

Overcoming Treatment Access Challenges in Indonesia

Advocating for IVIG Treatment with Doctors

Indonesia Primary Immunodeficiency Patients Society - Dimas Adhi Sugiharto



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

Indonesia Primary Immunodeficiency Patients Society



- Initiated in 2015 with only 2 patients with full support from IPOPI we held our first meeting in 2017.
- Registered in Ministry of Justice in 2018 we have now 25 registered members across Indonesia.

Indonesia: Challenges and Impact to Life Quality

Limited access and supporting facilities for Primary Immunodeficiency are our challenges

- **Awareness** is key challenge for us as the society, government and medical professionals still have low awareness for PID condition
 - The past 5 years, only 70 patients are diagnosed properly
- **Diagnostic** facilities is very limited with 2 out of ~2.5k hospital that can diagnose and treat PID
- **Therapies** option are limited, where IVIG usage are limited with BMT not available as well as newborn screening.



With Doctors supporting our advocacies, we have managed to get IVIG reimbursement support

Challenges

- Currently IVIG are reimbursed with partial reimbursement of the treatment (up to 7.5 gram of IVIG), however there are recent success in getting full reimbursement of the treatment in top referral hospital.
- With supports from doctors we are now on our pathway to full reimbursement covered by National Health System (JKN) in the secondary and tertiary.

Doctors Support to Overcome Challenges

- Getting doctors to advocate together with patients
 - Gathering supporting data for the needs of IVIG for PID treatment.
 - Adding PID as IVIG indication in National Formulary that currently not in National Formulary that is *Myasthenia gravis*, *Guillain Barre Syndrome*).



Thank You

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