

Regional Toolkit: Europe



Jeffrey Modell
Foundation

- ▶ **10 Warning Signs of PI**
- ▶ **4 Stages of Testing**
- ▶ **Immune System Posters**
- ▶ **Patient Organizations**

10 Warning Signs of Primary Immunodeficiency

We developed the 10 Warning Signs of Primary Immunodeficiency to promote earliest possible diagnosis. If you or someone you know is affected by two or more of the warning signs, **Speak to an expert physician** about the possible presence of an underlying PI.

- ▶ **10 Warning Signs - Bulgarian**
- ▶ **10 Warning Signs - Bosnian**
- ▶ **10 Warning Signs - Croatian**
- ▶ **10 Warning Signs - Dutch**
- ▶ **10 Warning Signs - Estonian**
- ▶ **10 Warning Signs - Finnish**
- ▶ **10 Warning Signs - French**
- ▶ **10 Warning Signs - German**
- ▶ **10 Warning Signs - Greek**
- ▶ **10 Warning Signs - Hungarian**
- ▶ **10 Warning Signs - Italian**

10 Warning Signs of Primary Immunodeficiency

- ▶ **10 Warning Signs - Lithuanian**
- ▶ **10 Warning Signs - Polish**
- ▶ **10 Warning Signs - Romanian**
- ▶ **10 Warning Signs - Russian**
- ▶ **10 Warning Signs - Serbian**
- ▶ **10 Warning Signs - Slovak**
- ▶ **10 Warning Signs - Slovene**
- ▶ **10 Warning Signs - Spanish**
- ▶ **10 Warning Signs - Swedish**
- ▶ **10 Warning Signs - Turkish**
- ▶ **10 Warning Signs - Ukrainian**

4 Stages of Testing

We developed the 4 stages of testing poster (algorithm) to aid physicians in making a proper Primary Immunodeficiency diagnosis.

- ▶ **4 Stages of Testing - Bulgarian**
- ▶ **4 Stages of Testing - Polish**
- ▶ **4 Stages of Testing - Romanian**
- ▶ **4 Stages of Testing - Spanish**
- ▶ **4 Stages of Testing - Ukrainian**



Immune System Posters

We created educational illustrations for children and adults to better understand how our immune system works.

- ▶ **Immune System Poster - Dutch (child)**
- ▶ **Immune System Poster - Dutch (adult)**
- ▶ **Immune System Poster - German**
- ▶ **Immune System Poster - Polish**
- ▶ **Immune System Poster - Serbian**
- ▶ **Immune System Poster - Slovene**
- ▶ **Immune System Poster - Spanish**
- ▶ **Immune System Poster - Russian**
- ▶ **Immune System Poster - Romanian**

Patient Organizations

The Jeffrey Modell Foundation is proud to share global patient organizations that provide support, knowledge, and community for patients and their families to learn and connect with each other.

Austria

- ÖSPID–Österreichische Selbsthilfegruppe primärer Immum Defekte
 - oespid.at
 - modl.karin@gmx.at

Belarus

- Save the Immunity
 - save-immunity.by
 - Andron116@yandex.ru

Belgium

- BePOPI
 - bepopi.be
 - info@bepopi.be

Bosnia and Herzegovina

- POPID - Udruženje za podršku osobama sa Primarnom Imunodeficijencijom - Udruženje
 - pospid.org.rs/sr
 - dzenita.subasic@sos-ds.ba

Patient Organizations

Bulgaria

- Association of People with Congenital Immunodeficiency
 - stoil_lazarov@abv.bg

Cyprus

- Cyprus PI Association and Friends
 - Maria.g.charalambous@cyta.com.cy
- Group of People with Congenital Immune Deficiency and Friends
 - facebook.com/primaryimmunodeficiencycyprus

Czech Republic

- Rare Disease Czech Republic (CAVO)
 - vzacna-onemocneni.cz
 - cavo@vzacna-onemocneni.cz

Denmark

- Immun Defekt Foreningen
 - idf.dk
 - Information@idf.dk

Estonia

- Immuunpuudulikkuse Selts
 - immuunipuutospotilaidenyhdistys.fi
 - immuunpuudulikkus@gmail.com

