Clinical Management of Primary Immunodeficiencies in South East Asia

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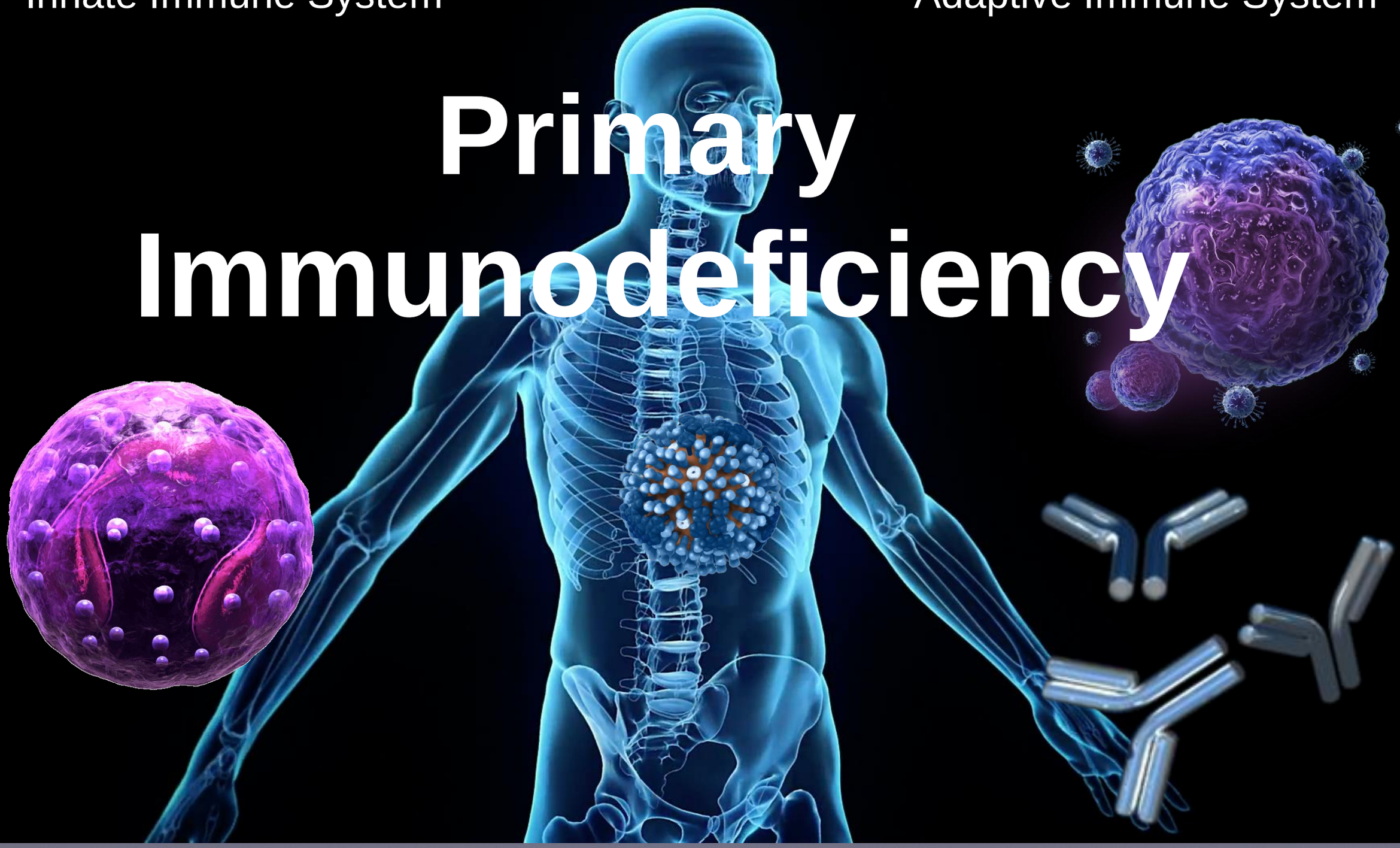
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Our Immune System

Innate Immune System

Adaptive Immune System

Primary Immunodeficiency



PID Manifestations

Hereditary or Genetic Defects
Can affect anyone, regardless of age/sex

Infection- Severe, Persistent, Unusual, Reccurent
Autoimmunity & Skin Diseases
Early Neonatal Death

PID FACTS

During the 1st ESID Meeting in Oxford 1985,
there were only 15 recognised PID.
In 2015, at ESID meeting in Prague,
the number had increased to over
285 different PIDs!!!



