

PID Forum: Breaking the Silence on Mental Health & PIDs

5 December 2023

BREAKING THE SILENCE ON MENTAL HEALTH AND PIDs



PID FORUM

Hosted by
Estrella Durá Ferrandis
(S&D, Spain),
Tomáš Zdechovský
(EPP, Czechia) &
Radka Maxová
(S&D, Czechia)

An IPOPI
Event





EVENT PROGRAMME

15:30 - Welcome Address

15:45 - Setting The Scene

15:55 - Panel: Supporting the Mental Health of Rare Disease Patients

16:30 - Open Floor Discussion

16:45 - Closing Statements

WiFi: *(to be inserted)*

Social media: *@ipopi_info*

Hashtag:

#PIDForum

MEP Estrella Durá Ferrandis (S&D, Spain)

Welcome Address

MEP Radka Maxová (S&D, Czechia)

Welcome Address



Setting the Scene

Jose Drabwell, Executive Committee Member of IPOPI

Setting the scene on mental health and PIDs

Jose Drabwell

Member of the Board, IPOPI

IPOPI PID Forum

Breaking the silence on mental health & PIDs

5 December 2023, European Parliament, Brussels

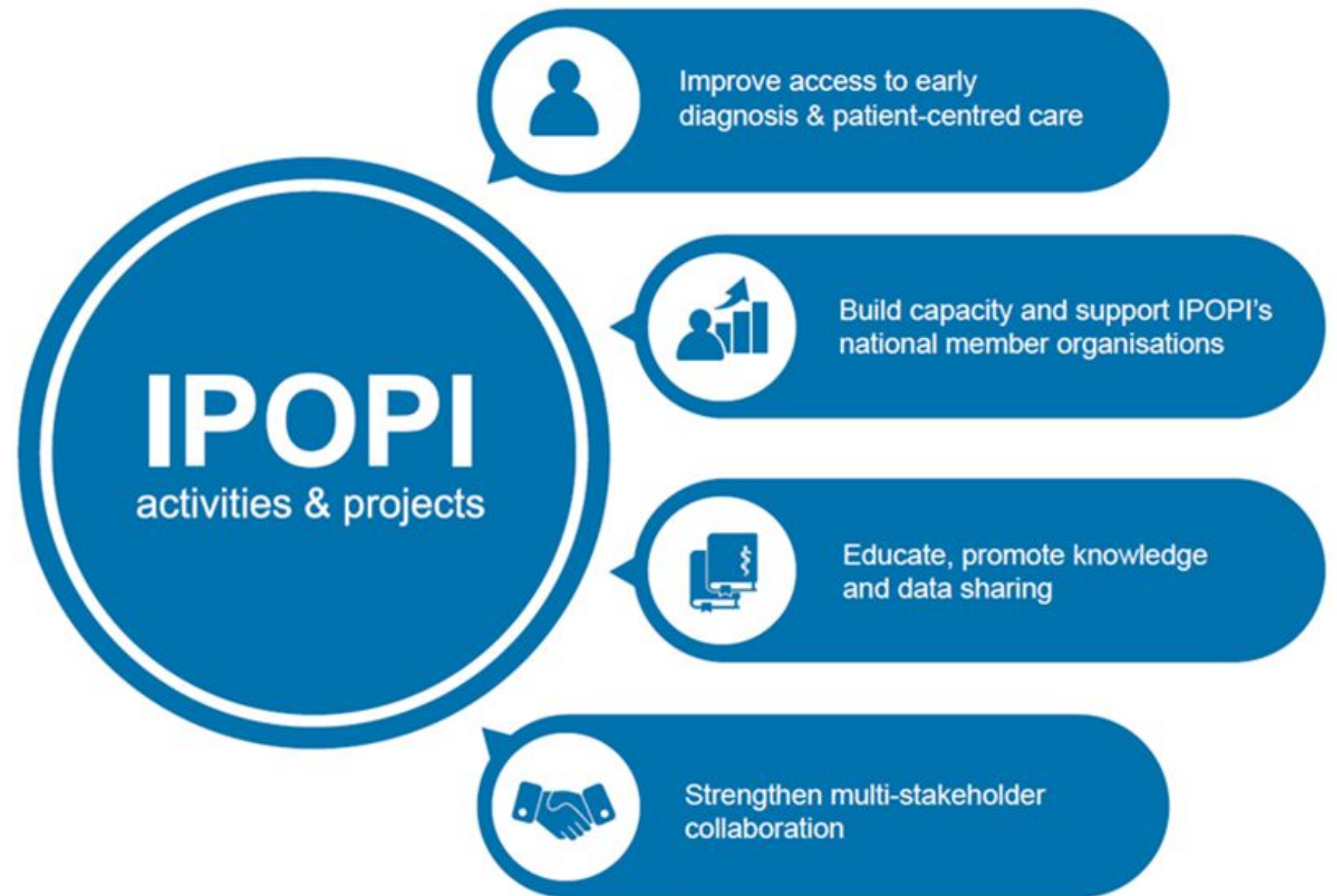


Introduction to IPOPI

The association of national patient organisations dedicated to improving:

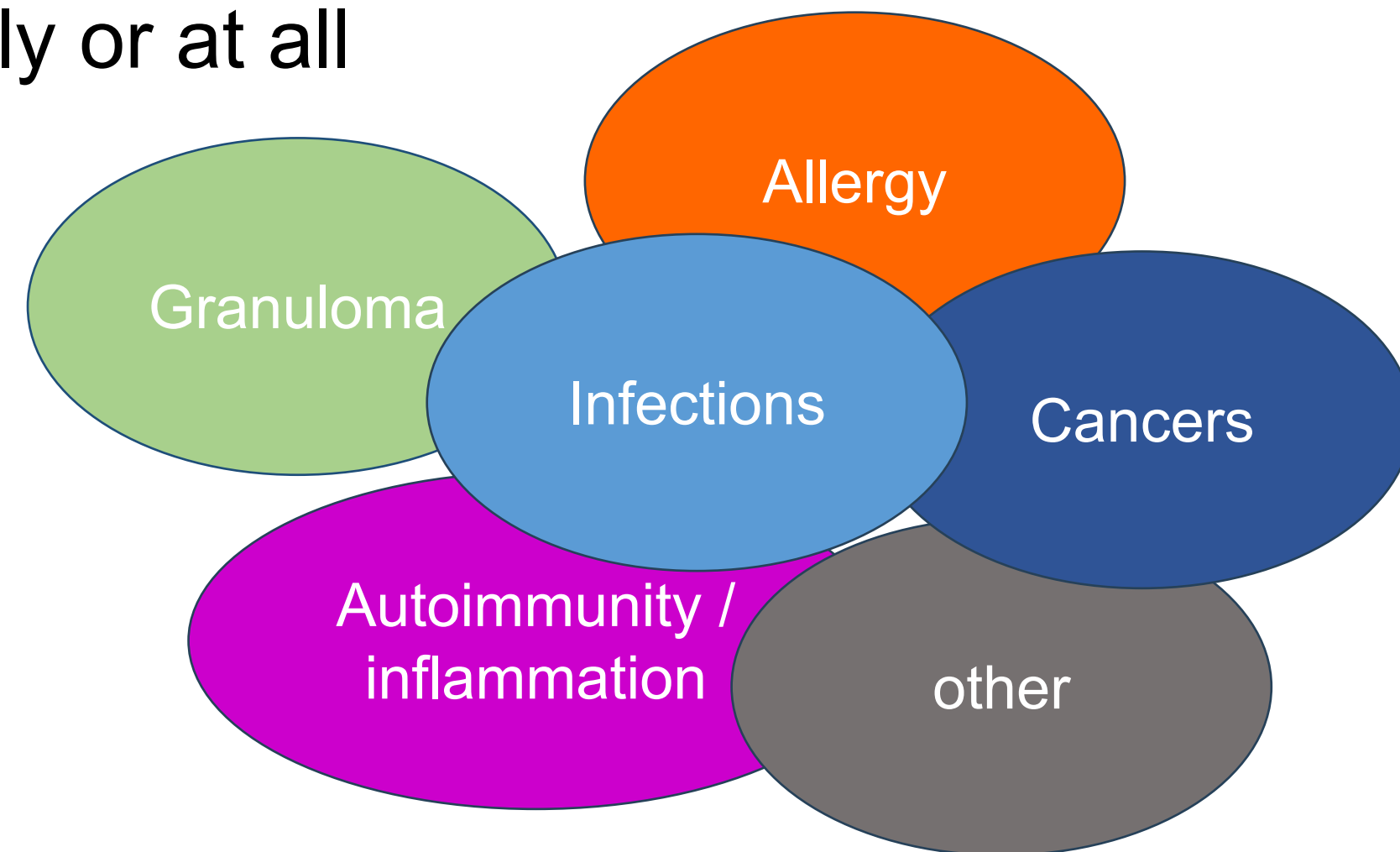
- Awareness
- Access to early diagnosis
- Access to care

For patients living with primary immunodeficiencies (PIDs) worldwide



What are Primary Immunodeficiencies (PIDs)?

