

Order this book



It's MY life

A NEW REVOLUTION
PATIENT POWER

Simon Rozendaal

For every copy ordered through the **European Genetic Alliances' Network** a donation will be made towards patient support activities.

Your order can be send to egan@egan.eu
Price: € 15 (± US \$ 20) excluding shipping costs

The invoice will be sent to you upon receipt of your order

The book is also available at your bookstore

It's MY life

A NEW REVOLUTION PATIENT POWER

Simon Rozendaal



For centuries patients have been passive – but not any more. It's their body, it's their life. This book shows people who decided not to wait until others did something for them. Patients and their family members rolled up their sleeves and refused to throw in the towel. 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 all over the world. Their stories show a determination to take charge, to make a real difference. The Bulgarian biologist who established a European science network to address the rare disease of her

daughter, The American business man who founded new companies to address his children's disease, The former banker in Ireland frustrated by conservative views on stem cell therapy, The Chinese Professor in Economics who organized a scientific meeting and started a patient organization in China. The Dutch Cultural Anthropologist who wants to get the most out of her life and tries to support others as well. The Polish Biochemist who fought to get treatment for his daughter and now tries to find treatment for other diseases. They all embody a new energy with the promise to change medical science the pharmaceutical Industry and health care: Patient Power, a new revolution.

Titles of chapters in this book are:

- 'I was born to live'
- 'I'm trying to reach the stars'
- 'Think of the brothers and sisters'
- 'I'm living in injury time'
- 'We were planning to get married'
- 'Ethics must not be used as a delaying tactic'
- 'My mother never touched a drop'
- 'It's easier to carry out tests on people than on mice'
- 'This illness is stealing my daughter'
- 'I always used to say: I'll never get to fifty'
- 'Without tests on animals Laura wouldn't be here now'
- 'My children's illness has been godsend'

This publication is recommended and supported by:

IGA is promoting medical genetic services, research, technologies, and access to information & treatment, in order to alleviate the burden of genetic conditions for individuals, families and communities.



IGA
International Genetic Alliance

Helios, NL 2592 CV, Gerstkamp 130,
The Hague, The Netherlands
Tel.: +31 35 683 1920 / +31 70 3855170
Fax. +31 35 683 1891

E-mail: y.poortman@vsop.nl
RABO bank account number: 1389.71.099
IBAN: NL26 RABO 0138 9710 99
BIC or Swift Code: RABONL 2U