

Dear Members of the Albinism Fellowship,

This is a serious request to everyone with albinism to wear their full correction of their refractive errors either with spectacles or with contact lenses!

During my stay in York at the conference of the Albinism Fellowship there were numerous questions concerning spectacles, contact lenses and the question as to when children should receive correction and whether correction in visually impaired adults is of any use. I had the following impressions from my talks:

Too many children do not wear glasses at all.

Too many children receive their spectacles relatively (too) late.

Too many adults do not wear the correction they were prescribed.

From my experiences with my own patients I have a very strong opinion on this topic. First of all, children should get their correction as soon as possible, as early corrected refractive errors can lead to a better visual acuity in later life. In adults visually impaired by albinism a correction can improve the visual impression, can elevate visual acuity one line on the testing chart or more and makes reading much easier.

The following text hopefully clarifies my point of view for you - if only one person with albinism or one couple with their child go to get a correction prescribed, it will have been worth the effort of writing the paper.

Refractive errors in albinism, visual acuity in albinism and the visual development in the first 6 years of life.

Details on spectacles and contact lenses

1. Refractive errors in albinism

In the different types of albinism there are usually moderate to high refractive errors. The following table shows a definition of the three different kinds of refractive errors, their Latin and English names and the consequences they have on visual acuity. "Moderate to high" refractive errors means usually a hyperopia of +3 to +6 diopters, a myopia of -2 to -5 diopters and an astigmatism of around 2 to 4 diopters. About a third of the patients have higher or lower levels of refractive errors. (**Table inserted here**)

Just to clarify the needs of correction in persons with albinism: of the 103 patients with albinism I care for personally there is only one who does not need a correction!

	HYPER-OPIA	MYOPIA	ASTIGMA-TISM
English term	Far-sightedness	Short-sightedness	a-stigmatism (not sharp) vision
Value (Term to measure) the refractive error	"Plus"-Dioptres	"Minus"-Dioptres	"Plus or Minus" according to way of glass fabricate.
Changes in the eye	eye too short	eye too long	
Changes in vision	near objects are blurred	distant objects are blurred	objects far and near are distorted
Correction by spectacles	concave glasses	convex glasses	toric glasses
Correction by contact lenses	possible	possible	possible
Improvement of vision by wearing correction	yes	yes	yes

2. Visual acuity in albinism

A word on visual acuity: I believe in England visual acuity is given in feet, 20/200 etc. In Germany we range visual acuity in ranges from 0,0 to 1,0 or in percent, 1.0 or 100% (20/20) is what a person with healthy eyes sees, 0,1 or 10% would be 20/200 for example.

Visual acuity in albinism is on average around 10% to 20%. There are exceptions to that rule but not too seldom: the possible individually achieved visual acuity can be quite high: I see patients with OCA1 with a visual acuity of 50%, patients with OCA2 who have a visual acuity of 80% (and happily drive a car!) - the range of visual acuity is very broad indeed.

3. Visual improvement by spectacles or contact lenses

Spectacles or contact lenses do make a difference in persons with visual impairment! The improvement with glasses may not be as remarkable as in a person with otherwise healthy eyes who needs glasses, but there definitely will be an improvement. Who would, as a visually impaired person, neglect easy opportunities to improve vision as much as possible?

In a person with visual impairment all things which can be corrected should be corrected!

An example for myopia (short-sightedness)

Person A, healthy eyes, myopia of -5,0 Diopters.

Person B, albinism, myopia of -5,0 Diopters.

Visual acuity of Person A: without correction 10%, with correction 100%.

Visual acuity of Person B: without correction 5%, with correction 20%.

The improvement for the visually impaired person is not as impressive as in another person, but consider the following: if you do have a visual impairment, you should do everything to make vision as clear and visual acuity as optimal as possible!

An example for hyperopia (far-sightedness)

Persons with albinism are very often hyperopic (far-sighted). That means that near objects are seen blurred, especially in older children, adults and ageing people when the capacity to overcome hyperopia by accommodation and closing up to the text becomes less and less (think about the reading glasses all persons need from the age on 40 to 50 years onwards).

Glasses which correct hyperopia have two advantages: 1. the objects become more clear, less effort is needed to see clearly. 2. the glasses enlarge the seen image! So alone by wearing the appropriate glasses the person has an "in-built" enlarging visual aid, a form of Low Vision Aid which can be used all the time. The stronger the glasses, the more the image enlarges. An overcorrecting however would again blur all objects in the far distance, so the optimum can only be achieved by the perfect and appropriate individual correction.

Astigmatism

For astigmatism no example is necessary, because facts are so evident. Astigmatism is caused by an irregular curvature of the cornea leading to distortions in vision: a light which is shaped like a point is reflected on the

retina as a line-like light with shadows. Spectacles and contact lenses can completely correct astigmatism and thus make objects and lights sharper and with better defined margins. As persons with albinism often have astigmatic refractive errors of up to 4-5 Diopters one should definitely get that prescription!

