



# IPOPI 4<sup>TH</sup> REGIONAL ASIAN PID MEETING

19-20 NOVEMBER 2022  
KUALA LUMPUR, MALAYSIA

an **IPOPI** event

**CARE FOR RARE**  
GLOBAL ALLIANCE EDUCATIONAL SEMINAR



SUPPORTING ORGANISATIONS



SUPPORTED BY



# Driving Engagement and Awareness through social media

Lenny Susanti - Indonesia Primary Immunodeficiency Patients Society



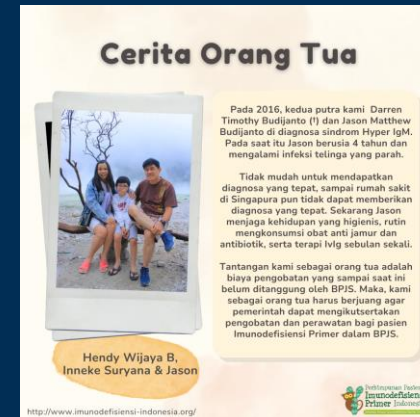
**IPOPI**  
**4<sup>TH</sup> REGIONAL**  
**ASIAN PID MEETING**  
19-20 NOVEMBER 2022  
KUALA LUMPUR, MALAYSIA  
an IPOPI event

# What we have done so far

Patients engagement riding on Big Moments – World PI Week

Public awareness on PID through patient stories in social media

Collaboration with Indonesian Pediatrics Society to share about Primary Immunodeficiency



# Challenges

High treatment cost, no health coverage for PID diagnosis and treatments, centered health facilities, and also limited health professionals that understand about PID

To change public policy that eventually helps PID patients to get better support and treatment e.g. insurance, low treatment cost, etc

How to keep engage with patient community and to support and facilitate their needs that relate with treatments.



**IPOPI**  
**4<sup>TH</sup> REGIONAL**  
**ASIAN PID MEETING**  
19-20 NOVEMBER 2022  
KUALA LUMPUR, MALAYSIA  
an IPOPI event