Management of PID

Prophylaxis Antibiotic



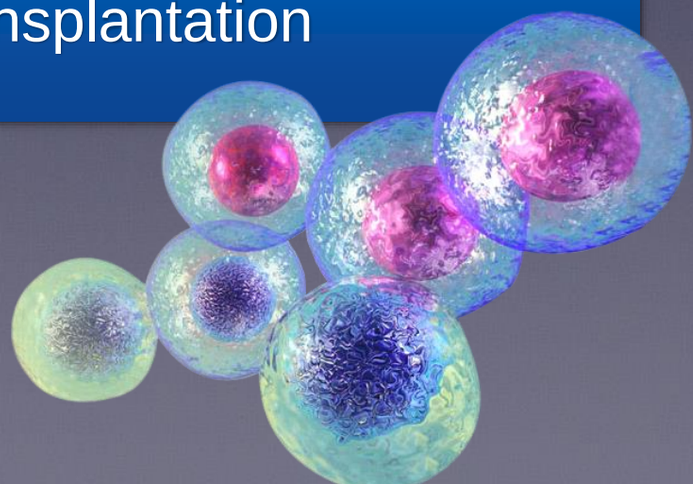
Immunoglobulin Replacement Theraphy



Gene Therapy



Hematopoeitic Stem Cell Transplantation



Immunoglobulin Therapy in PID

Lifelong treatment- Immunoglobulin Replacement Therapy

Persistent physiological immunoglobulin level in the blood

Regular interval with monitoring of blood level

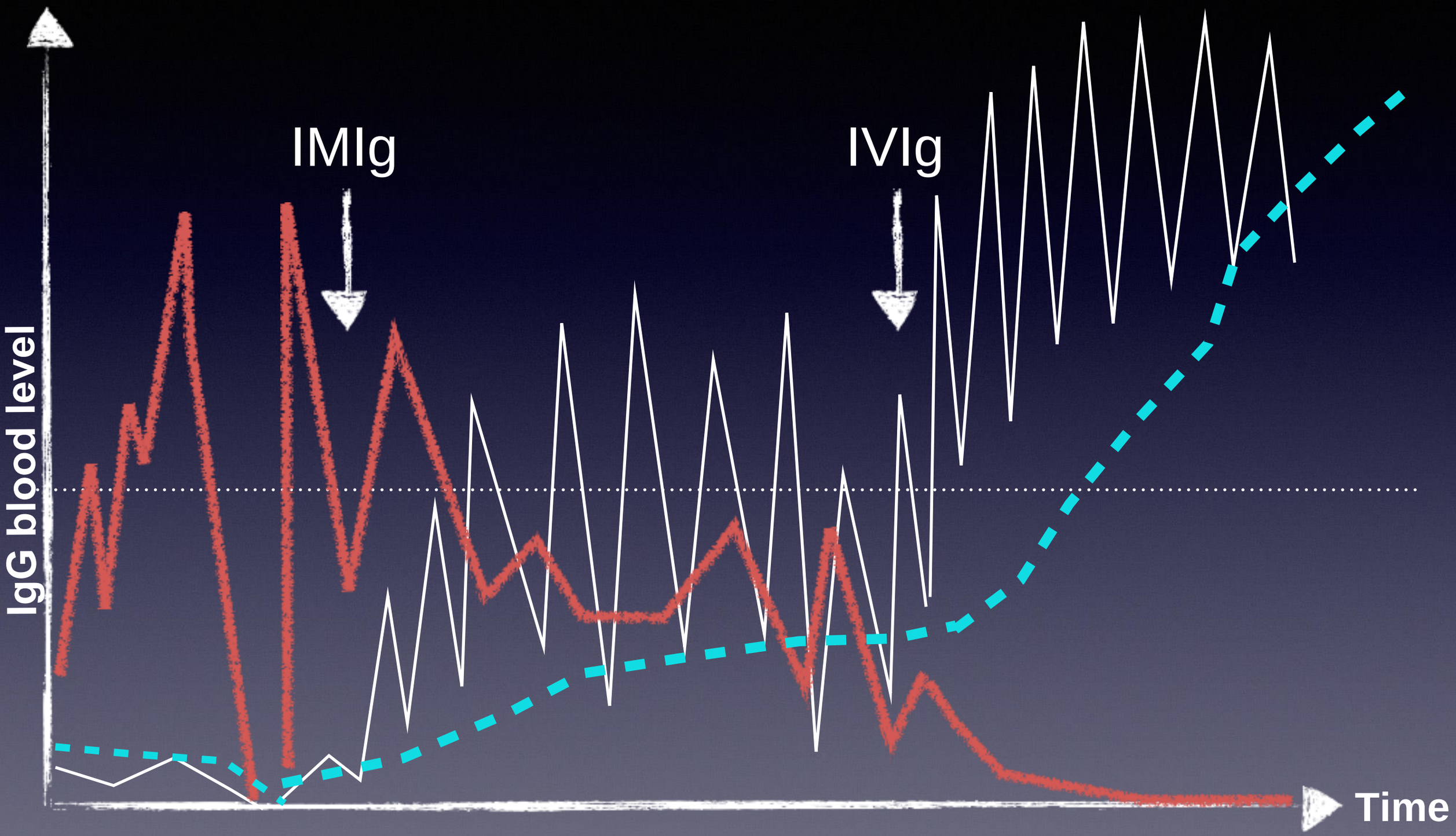
IVIg & SCIg- Proven to prevent infections and deliver good quality of life to PID patients