Patient Organizations

Finland

- Immuunipuutospotilaiden Yhdistys RY
 - immuunipuutospotilaidenyhdistys.fi
 - puheenjohtaja@imppu.fi

France

- IRIS–Immuno-Déficiency Primitive Recherche Information Soutien
 - associationiris.org
 - info@associationiris.org

Germany

- DSAI – Deutsche Selbsthilfe Angeborene Immundefekte e. V.
 - dsai.de
 - info@dsai.de

Greece

- APMONIA–Association of Greek Friends for Pediatric Immunology - Primary Immunodeficiency
 - paed-anosia.gr
 - manolakakis@windowslive.com
- Galinos Immune Deficiency Association of Greece
 - galinossilogos.wixsite.com/galinos
 - galinos.silogos@gmail.com

Patient Organizations

Hungary

- HOPI–Hungarian Patients' Group for Immunodeficiency
 - xn--immunhiny-mibe-1gb.hu
 - hzsu86@gmail.com

Iceland

- Lind–Icelandic Organization
 - gmb@bhs.is

Ireland

- IPIA–Primary Immunodeficiency Association of Ireland
 - ipia.info
 - ipiasecretary@gmail.com

Italy

- AIP–Associazione Immunodeficienze Primitive
 - aip-it.org
 - info@aip-it.org

Macedonia

- Parent Organization of Children with Primary Immunodeficiency
 - kstavric@hotmail.com

Patient Organizations

Netherlands

- Stichting voor AfweerStoornissen
 - stichtingvoorafweerstoornissen.nl
 - info@stichtingvoorafweerkleding.nl

Norway

- Norsk Immunsviktforening
 - immunsvikt.no
 - info@immunsvikt.no

Poland

- Immunoprotect – Association for Patients with Primary Immunodeficiency
 - immunoprotect.pl
 - biuro@immunoprotect.pl
- Razem Zdążymy Foundation
 - razemzdazymy.org.pl
 - fundacja@razemzdazymy.org.pl

Portugal

- APDIP–Associação Portuguesa de Doentes com Imunodeficiência Primária
 - apdip.pt
 - geral@apdip.pt

Patient Organizations

Romania

- ARPID – Romanian Association for Patients with Primary Immunodeficiency
 - facebook.com/ImunodeficientePrimare
 - arpid_life@yahoo.com

Russia

- Sunflower – The Association for Primary Immunodeficient Patients
 - fondpodsolnuh.ru
 - fond@fondpodsolnuh.ru

Serbia and Montenegro

- POsPID – Support of Persons with Primary Immunodeficiency
 - pospid.org.rs/sr
 - + 381 11 2602030

Slovakia

- Združenie pacientov s primárnou imunodeficienciou - Slovak Association for PI patients
 - imunodeficit.sk
 - info@imunodeficit.sk

Patient Organizations

Slovenia

- Društvo za pomoč otrokom z imunskimi boleznimi - Slovenian society for children with immune disorders
 - imuno.si
 - tadej.avcin@kclj.si

Spain

- ABADIP – Associació Balear de Dèficits Immunitaris
 - abadip.com
 - info@abadip.com
- ACADIP – Associació Catalana de Déficits Immunitaris Primaris
 - acadip.org
 - info@acadip.org
- AEDIP – Asociación Española de Déficits Inmunitarios Primarios
 - aedip.com
 - aedip@aedip.com
- Barcelona PID Foundation
 - pidfoundationbcn.org
 - pid_barcelona@pidfoundationbcn.org

Patient Organizations

Sweden

- PIO – Primaer Immunbrist Organisationen
 - pio.nu
 - info@pio.nu

Switzerland

- SVAI – Schweizerische Vereinigung für Angeborene Immundefekte
 - svai.ch
 - info@svai.ch

Turkey

- İmmün Yetersizlik - Türk İmmünoloji Derneği
 - turkimmunoloji.org
 - turkimmunolojidernegi@gmail.com

United Kingdom

- CGD Society – Chronic Granulomatous Disease Society
 - cgsociety.org
 - hello@cgsociety.org
- PID UK–Primary Immunodeficiency UK
 - immunodeficiencyuk.org
 - hello@immunodeficiencyuk.org



Patient Organizations

United Kingdom

- The XLP Research Trust
 - xlpresearchtrust.org
 - info@xlpresearchtrust.org

