

Campaign

People with rare diseases exist on the margins of the German health care system, although rare diseases are not at all that rare! Under the auspices of the German Self-Help Organisation for Congenital Immunodeficiency (Deutsche Selbsthilfe Angeborene Immundefekte, DSAI e.V.), many of those affected have joined forces in the campaign “**Rare diseases – not at all that rare. Early diagnosis saves lives and reduces treatment costs**” to inform politicians and the public about rare diseases, and in particular about primary immunodeficiency. Our campaign is supported by the Alliance for Chronic Rare Diseases (Allianz Chronischer Seltener Erkrankungen, ACHSE e.V.), the International Patient Organisation for Patients with Primary Immunodeficiencies (IPOPI), the European Organisation for Rare Diseases (EURORDIS), the European Federation of Immunological Societies (EFIS) and the German Society for Immunology (DGfI).

Problem

Rare diseases are often life-threatening and can cause chronic disability. Nevertheless, they are underdiagnosed and sufferers are left to fend for themselves. In total there are more than 30 million people living with rare diseases in the EU, in Germany some 4 million. Among these, around 100,000 people are affected by primary immunodeficiency, such as antibody-deficiency syndrome. Only around 700 have been diagnosed.

Rare diseases have, to date, figured only very marginally on the health policy agenda and in the discussions regarding reforms to the health care system. Even in medical circles, knowledge and education about rare diseases is often lacking.

Objectives

Our **objectives** are:

- Securing early diagnoses and adequate treatment in line with current medical standards for all sufferers.
- A fundamental improvement in the quality of life of sufferers.
- A long-term increase in the cost efficiency of the health care system by avoiding expensive and erroneous therapies and the high social costs incurred through invalidity and early retirement.

Demands

We would therefore like to present the following **pivotal political demands** to the **Federal Government**, the **German Bundestag**, the **Federal Joint Committee** and the representatives of the **health insurance companies**, the **medical fraternity** and **hospitals**:

- **Increase awareness in the political and public spheres** about the difficult medical and social situation of people with rare diseases, in particular primary immunodeficiency.
- **Improve cooperation** between politics, science, industry, research and practicing doctors in order to provide the best possible health care for those affected.
- **Educate and inform medical experts** by placing more weight upon the subject of rare diseases and immunology in medical education. Expand further education and training programs for practicing doctors so that patients can receive an early diagnosis and can be adequately treated.
- **Early diagnosis** for all sufferers in order to give them certainty and improve their quality of life.
- **Guarantee proper treatment** and ensure nation-wide medical care with specialist clinics and research centres.

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- **Mandatory inclusion of treatment costs** for rare diseases in the **health insurance companies' rebate policies**.

Actions

In order to achieve our objectives we call for the implementation of **three concrete measures**:

1) Guarantee of finance for contracts under § 116 b, sub. para. 2, 3 German Social Security Code V

Health insurance funds must be obligated to conclude separate contracts, where requested, with hospitals regarding additional outpatient treatment of rare diseases in order to redress the inadequacies in treatment. The financing of such contracts needs to be guaranteed in the future. None of the health insurance companies has hitherto been prepared to finance such a contract.

2) Classification of antibody-deficiency syndrome replacement therapy as a practice budget exemption

The pharmaceutical treatment for primary immune deficiency (antibody-deficiency syndrome) should be included in the catalogue of practice budget exemptions under budgetary agreements between doctors and insurers in order to guarantee adequate treatment. This way, the additional financial requirements will be automatically exempt from the normal budgeting guidelines and thus will not place an additional burden on the pharmaceutical expenses of a practice.

3) Inclusion of screening for antibody deficiencies in the obligatory preventative medical check-up for infants

In order to secure an early diagnosis, screening for antibody-deficiency should be included into the preventative medical check-up for infants (U3-U5).

Appeal to policy makers

With the **Berlin Signal**, we urgently call upon the Federal Government, the German Bundestag and all relevant health policy institutions to act on our **demands and concrete measures** and to integrate them into the **current reform process of the German health care policy**.

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