

About PRO RETINA



**PRO RETINA
Deutschland e.V.**

Selbsthilfvereinigung von Menschen
mit Netzhautdegenerationen



PRO RETINA makes a difference!
for people with retinal degeneration



"PRO RETINA makes many essential contributions to those affected by retinal diseases – contributions that go far beyond what we as physicians can offer in terms of diagnostics and therapy. PRO RETINA offers highly targeted counselling programmes to help patients and offer them a wide range of options, ranging from rehabilitative measures, financial support, coping strategies, training for everyday life to raising awareness."

Prof. Dr. Frank G. Holz,
Director
Universitäts-Augenklinik Bonn



Together we are strong

PRO RETINA Deutschland e. V. is a Germany-wide self-help organisation of and for people with genetic retinal diseases.

It was founded in 1977 as the "German Retinitis Pigmentosa Association" by those affected and their relatives to offer them a means of helping themselves. Today, PRO RETINA has around 6,000 members throughout Germany. Each member can join one of the approximately 60 regional groups.

The Managing Board and all active members work on a voluntary basis.

We offer counselling to those affected and their relatives on diagnosis-specific and social issues, as well as on the selection of suitable aids. We promote research in the field of retinal diseases and represent the interests of those affected in politics and the public sector. Our work is supported by a scientific/medical advisory board.

PRO RETINA offers support for, among other diseases:

- Atrophia gyrata
- AVMD (adult vitelliform macular dystrophy)
- Bardet-Biedl syndrome
- Choroideremia
- DME (diabetic macular oedema)
- HJMD (hypotrichosis with juvenile macular dystrophy)
- Kearns-Sayre syndrome
- Leber's congenital amaurosis
- LHON (Leber's Hereditary Optic Neuropathy)
- Macular degeneration
- Age-related macular degeneration – AMD
- Juvenile macular dystrophies
- Macular telangiectasia (Mac Tel)
- Best disease
- Morbus Stargardt
- Pathological myopia
- Retinopathia centralis serosa / Chorio-retinopathia centralis serosa (RCS / CSS)
- Refsum syndrome
- Retinitis pigmentosa
- Usher syndrome
- Cone dystrophy
- Cone-rod dystrophy
- Central areolar choroidal dystrophy

