

Appeal of the the campaign "Rare diseases – not at all that rare. Early diagnosis saves lives and reduces treatment costs"

«Berliner Signal»

Your signature for an improved diagnosis and treatment of rare diseases



People with rare diseases exist on the edge of the German health care system, although rare diseases are not at all that rare! Under the auspices of the "German Congenital Immune Deficiency Self-Help Group" (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 primary immune deficiency.

Our campaign is supported by the Federal Government's Commissioner for the Concerns of Patients Helga Kühn-Mengel MdB, the Federal Government's Commissioner for the Concerns of People with Disabilities Karin Evers-Meyer MdB, the Alliance of Chronic Rare Diseases (Allianz Chronischer Seltener Erkrankungen, ACHSE e.V.), the International Patient Organisation for Patients with Primary Immunodeficiencies (IPOPI), the German Association for Immunology (Deutsche Gesellschaft für Immunologie (DGfI)), the European Federation of Immunological Societies (EFIS) and the European Organisation for Rare Diseases (EURORDIS).

Rare diseases are often life-threatening and can cause chronic disabilities. Nevertheless, they are underdiagnosed and those affected are left to their own devices.

In total there are more than 30 million people living with rare diseases in the EU, in Germany some 4 million. Amongst those are around 100,000 people affected by primary immune deficiency, such as antibody-deficiency syndromes. Only around 700 have been diagnosed.

Rare diseases have, to date, played a very marginal role in the context of the health policy agenda and in the discussions regarding reforms of the health care system. Even in medical circles in many cases a lack of knowledge and education can be observed.

Our objectives are:

- Securing an early diagnosis and an adequate treatment for all those affected in accordance with current medical standards.
- Fundamental improvement of living conditions for those affected.
- Long-term increase in cost efficiency in the health care system by avoiding expensive and erroneous therapies as well as high social costs due to invalidity and early retirement.

Please support those affected by returning the reply fax below. Up to 5 family members and friends can sign the form. For further information please refer to our website **www.berliner-signal.de**, where you can submit your signature on-line, or ring **0049/8074/8164**

Supported by



Please send to DSAI e.V. – via fax: 0049/8074/9734 – via mail: DSAI e.V., Hochschatzen 5, D-83530 Schnaitsee, Germany

I support the demands of the Berlin Signal

	Name, Surname	Place of residence	Organization	Email	Signature
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With my signature I agree to the publication of my name and place of residence by DSAI e.V. (print, website).