



It is *MY* life Patient Power A new revolution

Simon Rozendaal, science writer

For centuries patients have been passive- but not anymore. It's their body, it's their life.

They don't want to lie down any longer. They want to get into the driver's seat. They want to get involved in the process of decision making. About their medicines, about their treatments, about their bodies, about their lives.

This book portrays a revolution that is taking place now. Simon Rozendaal interviewed twelve patients with hereditary diseases from all over the world. Their stories

show a determination to take charge, to make a real difference.

The Bulgarian biologist who has established a European science-network to address the rare disease of her daughter, the American businessman who founded new companies to address his children's disease, the Irishman frustrated by conservative views on stem cells because he desperately needs new treatments, the Dutch woman with a hereditary disorder and sitting in a wheelchair, they all embody a new energy with the promise to change medical science, the pharmaceutical industry and health care: **Patient Power, a new revolution.**

It is *MY* life

Can be ordered at your bookstore or at the European Genetic Alliances' Network (EGAN)

Price: 15 €; 20 US \$\$ (excl. mailing costs)

ISBN: 978.90.5911.538.5

E-Mail: egan@egan.eu

This publication is recommended and supported by

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

CEEEN 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.

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"