



# RESOLVING BARRIERS TO THE TREATMENT OF PRIMARY IMMUNODEFICIENCIES

Continued Progress in Germany

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## What are Primary Immunodeficiencies?

Primary Immunodeficiencies (PIDs) are rare, congenital disorders of the immune system. Patients suffer from increased susceptibility to infections, autoimmune diseases or cancer. Severe forms of PID cause death in early infancy. Timely diagnosis and optimal treatment are important to reduce morbidity and mortality. The use of immunoglobulin products is established for many PIDs, especially the most common forms such as Common Variable Immune Deficiency (CVID) and other deficiencies in the body's production of immunoglobulin, which is crucial for defense against infection.

## Current situation of patients with PID in Germany

As also recognized in the EU PID consensus conference report<sup>1</sup> PIDs are widely undiagnosed. The most obvious explanation for the situation is lack of awareness, hindering early diagnosis. In addition, insufficient knowledge about the diseases may lead to inappropriate therapies.

The network initiative FIND-ID has been formed to improve this situation<sup>2</sup>. Initiated by PID experts and patients, the steering committee currently consists of experts for adult and pediatric PID

patients as well as the patient organization. Two aspects were regarded as crucial to the success of the initiative: a proper analysis of the situation in Germany to arrive at the right measures and the early buy-in of all important stakeholders. Both aspects were met by conducting semi-structured, face-to-face interviews, for which a suitable questionnaire had been developed.

## Results of analysis

Analysis of the interviews revealed three major barriers to PID treatment: awareness, financing and structure of the care-system (see figure 1).

Interestingly, most interview partners underlined the need for more **awareness** among healthcare professionals for adult patients, while pediatricians are seen as being much more aware of those diseases.

With regard to **financing** the care of PID patients, the situation in Germany is very heterogeneous. There are outpatient clinics treating patients without proper reimbursement for the

medical care, thus generating financial losses. Some university hospitals have individually negotiated special flat-rates for the patients treated in their outpatient clinic. Pediatric centers can charge higher rates according to a special legal basis for interdisciplinary patient care in children. Others make use of a relatively new option of the so-called *specialized outpatient clinics according to §116b, SGB V*. This allows them to get reimbursement not only by a flat-rate, but for any procedure they perform, including laboratory assays. The reimbursement is based on a large catalogue (called "Einheitlicher Bewertungsmaßstab", EBM), listing all procedures and the corresponding reimbursement figures. To make it even more complicated, the figures not only depend on the activities performed, but also on the specialization of the caregiver, as different figures apply to physicians of different medical specializations. Though very complicated, this system at least allows for covering of costs. Hospitals which would like to use this option have to apply and to fulfill special criteria.

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Concerning the **structural** barriers, huge challenges are again faced by adult PID patients. While a number of university hospitals offer specialized centers for children, the number of specialized centers for adults is very limited. Long distances and limited capacities at those centers may hinder access. As a consequence, patients are treated by non-experts and/or practice “doctor-hopping.” In both situations, quality of care can’t be guaranteed. A further structural barrier is the transition from pediatric to adult care (“transition medicine”).

The situation is especially difficult for adult PID patients.

### Measures by FIND-ID

The FIND-ID initiative has started to tackle those barriers simultaneously. To increase **awareness**, workshops have been performed, and extensive information on the website as well as printed material tailored to different stakeholders has been published. The initiative has been

presented through oral and poster presentations at different congresses. As many adult PID patients present with symptoms treated by ear, nose and throat (ENT) specialists, ENT became the focus for 2011, with both booths and symposiums at ENT-congresses.

With regard to **financing**, an extensive information package has been prepared and made available. It includes information about the legal background, calculation tools, application and reporting forms.

To improve the **structural** aspects FIND-ID has created a three layer network, embracing general practitioners and peripheral hospitals as well as specialized PID centers. It provides support for a new outpatient clinic for adult patients, which serves as a “model center.” Special workshops for caregivers new to the field of PID are planned. In addition, FIND-ID has started initiatives in the field of transition medicine, by presenting at a symposium on this topic.

The network initiative FIND-ID addresses awareness, financing and structural aspects.

### Conclusion

In Germany, improvements in the field of awareness, financing and structure of care are needed to improve the situation for PID patients. The network initiative FIND-ID strives to adequately address all these fields.

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1 Expert Recommendations for better Management of Primary Immunodeficiency (PID), EU-PID Consensus Conference. <http://www.ipopi.org/news/epicc-statement.html>; [www.eupidconference.com](http://www.eupidconference.com)

2 FIND-ID – a physician-driven, multi-disciplinary and multi-professional initiative to increase the diagnosis-rate of Primary Immunodeficiencies (PID) in Germany. FIND-ID Group: Steering Committee: \*Wahn, V., Gründl, G., Niehues, T., Zepp, F., Franke, K., Schmidt, R., Warnatz, K., Med. Coord. Schoendorf, I. Poster presentation at the ESID congress October 2010, Istanbul



## FIGURE 1 - STAKEHOLDER SURVEY

Important issues of PID as possible objectives of FIND-ID