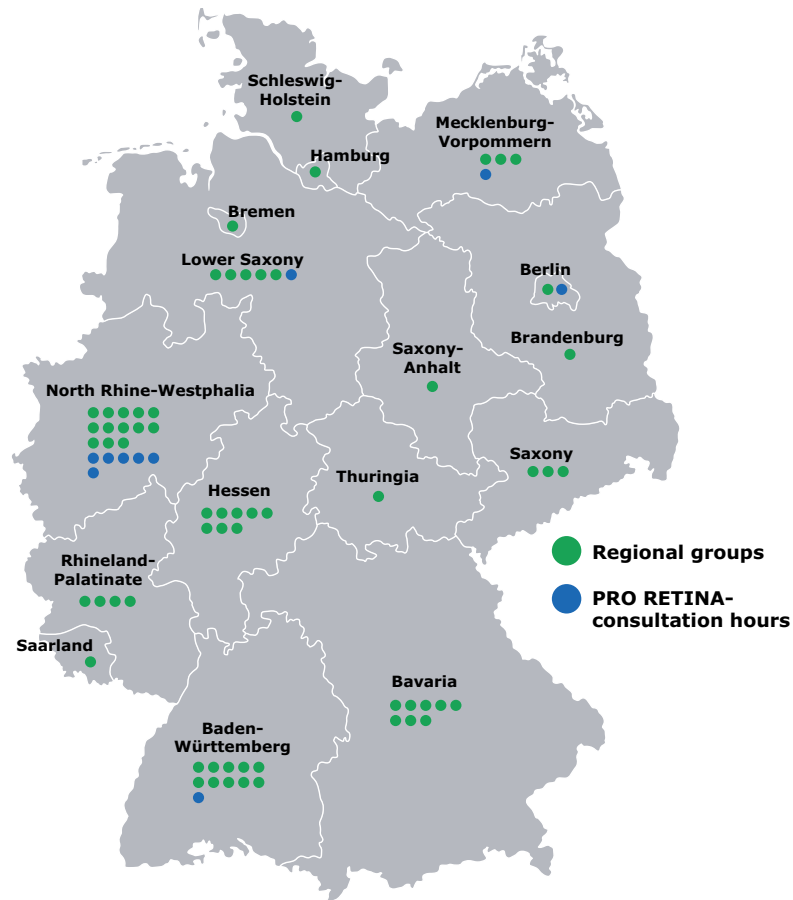


In around 60 regional groups, those affected exchange information about the social, professional and private consequences and opportunities associated with their condition.

Not only do patients receive reliable and independent information about their condition. Sharing with others affected also gives courage and reassurance.

As one participant relates: "We share experiences and tips that help us in our daily lives – with a prevailing mood of optimism.

I had not expected that. It feels so incredibly liberating to be able to talk about my illness and related problems without having to explain the illness and without inciting helpless pity."





Counselling

About **150 volunteer PRO RETINA counsellors throughout Germany, who are themselves affected**, advise other affected persons and their relatives by telephone on all issues related to coping with the disease, diagnosis-specific and socio-legal topics and aids.

Throughout Germany, we also offer regular PRO RETINA consultation hours in Ahaus, Berlin, Bonn, Düsseldorf, Göttingen, Cologne, Münster, Rostock and Tübingen. Counselling during consultation hours is free of charge. Here, too, affected persons advise other affected persons at eye level and provide help for self-help in all areas of life in order to give them courage and a positive outlook.

All PRO RETINA counsellors undergo training before their first assignment and regularly attend further training courses. Members of our association PRO RETINA Deutschland e. V. also receive free professional legal advice.



PRO RETINA's extensive self-help and counselling services offer an important complement to the work of ophthalmologists.

They offer a space to ask questions for which there is hardly any time to answer in daily practice.



Public relations

One of the goals of our work is to inform and educate the public about retinal degenerative diseases and their impact on the lives of sufferers, as well as to raise awareness of the needs of visually impaired people. We reach out to interested private individuals as well as to public and private institutions, socially relevant associations, multipliers and opinion leaders in the press and the public.

PRO RETINA regularly publishes up-to-date, high-quality brochures, also in audio and electronic formats, which provide information about retinal degenerative diseases, therapies, aids and much more, all based on current findings. All the information provided is written in cooperation with renowned scientists, physicians, experts and sufferers.

The member magazine "Retina aktuell", a research newsletter and the PRO RETINA website also provide comprehensive information about the different diseases, the latest research findings and the activities of the association.



Research

We are actively involved in research funding through the PRO RETINA Foundation for the Prevention of Blindness. For example, we have funded endowed professorships in Germany specialising in retinal research. Both basic research and making the results available to clinics are of particular concern to us.

PRO RETINA was a partner in the EU project EYE-RISK, with the aim of identifying risk factors in the development of age-related macular degeneration (AMD).

And to improve research for therapies, we have established a supra-regional independent patient registry. This makes it easier for patients to access clinical trials and for researchers to recruit patients.



Donations

With your donation of **€1,700**, for example, you will finance the training of a counsellor. Counsellor training includes seminars on communication/counselling as well as specialised seminars on a range of topics, such as aids, social issues or a specific medical condition.




We require **€850** per week in postage alone to be able to send information material to affected and interested parties and to display it at information stands. Your donation of **€170** helps us to offer this service free of charge for another day!

With a donation of **€28**, our volunteer counsellors can provide counselling for another week in one of the ten PRO RETINA consultation hours currently available. In Bonn, for example, around 250 counselling sessions are held each year.

**Promoting research
Coping with illness
Living self-determined**

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