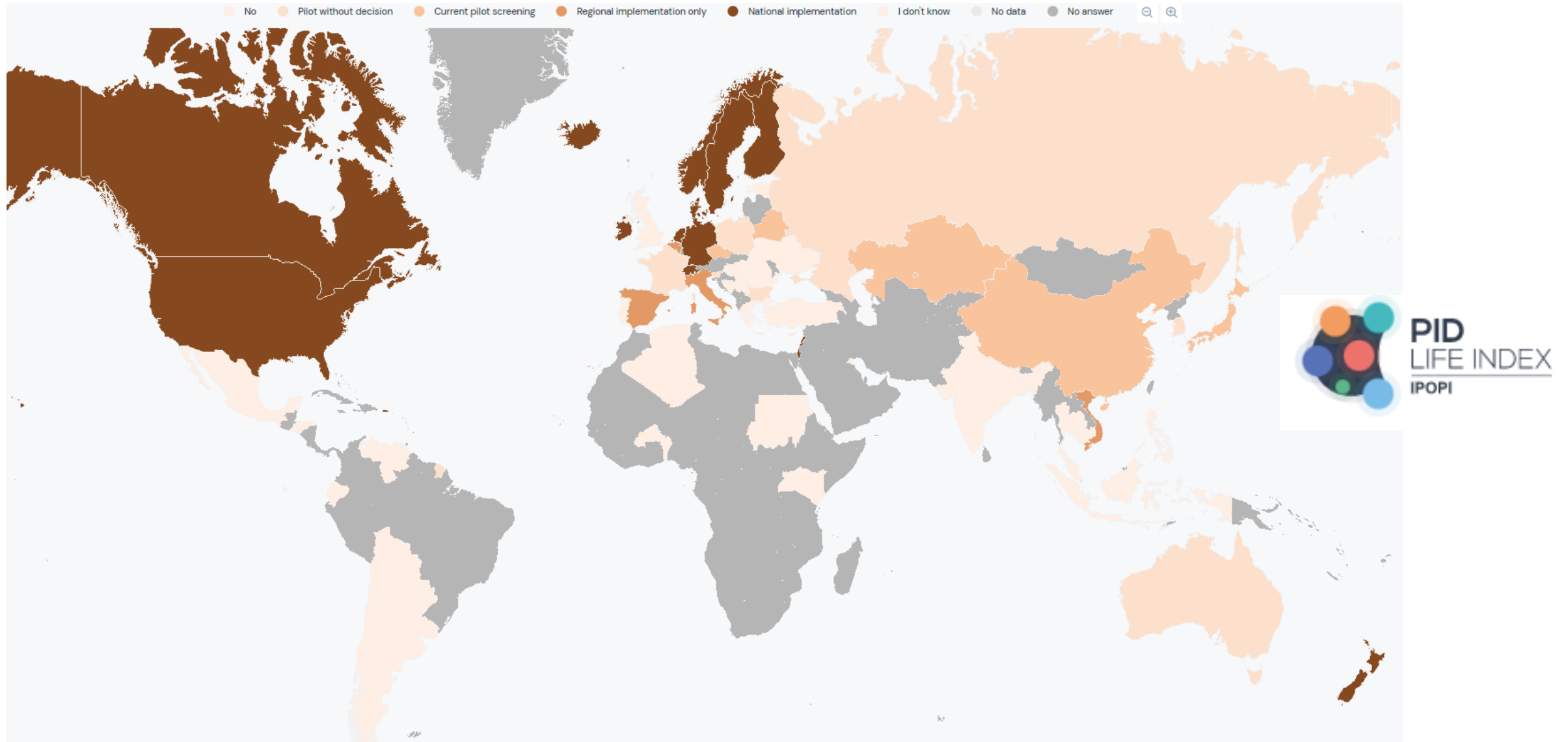
SCREENING FOR SEVERE COMBINED
IMMUNODEFICIENCY (SCID)

