



Primary Immune Deficiency Diseases - Resolution Proposed by Prof Giuseppe Nistico MEP

Primary immune deficiency diseases (PIDs) are a group of genetic conditions that damage the immune system, making sufferers susceptible to infection. Undiagnosed & untreated sufferers can undergo a lifetime of unexplained illness, repeated hospital visits and continual treatment on antibiotics, as physicians treat the repeated infections, without addressing the underlying cause of immune deficiency. A life-time of repeated infection often leaves the sufferer with unnecessary organ damage, permanent disability, hospitalization and dependence on social care. A simple and inexpensive blood test can identify over 95% of PID diseases.

Once diagnosed, there are several treatment options. These include antibody replacement therapies and for sufferers with the most severe forms of PIDs, bone marrow transplantation. These treatments have proven to be not only life saving, but also the breakthrough for sufferers to start leading healthy "normal" lives. This reinforces the need for appropriate actions within the EU that ensure awareness of these diseases and collaboration among centers and professionals.

The number of identified patients with PIDs in the EU is currently many times below what scientific studies argue is the real prevalence figure. However it means that cross border collaboration between patient, nurse and physician groups is essential, to ensure information, knowledge & expertise gained from diagnosing & treating the current patient population is shared.

It is for this reason that, jointly with other MEPs at the European Parliament, it is my wish to enhance the recognition of this disease. I am calling upon the European institutions to urgently take the following actions:

- European Commission DG Consumer Health & Protection, to ensure that primary immune deficiency diseases (PIDs) are named as a priority for action in rare diseases within the 2005 Work Plan of the Public Health Programme.
- European Commission DG Research to include PIDs as part of the Life Sciences Programme within the Seventh Research Framework Programme.
- Ministries of Health in all Member States should support the development of expertise to increase accurate diagnosis and eliminate senseless suffering.

The following Members of the European Parliament support this Resolution:

Giuseppe Nistico (EPP-ED Group/Italy)	Imelda Read (PES Group/United Kingdom)
Antonios Trakatellis (EPP-ED Group/Greece)	Philip Whitehead (PES/United Kingdom)
John Bowis (EPP-ED Group/United Kingdom)	Caroline Jackson (EPP-ED Group/United Kingdom)
Patricia McKenna (Greens/Ireland)	Minerva Malliori (PES/Greece)
Cecilia Malmström (ELDR/Sweden)	Godelieve Quisthoudt-Rowohl (EPP-ED/Germany)
Marieliese Flemming (EPP-ED Group/Austria)	Martin Kastler (EPP-ED Group/Germany)

Peter Liese (EPP-ED Group/Germany)
Per-Arne Arvidsson (EPP-ED Group/Sweden)
Stephen Hughes (PES/United Kingdom)
Catherine Stihler (PES/United Kingdom)
Chris Davies (ELDR/United Kingdom)
Paul Rübig (EPP-DE Group/Germany)