It is MY life
A new revolution
Patient Power

Simon Rozendaal

This book contains twelve interviews with patient leaders who all contributed to research into hereditary diseases and development of medical treatments. The interviewees are amongst others Cees Smit (The Netherlands), Patrick Terry (U.S.A.), Tsveta Schyns (Austria), Dianne Petrie (Australia), Grzegorz Wegrzyn (Poland) and Michael Griffith (Ireland). The stories tell how these people, all involved in rare diseases, managed their own life and how they guided other patients by founding organisations, by contributing to the drug development process for their disease. In one case a biotechnology firm was started, where the patient organisation became owner of the patent of the gene in question. These portraits show that patients are a serious partner in the dialogue with politicians, researchers and industry and are very important in their role as ‘expert patients’. Patient organisations have great expertise about their diseases and can play an important role in therapy development and disease management. Especially with rare diseases patient organisations can play a big role. International cooperation between the patient organisations on the one hand and with science and industry on the other, is therefore necessary. The publication is another proof of the rapidly increasing, very committed and very (pro-) active role of patient organisations towards the route to treatments.

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EGAN, European Genetic Alliances Network
This network is an alliance of national genetic alliances and European disease specific patient groups with a special interest in genetics, genomics and biotechnology. EGAN is working for a voice in research and health
CEEGN Central & East European Genetic Network
This coalition of patients, family support groups and individuals, working together with scientists and industry to support people with common and rare genetic and congenital conditions and their families in countries of Central and Eastern Europe.
EPPOSI European Platform Patient Organisations, Science and Industry
This EU patient-led partnership between patient organisations, industry and academic science, founded in 1994, is working on healthcare policies towards treatment and prevention of serious diseases.
IGA, International Genetic Alliance of Parent & Patient organisations
This global alliance, representing over 2000 associations, seeks a world where genetic conditions are understood, prevented, treated, ameliorated, and cured
WAO World Alliance of Organizations for Prevention and Treatment of Genetic and Congenital Conditions
This organization strives to decrease the gap between new scientific discoveries and their practical application in healthcare and prevention.”