REAL LIVES

PERSONAL AND PHOTOGRAPHIC PERSPECTIVES ON ALBINISM

ARCHIE W. N. ROY AND ROBIN MACKENZIE SPINKS

PHOTOGRAPHY BY RICK GUIDOTTI

'A "must read" for anyone living with albinism and indeed, anyone else seeking insight into this subject. Well written, easy to read and easy to understand. As an educator, I also found this book illuminating and thought-provoking and I particularly liked the ideas of assertiveness training and positive thinking.'

JOAN HASTEN, DEPUTE HEAD,
Uddingston Grammar School, South Lanarkshire Council, Scotland

REAL LIVES: PERSONAL AND PHOTOGRAPHIC PERSPECTIVES ON ALBINISM portrays the past and present lives of twelve people living with albinism in Great Britain and Northern Ireland. Through interviews and analysis, the authors examine the many challenges and barriers these people have faced. And they explore with the twelve the strategies they have adopted in life to overcome such challenges.

The book raises key questions about stigma and about how difference in appearance can affect relationships and the experience of family, school, college and work. Through discussion, photography and interview, it also shows that albinism is about a journey towards a view of oneself that includes beauty, fulfilment and self esteem.

This will be essential reading for parents and teachers of children with albinism, people living with albinism, ophthalmologists and other eye specialists.

DR. ARCHIE ROY is a Careers Adviser at the University of Glasgow. He has also researched and written extensively in the field of sight loss and education.
ROBIN SPINKS is the International Advocacy Adviser for Sightsavers International and is based at their headquarters in Haywards Heath, England.
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About the creators of Real Lives

Archie Roy gained a BA (Hons) degree in psychology from the University of Strathclyde in 1982. His research on the effects of conflict on children's social perceptions then gained him his PhD in social-developmental psychology from the University of Strathclyde in 1987. From 1989 to 2003 he worked throughout Scotland and the UK for RNIB as a student adviser and education officer. Through that time, he also worked extensively on European Union and Eastern European disability projects to raise awareness and develop provision.

Archie has published over thirty journal articles and book chapters, mainly on blindness and low vision. He has also co-authored several major reports for the EU, RNIB and the Quality Assurance Agency. In 2003 he joined the Real Choices Social Inclusion Partnership based in Nottingham and evaluated Scottish projects funded by the European Year of Disabled People. He is also qualified as a guidance practitioner and since 2004 has worked as a Careers Adviser at the University of Glasgow.

Robin Spinks gained a BA(Hons) degree in Sociology and Social Policy from the University of Stirling in 1997 and is a qualified careers adviser. From 1999 to 2005 he worked throughout Scotland and the UK for RNIB as an employment officer. He also has albinism and for the past two years has served as President of the Albinism Fellowship. In that time, he has done much to raise positive awareness of albinism and to develop the organisation.

Real Lives is his first book but not his last.

Since 2005 Robin has worked as the international advocacy adviser for Sightsavers International. Based in Haywards Heath in Sussex, he frequently works in Africa. He has extensive experience as an adviser, trainer, radio presenter and consultant.

Rick Guidotti completed his education in photography and filmmaking at New York's School of Visual Arts and established a studio in Manhattan, specialising in portraiture and fashion photography for fifteen years. During that period he also worked in Milan, Paris and London for commercial and editorial clients such as Yves Saint Laurent, Elle, Harper's Bazaar, L-Oreal, and Life Magazine.

Rick has been a Director of the Positive Exposure project since 1998 and has travelled extensively in Africa, the South Pacific, the UK and North America, photographing people with albinism within their communities. His photo essay "Redefining Beauty" in Life Magazine won the Genetic Alliance's "Art of Reporting" award. His recent work on albinism has been exhibited widely, including at the Smithsonian as part of "The People's Genome Celebration". He also seeks to create a bridge between art and other genetic conditions, doing a photo shoot in 2005 with teens and young adults at the Sturge-Weber International Conference, Pennsylvania. Rick is based in Manhattan, New York City.

Contents

Preface

Real Lives portrays the past and present lives of twelve people living with albinism. These individuals come from many walks of life and they have chosen to share with us their unique journeys from past to present, exploring the challenges they have faced individually, socially and professionally. They reflect on the impact of the condition on their daily lives and help us to record the strategies they have found effective when combating negative and stereotyping attitudes. We hope therefore that on a practical level, this book says positive things to parents of children with albinism, to teachers and others working in education, and to ophthalmologists and other eye specialists working in the fields of assessment, diagnosis and eye health. At other levels, of social commentary and even the inner city bookshop, we hope that our book raises awareness about people living with albinism. It seems strange to us that some of the most casually visible people on Earth are really quite invisible in other ways. There has been little written to date on people with albinism, partly because it is a stable condition, with associated visual impairments unlikely of themselves to deteriorate with the increasing age of someone with the condition. Is albinism often of less intrinsic interest, therefore, to the medical professions?

