

Pro Retina and its Foundation: Chronology of Achievements in Research Promotion by a Rare Disease Patient Community

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Introduction

In Germany about 30 thousand patients are affected by one of the over 100 forms of inherited degenerative diseases of the retina, worldwide about 2 million.

Typical symptoms are night blindness and loss of central or peripheral vision, often leading to complete blindness.

Therefore the establishment of a patient organization (1977) and a research foundation (2007) not only aimed at sharing experience in the management of the disease but also at the promotion of research into the causes and therapy of these blinding diseases.

Based mostly on minutes, personal experience and publications, the authors have documented the chronology of significant events and achievements related to patient-initiated promotion of retinal research. This short communication will hopefully stimulate the comparative investigation into the impact of patient activities aiming at the prevention, diagnosis and treatment of their own diseases [1-5].

Chronology of Events, Tools and Achievements

- 1977: German Retinitis Pigmentosa Society (DRPV) founded

Constitution: Promotion of self-help activities and promotion of biomedical research.

- 1978: Establishment of external account for funding RP research
- 1978: Co-founder of International RP Association in London

Constitution: Promotion of international RP research.

- 1979: Key article on research promotion and objectives of DRPV in "Die Zeit" (Federal German weekly journal)
- 1981: Participation in international RP research conference in Baltimore (result: Baltimore report on the international state of research)
- 1982: Medical and scientific advisory board founded (2018:12 members)
- 1983: Position of "research referee" established inside PRO RETINA
- 1984: Identification of the first gene mutation in the Rhodopsin gene by Professor S. Bhattacharya
- 1986: First International RP research conference in Germany (Bad Nauheim)
- 1988: First annual young researcher award, sponsored jointly by PRO RETINA and Retina Suisse
- 1990-2000: Organization of annual research colloquia
- 1992: First disease-specific patient sub-group (Usher Syndrome) with its own clinical and research network established inside Pro Retina (Today: 9 disease- and mutation-specific subgroups, incl. RP, CHM, BBS, STGD, CRD, LCA, Refsum Syndrome etc.)
- 1993: Clinical Advisory Board founded
- 1994: Initiation of the Retina Implant Project funded by Federal Ministry of Research and Technology
- 1996: Renaming of DRPV into PRO RETINA Deutschland e. V.

- 1997: Internal research fund founded
- 2007: Pro Retina Research Foundation Fighting Blindness founded

Constitution: Promotion of Retina research aiming at rehabilitation of retina patients.

- Since 2007 Annual Potsdam colloquium for young European researchers organized by Pro Retina Foundation, with average participation of 150 researchers
- 2012: 15th International research conference of Retina International in
- Hamburg, Germany (about 800 participants, incl. 80 clinicians and researchers)
- 2012: Guideline for research promotion by PRO RETINA: research needs and
- instruments for research promotion
- 2013: Guideline for research promotion by Pro Retina Foundation: Themes and project examples; decision-making process: scientific advisory board makes recommendations to board and council; additional advise by patients via research committee
- 2016: Clinical patient registry established for members of PRO RETINA; (number of registrants 2018:700)
- Since 1990s: participation of expert patients in Patient Advisory Committees of relevant EU research projects (e.g. Drugsford, RD Connect)

Scope of Research Funding by Pro Retina Foundation Fighting Blindness

Between 2007 and 2017 the Foundation invested an amount of 2.8 million Euro in retinal research. In 20 German universities the foundation funded:

- 2 sponsored university professorships (Stiftungsprofessuren) in Bonn and Regensburg
- 26 research fellowships
- 13 research projects (e.g. personnel costs, laboratory equipment)
- 13 small projects
- 19 research awards
- Hundreds of research publications and reports
- 68 researchers

Type of research funded: About 70% basic, 30% applied basic research.

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