

Too rare to be “precious”: the orphans of medicine

GENERALI'S GERMAN SPECIALIST IN HEALTH INSURANCE CENTRAL KRANKENVERSICHERUNG LAUNCHES INITIATIVE FOR RARE DISEASE PATIENTS



An estimated four million people in Germany, and between 27 to 36 million in Europe, are affected by one of over 5,000 rare chronic diseases described in medical literature. Considering that set against the total population only a small number of individuals are affected, chances are that a doctor may never actually come across a patient suffering from a rare disease. In fact, a disease is classified as “rare” if it affects no more than five out of 10,000 individuals. Therefore whoever suffers a condition that occurs only rarely can also be called an orphan of medicine – an orphan who has **not been “adopted” by the pharmaceutical industry** because developing and marketing medicines to cure such diseases is unsustainable.



Some 80% of rare diseases are genetic. Thus symptoms often appear immediately after birth or during childhood. Diagnosis can be a long and difficult process, and there is no guarantee that a satisfactory one can be determined. Most rare chronic diseases are in fact incurable and seriously impair the patients' quality of life.

Commitment to people with rare diseases

These facts have prompted Central Krankenversicherung, a Generali Group health insurance provider operating in



Germany, to launch a new initiative designed not only to improving the lives of people affected by rare diseases, but also to generating the necessary public awareness for this neglected issue. To this end, Central teamed up with a strong partner, the German organisation **ACHSE** (National Alliance for Rare Chronic Diseases).

The association acts as a point of reference for rare disease patients and their relatives. Among other things ACHSE gives these "orphan patients" a voice in the political and economic spheres.

The ACHSE – Central award's 1st edition

A joint initiative was launched in October 2010 by the partners who set up the **ACHSE – Central** award for innovative care for people living with a rare disease. In the following months, numerous applications were admitted. By allowing both ongoing and brand new initiatives to participate, the award was interesting for a wide spectrum of applicants. While most of the applications came - as expected - from the health care sector, namely clinics, medical practices, self-help associations, single individuals also applied. What mattered was that each project had to show an **innovative commitment** to improving medical support for patients with a rare chronic condition. Karin Koert-Lehmann, head of corporate communication at Central, explained: "We received over 30 applications, which is far more than we had expected for a new award".

In early March, a jury consisting of leading figures from health care management, medicine and scientific journalism selected the winning entry. The award was presented at a soiree in **Berlin on 12 May, 2011**. To maximise outreach, the date was carefully chosen to coincide with a major medical conference scheduled in the German capital at the same time.

Under the header *Gemeinsam für die Seltenen* ("Together for people living with a rare disease"), Central is actively working to promote the award and raise public awareness for this subject.



Gemeinsam
für die Seltenen

