

1. WHAT IS THE HUMAN RIGHTS SITUATION OF PERSONS LIVING WITH ALBINISM IN YOUR COUNTRY OR IN ANY COUNTRY YOU ARE FAMILIAR WITH? ARE THEY CONSIDERED A PARTICULAR SOCIAL GROUP? ARE THEY CONSIDERED DISABLED? ARE THEY CONSIDERED TO BELONG TO ANOTHER CATEGORY?

Human Rights Situation

The human rights situation of persons living with albinism (PWA) in Germany is generally good. The human rights are guaranteed by the Grundgesetz (German Constitutional Law, here: §§ 1-19 Fundamental Rights): § 3.3 in particular says that no one ought to be discriminated on account of a disability.

To the best of our knowledge, there have not been any physical insults or attacks against PWA in Germany, although we do indeed hear about mobbing and other forms of social and psychological hazards directed against PWA due to their looking different and due to their low vision.

“Particular social group”

To our knowledge and by personal experience by two of the signatories (C.G., R.G.) we would say that PWA are not considered a particular social group albeit the use of the term ‘albino’ might suggest such a consideration.

In Germany there is an estimated number of 4700 – 5000 PWA (Prevalence of 1:17.000 with a population of 82 Mio). This number is high enough to theoretically represent a “particular social group”. Fact is, however, that PWA do not wish or attempt to appear as or to form a “particular social group”.

They are rather seen as a rare phenomenon if they are recognized as albinistic persons at all. Due to the fact that Germans are Caucasian PWA often are not recognized as such by fellow citizens. This is due to two facts: lack of knowledge on albinism in the general population and the fact that their complexion (which may vary from white to strawberry-blonde to light brown) does not differ too much from that of the other citizens. We realize, however, that German persons with albinism who are born in families with a migration background tend to suffer more from bantering, scolding and despise than PWA of German native families.

Handicap / impairment

Depending on the extent of visual impairment PWA in Germany are considered disabled according to the WHO criteria of Low Vision. On the legal side, a handicapped person is acknowledged a certain degree of disability according to the Compensation Law for the Handicapped ('Schwerbehindertenrecht') which is part of the German Social Legislation.

For example, visual acuity of 0.2 in both eyes is classified as a degree of disability of 50%, visual acuity of 0.1 in both eyes is rated as a degree of disability of 70%. German law discriminates between disability (5% - 49%) and severe disability (50% - 100%). The degree of severity of disability leads to different monetary and tax-related compensations by the state such as reduced taxes or free public transport.

The issuing of a degree of disability (including a Disabled Person's Identity Card) has to be applied for and medical reports are evaluated by state physicians working in government agencies related to the German Social Legislation.

Based on our personal experience we would like to remark that PWA having been issued a degree of disability might not be judged as such by their environment, but this of course is true as well for other forms of congenital visual impairment which mainly reduces visual acuity for details and reading whilst orientation is far less impaired.

2. DOES YOUR COUNTRY, OR ANY COUNTRY YOU ARE FAMILIAR WITH, HAVE ANY PROBLEM OF PREJUDICE OR STIGMATIZATION AGAINST THE PERSONS WITH ALBINISM? HOW SERIOUS IS IT?

This, of course, depends on the individuals' personal experience and his or her estimation of seriousness. The country itself – i.e. the government of Germany – does not prejudice or stigmatize PWA.

On an individual basis, however, there definitely may be teasing about skin and hair colour, sometimes jokingly but still with adverse effects for the persons, sometimes with more psychological and social impact such as mobbing at school or at the work place. "Looking different" can lead to isolation of individuals with albinism even in a Caucasian country. The majority of PWA in Germany does not permanently suffer from that however.

This is, of course, in no way comparable to severe and life-threatening social or religious prejudice and stigmatization as it can be seen these years in certain African countries (Tanzania, Burundi).

3. WHAT ARE THE OBSTACLES THAT IMPEDE THE EFFORTS TO IMPROVE THE HUMAN RIGHTS SITUATION OF PERSONS LIVING WITH ALBINISM?

There are no such obstacles as the German Government strongly adopts a position of equal footing for non-impaired and impaired person. Any adverse conditions are of a rather individual and interpersonal sort.

4. WHAT MEASURES, IF ANY, (LEGISLATIVE, ADMINISTRATIVE, INSTITUTIONAL, OR OTHER POLICY/MEASURES) HAVE BEEN PUT IN PLACE IN YOUR COUNTRY TO ENSURE THE ELIMINATION OF VIOLENCE AGAINST PERSONS WITH ALBINISM AND THEIR PROTECTION FROM ALL OTHER HUMAN RIGHTS VIOLATIONS?

There is no violence against PWA.

All other rights are protected by the German Social Legislation and by the principle of equality of abled and disabled citizens.

5. WHAT IMPROVEMENTS (IF ANY) HAVE TO BE MADE TO SUCH MEASURES IN ORDER TO MAKE THEM MORE EFFECTIVE?

If any, a broader knowledge about albinism would be desirable. This applies as well to other congenital visual impairments as Low Vision often is less easily detected than other physical handicaps.

**6. HOW, IF AT ALL, DOES YOUR COUNTRY REHABILITATE VICTIMS OF
ATTACKS AGAINST PERSONS LIVING WITH ALBINISM?**

In any cases of physical attacks criminal prosecution is possible. The victim could take legal proceedings against his wrongdoer and might get compensation for pain and suffering.