For this project though, we have stayed well clear of medical models, preferring social commentary. We and the subjects also co-operated with Rick Guidotti, the New York based photographer. The interviews with, and reflections by, our respondents allow us to chart the flow of their lives through the decades. But Rick's photography shoots concentrated moments in their lives, capturing moods, postures and thoughts. We hope that the narratives and the photography combined will achieve something much more difficult to achieve by use of one of these methods alone. Sometimes they may fuse together into a whole while, at other times, they may act as distinctive lenses on experience with an individual's own perspective and our commentary on it diverging from the image. But the issue and the topic is the same throughout, lives lived with the experience of albinism.

We have sought to create intimacy and empathy with the people who kindly volunteered to share their lives with us. For their words, we provide accurate word for word extracts. For the nuances, the smile, and the thought behind the smile, we leave to Rick. But we hope that text and image combine in a portrayal of beauty, strength and difference.

We would particularly like to thank the following people for helping to make this book possible. Thanks go to everyone kind enough to participate in the interviews; to Mark Sanderson, President of Albinism Fellowship, for his proof reading and his thoughtful and constructive comments; and to the reviewers. Thanks also to Sightsavers International, University of Glasgow Careers Service and RNIB Scotland for their support. Special thanks go to Rick Guidotti and Roger Kilmartin for their photography and creative design input.

Archie W N Roy, Glasgow
Robin M Spinks, Haywards Hove
August 2005

Chapter 1

Albinism: An Introduction

What is Albinism?

The term 'albinism' refers to a group of conditions inherited through genes which do not produce the usual amount of melanin pigment. The physical characteristics this inheritance creates involve visual impairments, little or no colour in the eyes or hair, and very fair skin - hypopigmentation.

For nearly all types of albinism, people have parents who have both carried an 'albinism gene' but because the most common pattern of genetic inheritance is autosomal recessive, neither parent may have albinism characteristics such as loss of pigment. But if both parents carry the gene, there is a one in four chance that each child will have albinism. If only one parent carries an 'albinism gene', none of the children will have albinism though they could carry the gene. If the children inherit a gene for normal pigmentation from the second parent, this is sufficient information to create normal pigmentation.

Albinism, Schools and Employment

Children with albinism can be subjected to bullying. In school this should be checked and reported as soon as possible. Because of their visual conditions, people with albinism are also at greater risk of discrimination and they can lose out in learning contexts unless specific measures of support are put in place.
This needs to occur right through schooling, college and university education.

Employers also need to take appropriate measures to ensure that the workplace applies appropriate adaptations for the employee with albinism. Socially, people with albinism can be at risk of isolation. That is one of the main reasons why self-help groups such as the Albinism Fellowship exist.

Types of Albinism

There are many different types of albinism. Twelve types are discussed in recent medical biology literature but recognised variants within two or three of these types increases this figure to at least 22. However, it is helpful to remember that there are only two main types: oculocutaneous and ocular. These are usually abbreviated to OCA and OA and we will also use these abbreviated forms.

OCA involves reduced pigment (melanin) in the skin, hair and eyes while OA primarily entails reduced pigment in the eyes (and therefore a visual impairment) though skin and hair can be lighter than in other family members. People with OCA are very sensitive to light. Many wear tinted glasses or contact lenses to reduce discomfort from glare. They also have very pale blue or blue/grey eyes; having red or pink eyes is one of the more common myths associated with albinism. People with OCA also have either little or no pigment in their skin and hair. There are actually two different main types of OCA: OCA1 and OCA2.

OCA1 or OCA –ve refers to a tyrosinase negative condition: reduced pigment is caused by the lack of the enzyme tyrosinase, an essential part of the chemical process by which the body changes the amino acid tyrosine into pigment. People with this condition have absolutely no pigmentation in eyes and hair. The hair therefore appears white or platinum in colour and the skin appears very pale. The eyes appear pale blue or blue/grey. People with OCA1 have a significant visual impairment.

OCA2 or OCA +ve refers to a condition where tyrosinase is present but other factors still reduce the production of melanin. People with OCA2 also lack pigmentation in eyes, skin and hair but will still have some pigment. Their hair will be pale blonde and their eyes will be blue or light brown. Visual impairment is also usually less severe than for people with OCA1.

The third group, people with ocular albinism (OA), may not be diagnosed as having albinism until much later in life. Although they have the ocular characteristics of albinism, the condition is masked by near-normal pigmentation in hair, skin and eyes (though there is no pigment in the retinas). In one type of OA, the pattern of inheritance varies from autosomal recessive and is 'X-linked', meaning that this type of OA can be passed from mothers carrying the gene to their sons who may have OA. 'X-linked' means that the OA gene is on the X chromosome. Females carrying the gene can often be identified through an eye examination.

Detailed scientific research commonly splits the three main types into at least ten subtypes, mainly OCA subtypes, and suggests further

that there may be up to twenty additional variations within these ten subtypes. A rare type of albinism is Hermansky-Pudlak Syndrome (HPS). It seems only to be relatively common in Puerto Rico. Because it usually entails lung fibrosis and deficiencies in certain blood cells, it can involve further complications such as problems with bleeding, bruising and respiratory disorders. It is important to stress though that people with the more common forms of albinism have the same life spans as the rest of the population. At the same time, people with albinism living in tropical environments such as sub-Saharan Africa are at a higher risk of skin cancers if they do not regularly take measures to protect themselves from the sun.