4. Development of visual acuity (Phase of “Learning to see”) in children

All children, normally sighted and visually impaired children, develop their visual acuity in the course of the first 6 years. “Seeing” is a learning process of the brain, especially in the first two years of life. The brain is in that span of life very sensitive to external influence. Improving the seen image “helps the brain to learn to see”! What the brain has learned in these early years, it has for the whole life. It can not lose these capacities again.

Improving the retinal image can be done in babies, toddlers and children by giving them the adequate correction either with spectacles or contact lenses. They will see better and the brain has the possibility to develop a good visual acuity in spite of the visual handicap.

Correcting the refractive errors in babies does not result in wonders, but nearly. Of course a visual impairment will persist, but just imagine the possible difference you could achieve for your child: no correction: final visual acuity of 10%, correction for the toddler: final visual acuity of perhaps 30% as a youngster and for ever! No one should miss that opportunity.

An often heard argument even from eye specialists is that spectacles or contact lenses can not be prescribed in children under 2 or 3 years of age. This is not true. If you heard something like that, go get another opinion, and a third one if necessary, until you get the correction. Your child deserves to have the best as possible start position into life!!

5. How should spectacles look? What is important to know to get good and good-fitting spectacles?

Absorption (tint) of glasses

When a person with albinism has spectacles to correct refractive errors, they should have 2 pairs of spectacles with different levels of absorption to reduce the glare adequately for inside and outside. Persons with albinism are very sensitive to light (whom do I tell...) and glare reduces contrast and decreases visual acuity.

I usually prescribe glasses for indoors with 15% absorption (very slight, barely visible) and specs for outdoors with 80% absorption to effectively reduce the sensitivity to light outdoors and to improve the vision in bright weather.

Frames

The rules for good spectacle frames are the same for adults and children. Frames should be small, this is extremely important: small frames ensure that the centre of the optical lenses (glasses) is centred to the centre of the eye, the pupil. There the image is not distorted. In large frames, the glasses reach

down to the cheek and the eye looks through the upper third of the glass, there the glass is not centred. Small frames also have the effect that even high refractive errors are not too evident: large frames and glasses will produce "big eyes" of "small eyes" behind the glasses whilst with small frames the eye is not distorted behind the glasses.

Frames should also be lightweight for better wearing comfort.

Last not least fashion, the wearer should like the spectacles, this improves the motivation to wear them. I think for adults this would not be a problem, for children's frames - at least here in Germany - one has to look out for good and nice-looking frames. Good opticians will know more and will be able to order children's and baby's frames.

Contact lenses

A common belief is that contact lenses can not be given to toddlers and children, this is not true! Contact lenses are a wide field, let me only mention some important points.

Contact lenses guarantee a very good retinal image in all cases. Contacts are especially helpful in myopic (shortsighted) persons: when they look through corrective glasses, the seen image is smaller. With contact lenses, this is not the case, they see everything in the normal size. This may be important for visually impaired, they benefit from the regular sized image.

Contact lenses are especially good in correcting high astigmatic errors. The contact lens lies on the cornea and so minimises irregularities in the corneal curvature. Very high astigmatic errors (above 6 Diopters) can only be corrected sufficiently by contact lenses.

Contact lenses can be tinted. A tinted contact lens has even better protecting effects as the whole iris is covered from the lens, whilst with spectacles there is often a certain amount of light falling into the iris from the side. One should not use too dark an absorption for the lens, as this would impair vision indoors. Ideal: contact lens with a moderate absorption (30-40%) additionally moderately tinted spectacles for outside.

Disadvantages of contact lenses

Contact lenses need good handling and care! They need to be cleaned daily without exception in adults and every 2-3 weeks in very small children (special lenses exclusively for small children). Uncleanliness in lenses leads to opaqueness of the lens quickly, it is like looking through haze or fog. So the wearer has to know about his responsibilities for the lenses.

Contact lenses can not be worn 24 hours a day. The eye, the cornea need a rest every day or night. So additionally spectacles are necessary, no contact lens can live completely without specs.

Some toddlers co-operate when fitting and inserting the lenses, some do not. If there is a resistance and apprehension on the child's side, one should stick to spectacles for the time being and try again a couple of years later. The worst situation is a small child who refuses contact lenses and ends up with no correction whatsoever!

Dear Members of the Albinism Fellowship:

Hopefully I have explained my opinions on refractive errors and their correction adequately. If you don't remember anything of this paper, one thing should be remembered by all affected persons and parents:

- **Adult persons with Albinism:** see the multiple implications and possibilities of wearing appropriate correction, be it with spectacles or contact lenses. Do not deprive yourself of a better visual acuity!
- **Parents of children with Albinism:** go get this correction! Do not hesitate to get second opinions! Enable you child to "learn to see" in the first years of life and give him/her the chance for an optimal starting position into school life and into adult life in spite of the visual handicap.

Please do not hesitate to contact me in case of further questions!

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