To the best of our knowledge, there would not be any special rehabilitation or compensation offers if the person with albinism had been attacked due to his/her albinism.

**7. DO YOU HAVE ANY INFORMATION ON ALLEGATIONS, COMPLAINTS,
INVESTIGATIONS, PROSECUTIONS AND THEIR OUTCOMES?**

We have heard of occasional court hearings and court trials to elucidate whether a PWA has disadvantages in his/her professional life or during job interviews.

**8. DO RELIGIOUS/SPIRITUAL INSTITUTIONS IN YOUR COUNTRY PLAY A
ROLE IN HELPING PERSONS WITH ALBINISM? ARE THEY EFFECTIVE IN
PREVENTING ATTACKS AGAINST THESE PERSONS?**

Religious or spiritual institutions in Germany are open for everyone to ask for help and support.

To our knowledge, there is no religious institution, parish or spiritual group especially attending to PWA.

**9. IN WHAT WAYS CAN THE HUMAN RIGHTS COUNCIL AND THE OTHER
UN HUMAN RIGHTS BODIES ASSIST WITH IMPROVING THE SITUATION
OF PERSONS LIVING WITH ALBINISM WITHIN YOUR COUNTRY OR ANY
COUNTRY YOU ARE FAMILIAR WITH?**

Concerning Germany, there will be no need for the UN Human Rights Council to assist with the improvement of the situation of PWA living here.

Once again, we would like to stress the importance of knowledge about albinism and about congenital low vision of other causes – this applies for Germany as well, but we consider that to be our own work with the help of the albinism support group NOAH Germany and with the help of other patients’ associations for visually handicapped and blind citizens.

We would, however, sincerely like to offer our help for PWA in countries where there are threats to the life of PWA and where PWA are not being treated equally. Perhaps religious superstitions and prejudices could be alleviated by demonstrating how persons with albinism lead a normal private and professional life in our country.

We are sad and shocked about what we read and hear African PWA have to endure and to suffer. We think it is mandatory to help to erase false concepts and imaginations about PWA, and in our opinion this could mainly be achieved by demonstrating how “normal” a person with albinism is and how normal the life of a person with albinism can be, in spite of the visual impairment, visual adaptations or the use of low vision aids.

Of course we realize that many of the problems encountered in Africa are due to the fact that the physical appearance is so very different from that of his/her family and the general population, while in Germany the differences are far less.

Still – if we could be of any help by explaining that an individual with albinism, in spite of looking different and seeing less, is just as normal a person like anyone, and can live a fulfilling life, we would be very glad to be of assistance.

10. WHAT OTHER INSTITUTIONAL OR PRACTICAL MEASURES SHOULD THE HUMAN RIGHTS COUNCIL TAKE TO STRENGTHEN THE EFFORTS TO IMPROVE THE HUMAN RIGHTS SITUATION OF PERSONS LIVING WITH ALBINISM?

Not applicable for Germany.

We would like to add that we are very interested in the results of this world-wide questionnaire and would be happy if the results could be sent to us.

Signed (see next page for contact details!):

- Claudia Geißler MA
- Prof. Dr. Barbara Käsmann-Kellner MD
- Rico Geipel



For NOAH Albinismus Selbsthilfegruppe e.V. Deutschland:

- Claudia Geißler MA,
Regional Spokesperson for NOAH for the County of Hesse
hessen@albinismus.de

- Prof. Dr. Barbara Käsmann-Kellner MD
Ophthalmological & Low Vision Consultant for NOAH Germany
Member of the Scientific Board for Albinism Europe
University of Saarland Medical Center, 66424 Homburg
kaesmann@gmail.com or kaesmann@albinismus.info

- Rico Geipel
Chairman, NOAH Germany
1.vorsitzender@albinismus.de

Websites:

www.albinismus.de

Homepage of NOAH Germany

www.albinismus.info

Homepage of the Medical Advisor for
NOAH Germany

Please see page 9 for websites pointing to the future of albinism in Europe!!

Websites pointing to the future of albinism in Europe

<http://www.albinismo.es/> This is the website of the Spanish Albinism Association ALBA who hosted this year's Conference "2nd European Days of Albinism

<http://www.albinismo.es/2EDA/>" in Valencia from April 5th to 6th and of pictures from the conference: <http://www.albinismo.es/2EDA/pictures/>.

For media coverage see www.albinismo.es (scroll to middle of page)



This conference has been:

- a very successful 2nd meeting of European albinism associations planning the "Roadmap Albinism Europe"
 - the first EDA had been organized by Genespoir Albinism France, 11/2012, Paris
- the very first meeting of Young Persons with Albinism
- plus a very fruitful 2nd meeting of scientists discussing and sharing research results concerning all aspects of albinism such as: molecular biology, ophthalmology, dermatology, human genetics, neurophysiology, neuroanatomy, molecular genetics, gene therapy, pharmacotherapy, stem cell therapy and others.

In our opinion this is one of the most important ways to promote and stimulate further knowledge on albinism and to work for equal opportunities for albinists: working with the patients' associations, learning from their experiences and scientifically working in a truly inter- and transdisciplinary way.