FASCINATING Ig FACTS

It can takes as many as 3000 individual donations to treat one PID patient with immunoglobulin for a year



Immunoglobulin Replacement Theraphy

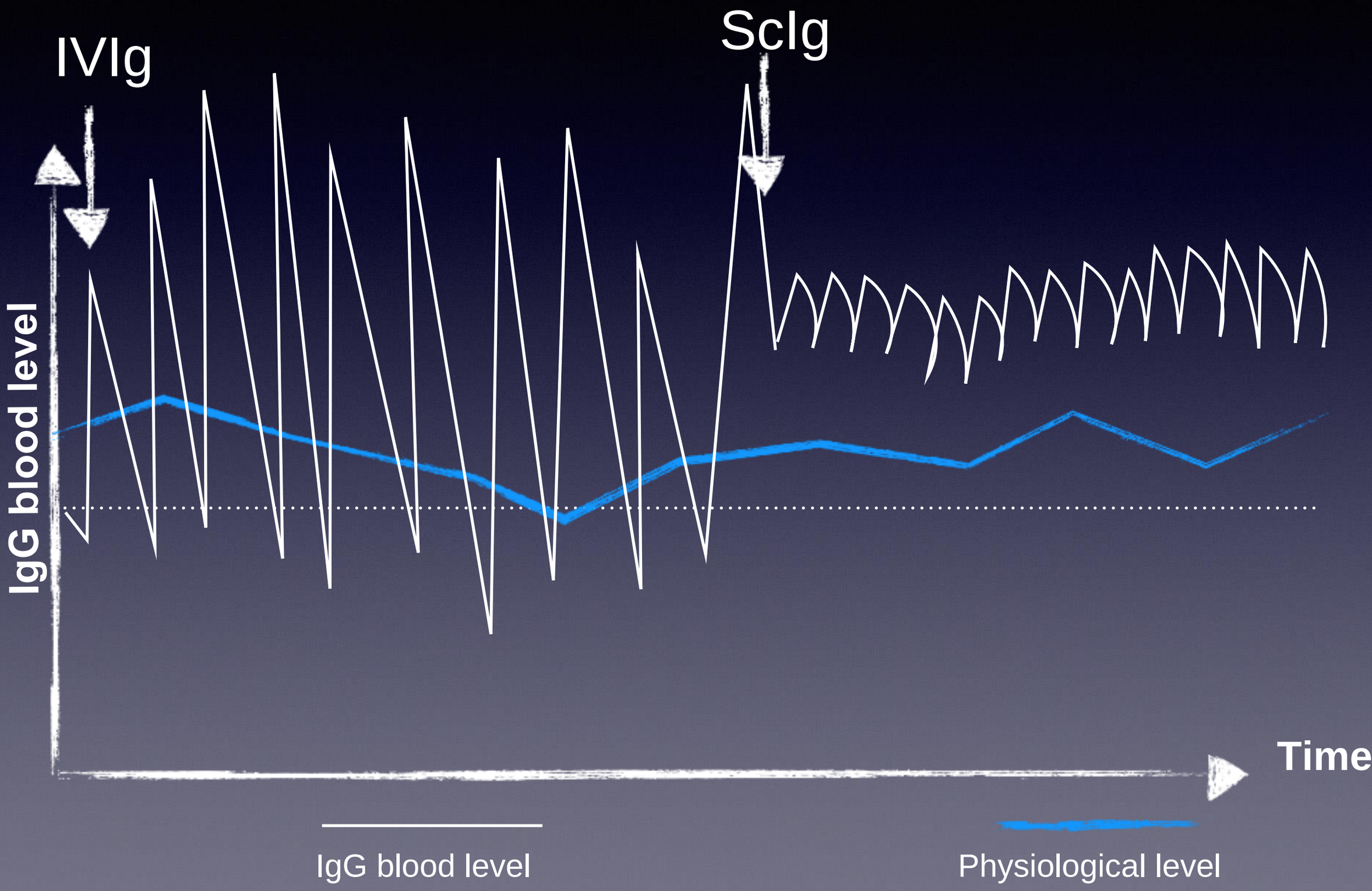


IgG blood level

Body Weight

No of infections

Ig Replacement Therapy



IVIg vs. ScIg

	IVIg	ScIg
Interval of Treatment	4-5 weeks	1-2 weeks
Logistic	Clinic-based	Home-based
Side Effect	Thrombophebitis	Skin discomfort
Advantage	Longer interval	Flexibility-Mobility
Serum Ig level	Higher peak level	More physiological level

Ideal PID Ig Treatment

- Fewer/ No side Effects
- Shorter Administration Time
- Therapy without needles (patch/tablet)
- Ability to administer at home
- Longer time between intervals
- Ease of administration
- Easy storage/transport
- Safe product & More efficient

What do PID patients want?

Painless, simple, long lasting treatment with no-side effects

To feel well and have a normal life



IPOPI PID Patient Needs & Outlook Survey

PID Management in SEA

Country	IVIg		SCIg		BMT/HSCT	
	A	R	A	R	A	R
Singapore	✔	✗	✔	✗	✔	✗
Thailand	✔	✔	✗	✗	✔	✔★
The Philippines	✔	✗	✗	✗	✗	✗
Malaysia	✔	✔	✔	✔O	✔	✔★
Indonesia	✔	✔	✗	✗	✗	✗
Vietnam	✔	✔	✗	✗	✗	✗
Laos	✔	✗	✗	✗	✗	✗

A	Availability
R	Reimbursement
✔	Available
✗	No/ No Reimbursement
✔★	Only with match sibling donor
✔O	Case to case basis

SEAPID Clinical PID Survey 2017

Key issues of PID Ig Therapy in SEA