We screen because we can treat and cure!
Norwegian National Unit for Newborn Screening, Oslo University Hospital

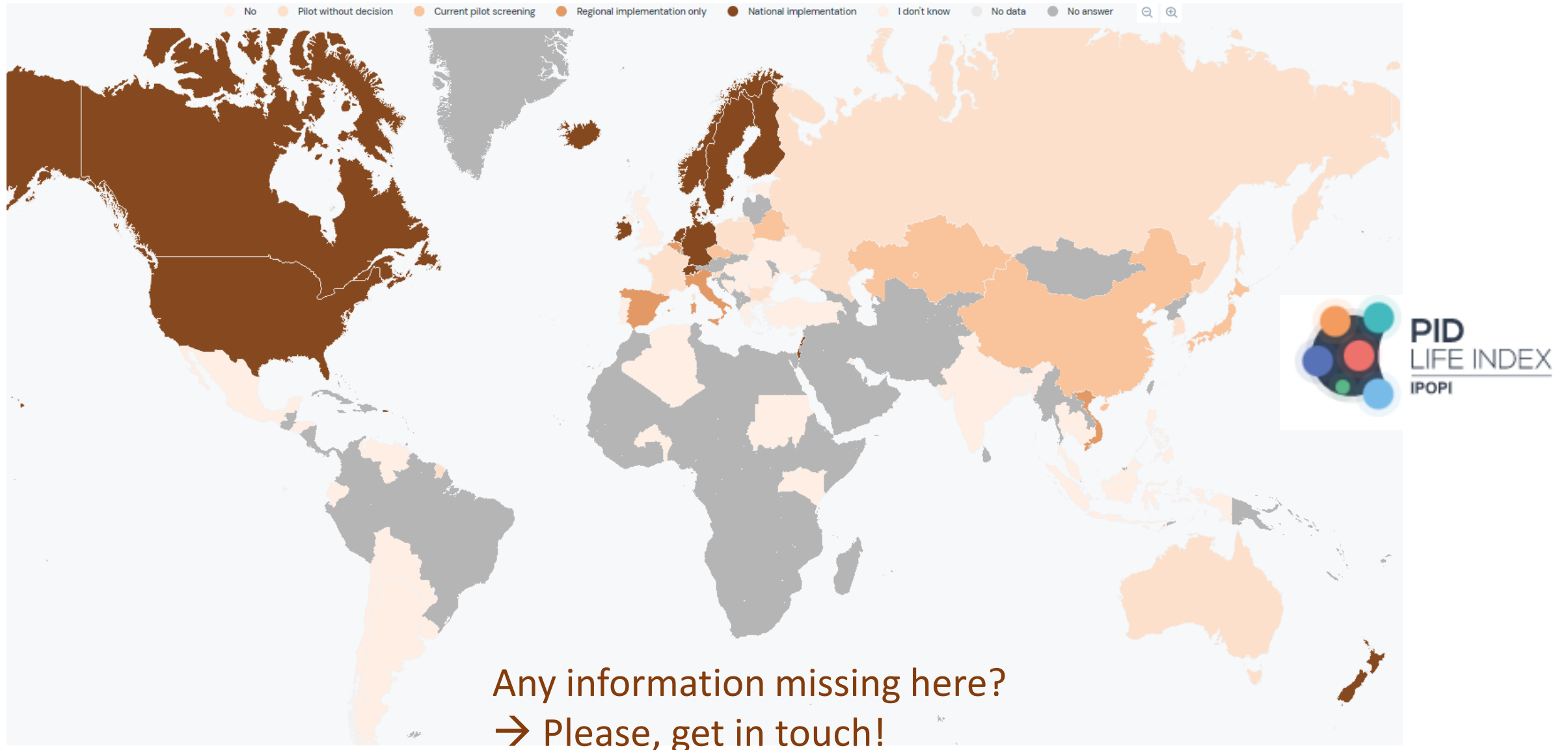


Source: https://oslo-universitetssykehus.no/Documents/Nyf%C3%B8dttscreening/SCID-brosjyre_engelsk.pdf

Newborn screening for SCID in the world



Newborn screening for SCID in the world



How we advocate?