- 485+ different genetic rare and chronic diseases
- The immune system does not work properly or at all
- Affect children and adults
- Clinical presentations are variable
- Patients with PIDs can have:
 - Increased susceptibility to infections
 - Autoimmunity
 - Inflammation
 - Lymphoproliferation
 - Allergy
 - Malignancy
 - ...



What are the treatment options for patients with PIDs?

- Anti-infectious therapies
- Vaccines
- Immunoglobulin replacement therapies
- Biological and targeted therapies
- Curative therapies
 - Hematopoietic stem cell transplantation / bone marrow transplantation
 - Gene therapy
 - thymic transplant / cultured thymic tissues

What does it mean to be a person with a PID? (1)

- In many cases, PID is not known by the patient / patient's family when the diagnosis is made
 - impact of the diagnosis
 - time to understand & learn about the condition
 - readjustment / reorganisation of day-to-day life
- The person needs lifelong therapy every month or every week
 - adjustment to the therapy and, in some cases, its side effects

What does it mean to be a person with a PID? (2)

- The person needs to be followed by a specialist / several specialists
 - Hospital & medical centres become a part of the routine
- Day-to-day of the family changes (little / a lot / ...)
 - the family needs to readjust to the new normal
- The patient & family need to evolve in a society that knows little about PIDs

How can a PID affect a person's mental health?

- Burden of the disease
 - Burden of living with a rare and chronic disease.
 - Stress, worry, anxiety, low esteem, social isolation, loneliness
- Burden of the treatment for the PID
 - Patients with PIDs are lucky to have in many cases a treatment for their PID
 - BUT requiring a treatment for life or for certain periods is not easy
 - transition of care
 - bone marrow transplantation
 - immunoglobulin replacement therapy

How can a PID affect a person's mental health?

- PID manifestations
 - Certain PIDs have symptoms that affect your mental health
- Society
 - Receiving a proper care from the system can be burdensome
 - COVID-19 as an opportunity for the general society to feel what it is to live with a PID

Key takeaways

- A good mental health is key for any person.
- Good mental health is key for a good quality of life.
- Persons with PIDs, rare & chronic disorders, have their mental wellbeing challenged throughout their lifetime.
- Patients with PIDs and their carers should have access to good quality psychological support, so that they are able to cope with the challenges posed by the disease.
- Facilitating good & affordable mental health is key to ensure that we leave no one behind.
- A comprehensive, prevention-oriented and multi-stakeholder approach developed with citizens, stakeholders, Member States and the EU.

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Thank you for your attention

Panel discussion: Supporting the Mental Health of Rare Disease Patients

- ***Dr Virgil Dalm***, Erasmus MC, Immunology Department, Principal Investigator
- ***Ellen Desmet***, Belgian Patient organisation for Primary Immunodeficiencies, Board Member
- ***Rosalind Fisher***, International Nursing Group for Immunodeficiencies, President
- ***Vida Ramšak Marčeta***, Slovenian Society for Immune Disorders, Patient Representative

Mental health in primary immunodeficiency

Janne Houben

Clinical psychologist & behavioral therapist
University Hospitals Leuven



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Supporting the Mental Health of Primary Immunodeficient Patients

