

SLOVENIAN PID CENTER AND SOCIETY FOR CHILDREN WITH IMMUNE DISORDERS

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PID CENTER

- University Paediatric Clinic in Ljubljana;
- Dept. of alergology, rheumatology and clinical immunology;
- JMF Diagnostic and Resurch Center for PID in Slovenia;



NATIONAL PID REGISTRY

- Until 2007 data was collected retrospectively and prospectively afterwards;
- ESID registry.

- 193 patients;
- 45 different PIDs;
- Children.

PID DIAGNOSTIC

- Routine testing for 24 different immune system gene defects.
- Important for the treatment, decisions (BMT);
- Diagnosis verification;
- Recognition of disease vectors;
- Prenatal diagnostics;
- Screening due to PID family history (genetic counseling).

NATIONAL ISSUES

- Transition process and care for adult PID patients.
- (Lack of) neonatal screening for SCID.

FOR PATIENTS

- Subcutaneous immunoglobulins;
 - Improved diagnostics;
 - PID registry.
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- Society for children with immune disorders;
 - Organized events.

SOCIETY FOR CHILDREN WITH IMMUNE DISORDERS (www.imuno.si)

- Established in 2011;
- Around 100 patients with their families;
- "staff meetings" and general assembly;
- 2 social events per year for children and their families (spring, autumn);
- Education/training, donations, global linkage (IPOPI, JMF).



SOCIAL EVENTS (1)

- Awareness day in September 2012 (scientific program for medical professionals, social program for families).



SOCIAL EVENTS (2)



SOCIAL EVENTS (3)



- PID Week in April – balloons.
- Presentations/lectures for parents and older children (about diseases, care, preparing food...).



SOCIAL EVENTS (4)

- Slovenia 's PID Patients got talent (May 2014);
- Invitation letter.



THANK YOU!