How we advocate?



How we advocate? – some suggestions

- Know your environment
- Make friends
 - To guide your work → medical advisors
 - To establish partnerships → supporting scientific / medical societies
 - To help you change things → policy & decision makers
 - To support your work → sponsors
- Establish a plan with concrete steps
- Be ready for the unexpected & adapt!



Upcoming campaigns June 2023



Julia Nordin
IPOPI Communications Manager

Upcoming campaigns – June 2023

MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY	SUNDAY
			1	2	3	4
5	6	7	8	9	10	11
12	13	14 WORLD BLOOD AND PLASMA DONOR DAY	15	16	17	18
19	20	21	22	23	24	25
26	27	28 INTERNATIONAL NEONATAL SCREENING DAY	29	30		

World Blood Donor Day 2023: Give blood, give plasma, share life, share often

When? 14 June every year

Why is this day important?

World Blood/Plasma Donor Day is a unique opportunity to raise awareness about why donating blood **and** plasma is crucial for our community.

How to join?

Any way that fits your organisation!

This year, the World Health Organization especially encourages testimonies from people who's lives have been saved through blood or plasma donation as a way of motivating new donors.

Keep an eye on WHO's website for campaign materials.

Tag your posts: #WorldBloodDonorDay #WBDD



JOIN US IN CELEBRATING



INTERNATIONAL NEONATAL SCREENING DAY

JUNE 28



ISNS
International Society
for Neonatal Screening



International Neonatal Screening Day

When? 28 June every year

Why is INSD important? INSD raises global awareness on neonatal screening's vital role in fast-tracking diagnosis and treatment for diseases like severe combined immunodeficiency.

JOIN IPOPI's SCID NBS CAMPAIGN ON JUNE 28

Share short videos on topics like:

- **Personal experiences:** Testimonies from families with babies born with SCID, sharing how screening made a difference or could have made an impact.
- **Spreading awareness:** Share powerful messages that emphasize the crucial role of neonatal screening in detecting SCID early and saving lives.
- **Success tales:** Inspiring narratives from countries that have successfully implemented SCID NBS, showcasing the progress made in identifying and treating SCID cases.
- **Why SCID NBS matters:** Share insights into the importance of SCID NBS through the perspectives of patients, families, NMO leaders, staff members, and medical advisors.



TAG YOUR POSTS: #SCIDScreeningMatters
#INSD #InternationalNeonatalScreeningDay #NeonatalScreeningMatters



Other ways to join INSD

- Download and share the INSD materials: <https://neonatalscreeningday.org/>
- Share IPOPI's and Screen4Rare posts
- Disseminate information about SCID NBS
- Share information about ongoing advocacy efforts to increase awareness of SCID and the importance of neonatal screening. Share calls to action and contact legislators.
- Create your own SCID NBS awareness event

Don't forget to share your plans:

<https://neonatalscreeningday.org/share-your-plans/>

With the successful implementation of SCID NBS in several countries, now is the perfect time to increase awareness, celebrate progress, and share best practices.

The INSD is an initiative led by IPOPI, ESID, and ISNS under 'Screen4Rare'.