ROSALIND FISHER – PRESIDENT OF INTERNATIONAL NURSING GROUP FOR IMMUNODEFICIENCIES

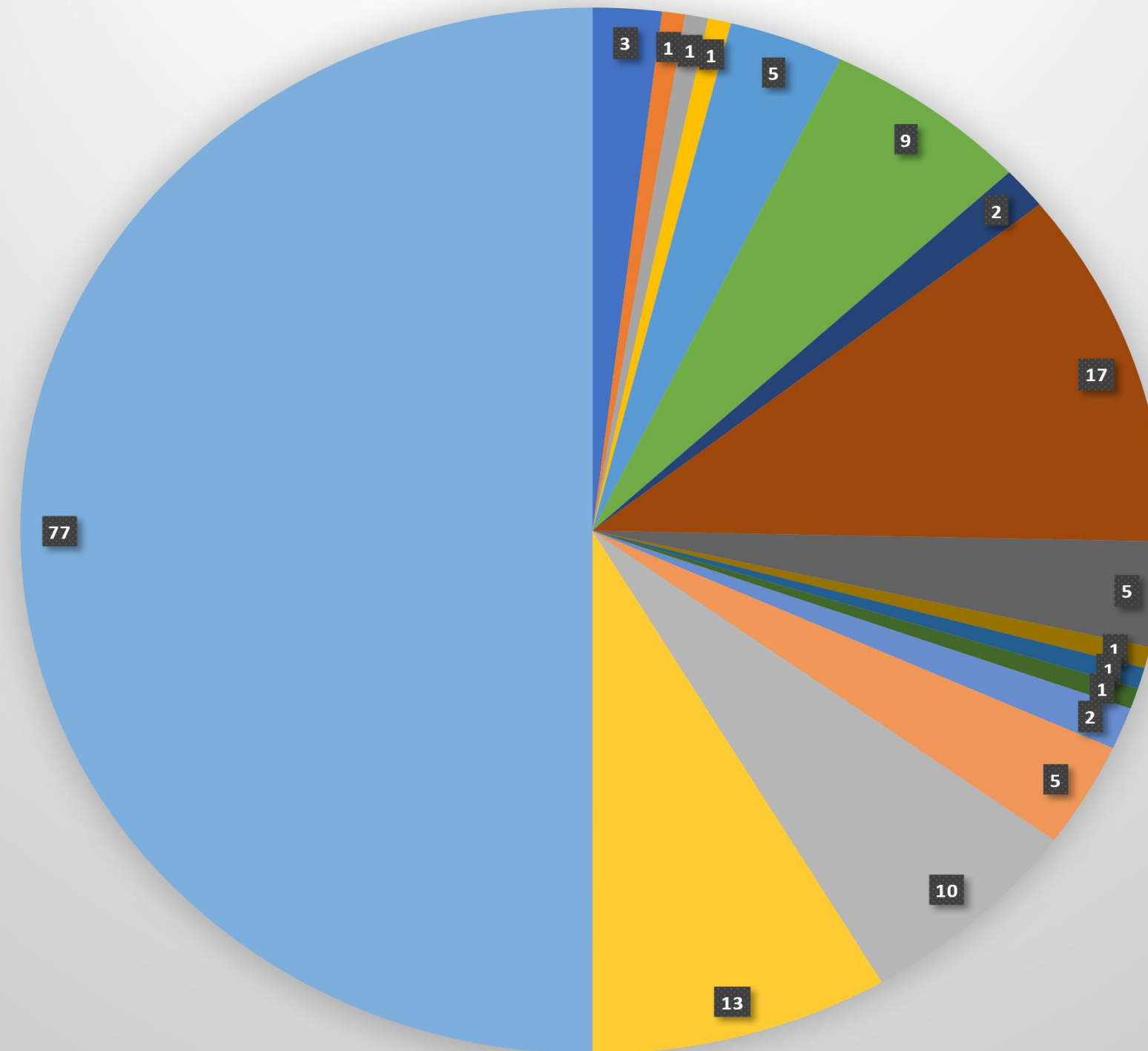
OXFORD UNIVERSITY HOSPITALS NHS FOUNDATION TRUST