Reimbursement policy- insurance, child vs.adult, severity of diagnosis

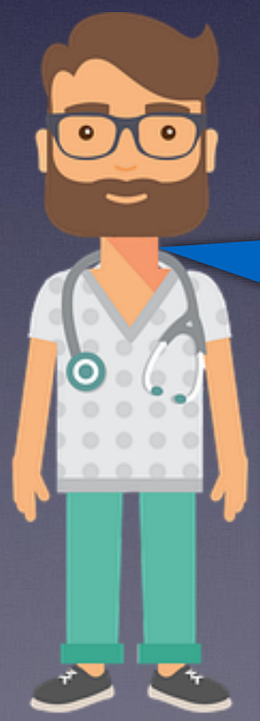
Ig options depend on hospital tender-bureaucratic process

Cycling on different generic brand

Adult management-undertreated

SCIg & Home therapy-
not available

Shortage of Ig supply



A DISTURBING FACT

In February 2018,
Romania did not have
a single drop of
Immunoglobulin supply.

PID Barriers & Opportunity in SEA

Barriers

- Lack of Medical Expertise/Awareness
- Economic & Social Disparity
- Limited Access to Clinical Services
- Lack of Attention at Health Policies

Opportunity

- ASEAN Regional Movement (SEAPID)
- Patients' support group (IPOPI SEA)
- Industry support
- International Collaborations

Conclusions

Ig Replacement Therapy in PID patients is their life line

Ig therapy should be made adequately available, easily accessible and affordable to all PID patients at all times

Different modalities of Ig therapies should be made available to all patients

Patients, physicians, stakeholders and pharmaceutical companies are responsible and work together to ensure proper and improved management of PID cases

With proper management, PID patients can have normal and healthy lives

Thank You

SEAPID™
South East Asia
Primary Immunodeficiency Network

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PATIENT ORGANISATION
FOR PRIMARY IMMUNODEFICIENCIES

My POPI