IPIIC2023

Miriam Ferreira
NMO Programmes Officer





IPIC2023

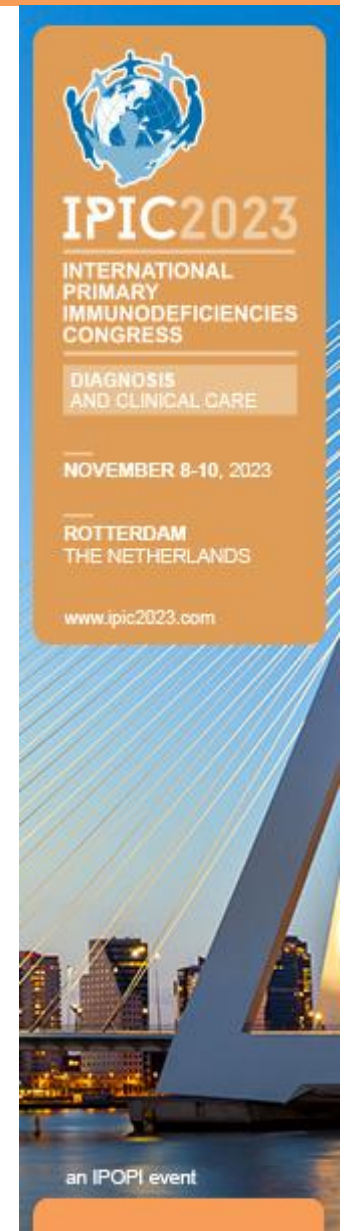
What? International Primary Immunodeficiency Congress

When? November, 8-10, 2023

Where? Postillion Hotel & Convention Centre WTC. Beursplein 37, Meent 110, 3011 AA, Rotterdam, The Netherlands

Why attend? Great opportunity for you to increase your knowledge on the diagnosis and clinical care of PIDs, interact and make new valuable contacts.

More info about programme in: ipic2023.com/scientific-programme/



IPIIC2023 NMO Travel Grants

How? Complete the application form on the [IPOPI website](#).

By When? May 15, 2023 🕒

Conditions:

- Applicants should be actively involved in their national PID patient organisation.
- We have limited funding to assist **1 person per NMO** for those *NMOs that have not been able to secure local funding to cover the expenses of their delegate*.
- Both associate and full NMOs can apply for financial support.
- The travel grant value is set to **€500 per grant, per applicant**.
- Travel grants are offered to financially *help* those NMOs wishing to attend, but they may not cover your full travel costs. No extra costs will be funded.
- IPOPI's financial assistance to NMOs is subjected to limitations and not all applications may therefore be accepted.



Relaunch of IPOPI's New Toolbox – Share your insights!

Miriam Ferreira
NMO Programmes Officer



Relaunch of IPOPI's New Toolbox – Concept

What? A new comprehensive collection of tools (resources, templates, and best practices).

Objective: Support new NMOs in their implementation and current NMOs in their development and achievement of their mission.

Characteristics: The tools in each category will have adaptable templates and examples to suit the needs of different NMOs.