International Nursing Group



for Immunodeficiencies

INGID membership, Europe

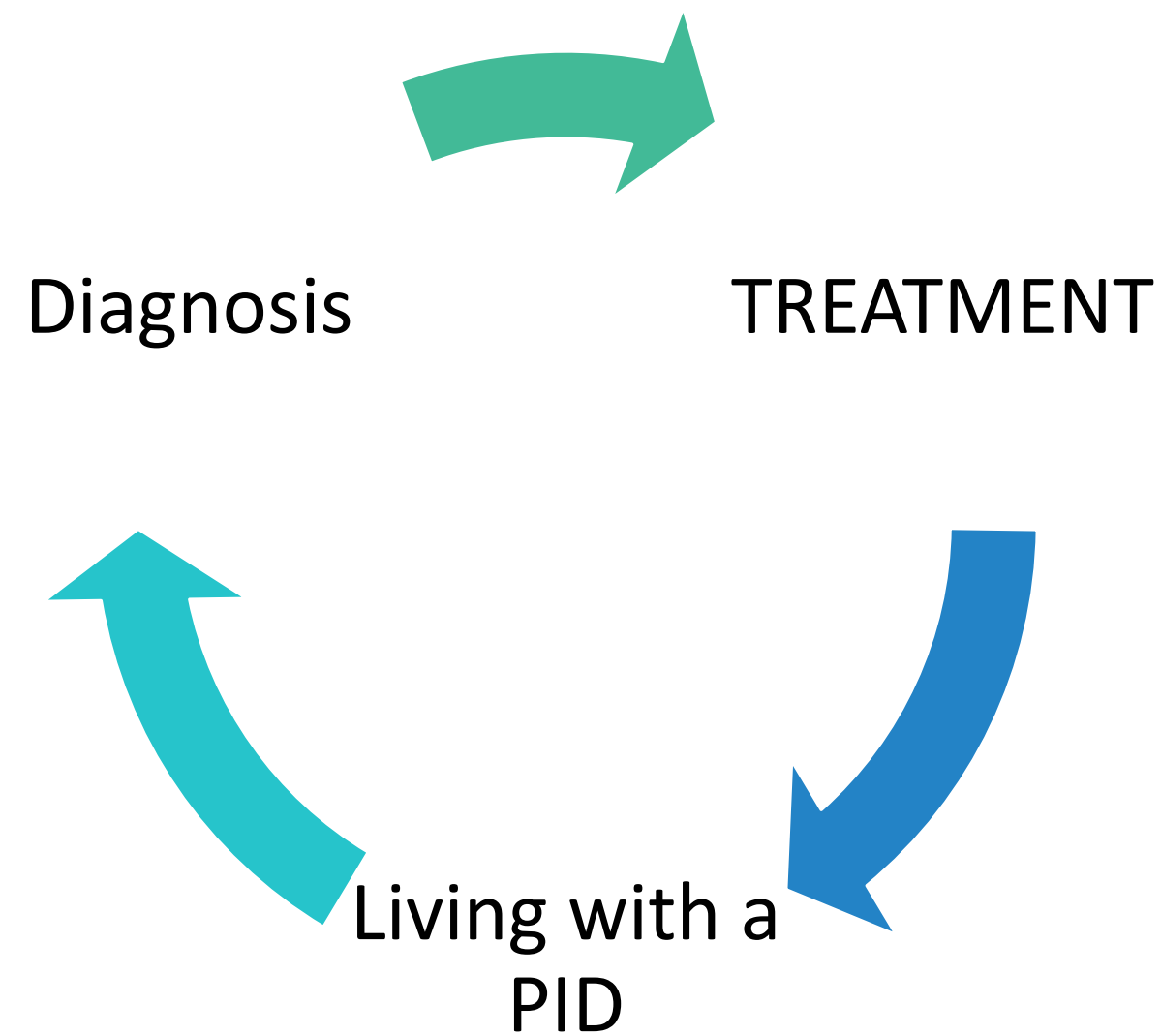


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| ■ Sweden | ■ Switzerland |
| ■ United Kingdom of Great Britain and Northern Ireland | |

International Nursing Group



for Immunodeficiencies



Psychological challenges for PID patients

Nursing Interventions: DIAGNOSIS

“It was nice to feel like, oh there is something wrong with me. It was a bit of a shock at the start. It took me a long time to come to terms with the fact my condition is long term”.

“Delay in diagnosis and the damage you sustain at that point is going to be with you for the rest of your life”

- CLEAR AND UNDERSTANDABLE INFORMATION
- ESTABLISH STRONG RELATIONSHIPS WITH NEW PATIENTS
- LOCAL AND NATIONAL SUPPORT GROUPS

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Nursing Interventions: TREATMENT

TREATMENT – OPTIMAL PLAN

IMMUNOGLOBULIN REPLACEMENT THERAPY

HOME THERAPY OPTION

COMPLIANCE WITH TREATMENT

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LIVING WITH A PID

RARE DISEASE

FEEDBACK FROM PATIENTS

RECURRENT INFECTIONS AND COMPLICATIONS

PROVIDE OPEN ACCESS

International Nursing Group



for Immunodeficiencies

Open Floor Discussion

Video Statement

MEP Tomáš Zdechovský (EPP, Czechia)



MEP Radka Maxová (S&D, Czechia)

Closing Statement

MEP Estrella Durá Ferrandis (S&D, Spain)

Closing Statement

**THANK YOU FOR ATTENDING
THE PID FORUM!**

Stay tuned for more...

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