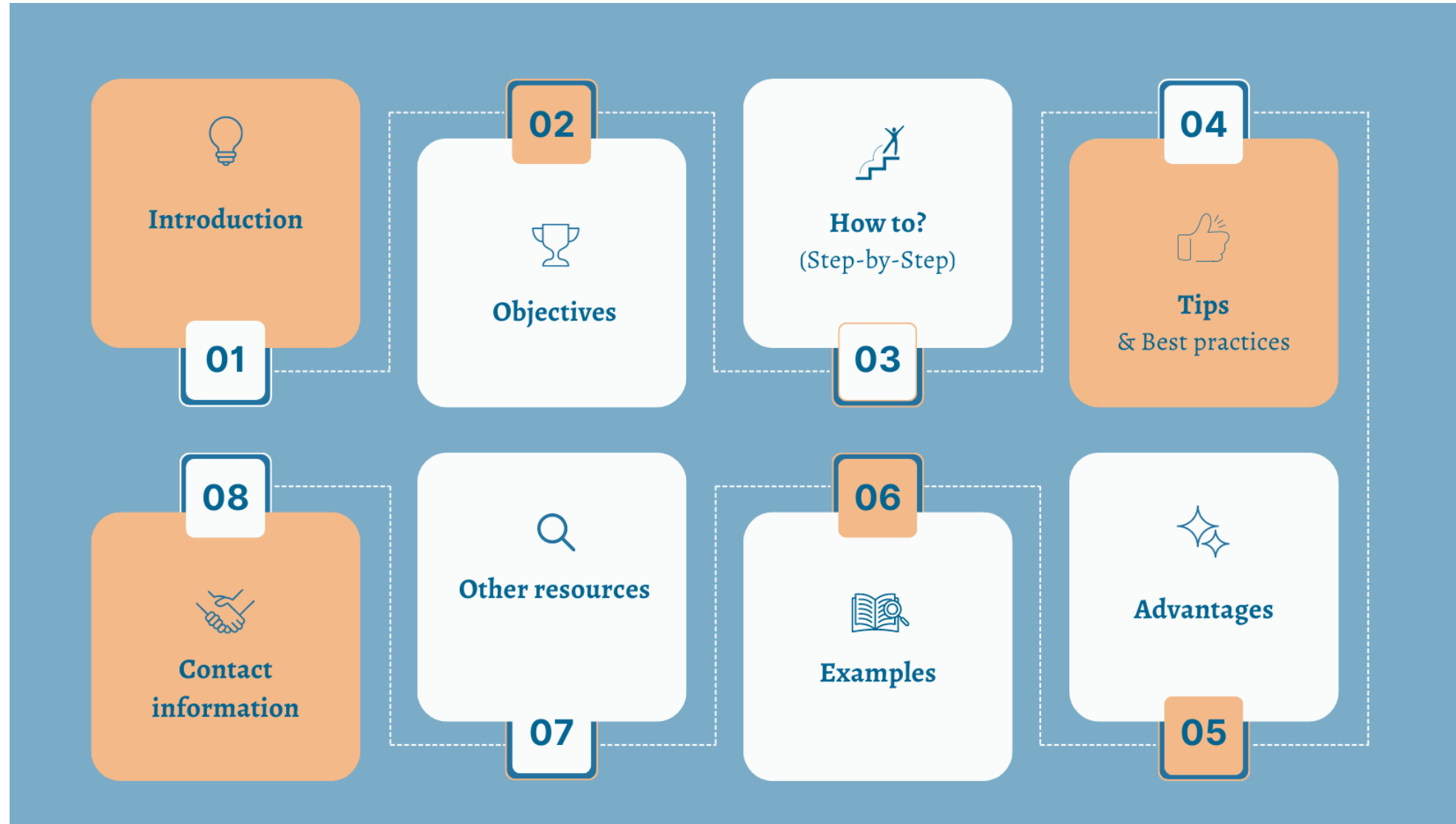
Relaunch of IPOPI's New Toolbox – Categories

The toolbox focuses on **9 different categories**, which are:

- I. Strategy and Governance
- II. Awareness
- III. Education
- IV. Patient support
- V. Fundraising
- VI. Community building (activities)
- VII. Advocacy
- VIII. Research and data collection
- IX. Communication and media



IPOPI's New Toolbox – Structure

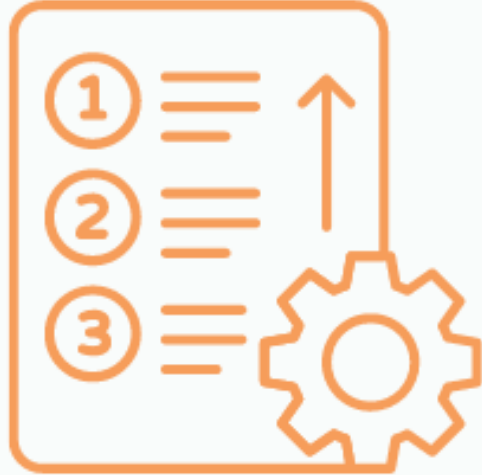


Share with us your
insights!



IPOPI's New Toolbox

Select your
TOP 3 priorities



IPOPI's New Toolbox

Thank you for joining us

Next webchat 4 July, 2023



Follow us on social media



www.ipopi.org