Of course, this book is primarily not about genetics. We would suggest that if readers are interested in these aspects, they could look at the review paper by Oetting, Brilliant and King (1996) and the updated version of this paper, along with similar resources, on the International Albinism Center's website, www.albinism.med.umn.edu/ .
The International Albinism Centre is at the University of Minnesota. See also "Albinism: A 3-In-1Medical Reference" by Parker and Parker (2003).

Albinism and its Effects on Vision

People with albinism always have visual difficulties and may appear to cope better than their visual acuity would suggest. This is because the brain makes adaptations and also because people follow a number of adaptive strategies such as making maximum use of coloured glasses or contact lenses.

The visual difficulties originate in the abnormal development of the eyes, particularly the retinas, and abnormal patterns of nerve connections between the eyes and the brain. The optic system requires melanin to develop properly and a critical or complete lack of melanin causes a range of visual problems.

For people with albinism, the retinas, the surfaces inside the eyes which receive light, do not develop properly before birth and during infancy. Vision is therefore lacking in detail even with corrective lenses. The fovea, the part of the retina allowing detailed visual activities such as reading, is under-developed since apparently the developing eye requires melanin to "organise" this important area. Also, the iris, the coloured area in the centre of the eye, lacks sufficient pigment to screen out stray light. The light which normally enters through the pupil, the dark opening in the centre of the iris, can pass through the iris as well for someone with albinism. Neither do the nerve signals from retina to brain follow the usual nerve routings. This unusual routing probably reduces depth perception and hinders both eyes from working well together. Since a minority of people with albinism do not appear to lack a normal degree of pigment, it is these visual problems which most characterise albinism. A standard test for albinism is an eye test, the result of which can allow someone with albinism to be registered as blind or partially sighted. But it is important to note that the definition of blindness here is about significantly lowered visual acuity and distance vision, and not about the lack of useful vision.

An encouraging statement which is often made by the Albinism Fellowship is "that the worst the vision can be is on the first day of life". In other words, the visual loss is a static and, to a limited extent, correctable condition. However, the abnormal development of the eyes as described briefly already leads to various other practical effects and we outline the main ones below.

One effect is nystagmus. This causes the eyes to move rapidly from side to side and sometimes up and down as well. Because the brain adapts to this movement, there is no perception of movement in the image seen by the person with albinism, just as the loss of detailed vision gives no sense of blur.

Muscular imbalance within the eyes may, for some people, cause a squint and also causes someone with albinism to use each eye separately rather than together. People with albinism therefore lack binocular vision but can adapt: the image seen is not seen in double vision. Photophobia is also a feature. Lack of pigment within the eyes causes too much light to enter them, making bright light very uncomfortable and causing glare. Wearing tinted lenses and a cap helps to reduce this glare.

Extreme far-sightedness or near-sightedness and astigmatism are also common effects. In such cases, the surface of the eye is not spherical and this causes distortion in the seen image. Again though, correction with lenses can greatly improve these aspects of the condition.

How much pigment do we require when the optic system is developing in order to assure the correct optic nerve routing and complete development of the fovea? The answer to this question is currently unknown but future research on the differential effects of varying amounts of pigmentation may help to define a threshold for the normal development of the optic system. This in turn could yield a therapeutic intervention for albinism.
At present, we know that foveal development continues to occur in humans for several months after birth but that for infants with albinism, this development proceeds at a much slower rate. It is possible that in future, the signal which causes this can be isolated and then mimicked in the developing eye of the infant with albinism to stimulate foveal development and increase visual acuity.

Prevalence Rates

Albinism is present within all ethnic groups and populations. In the UK, about 1 in 17,000 people are born with some type of albinism while in the USA and Australia, estimates vary between 1 in 15,000 and 1 in 20,000.
Prevalence rates can vary considerably though by type of albinism and type of population. For most populations, OCA1 occurs in about 1 in 40,000 people. The rate of carrying an

albinism gene is more common. About 1 in 70 people are unaffected carriers of a gene for OCA.

For the most common type of albinism, OCA2, prevalence ranges from 1 in 2,000 to 1 in 5,000 in Sub-Saharan African countries, as reported in some studies (e.g. Kromberg and Jenkins, 1982; Okoro, 1975). Sometimes this is linked to specific tribes such as the Tswana, a tribe which has encouraged marriage between cousins for generations (Small, 1998).

In North America, some Native American prevalence rates are very similar to this. Prevalence in Navajo Native Americans for instance was recently estimated at between 1 in 1,500 and 1 in 2,000. This is apparently caused by a Navajo specific gene deletion originating several hundred years ago in a single founder (Yi et al, 2003). This relatively very high prevalence rate actually increases for some central Native American populations, rising to 1 in 125 Kuna Native Americans of Panama (Guidotti and McLean, 2003). By contrast, prevalence within African Americans is about 1 in 10,000 and only 1 in 36,000 in Caucasian Americans (see e.g. King et al, 1995).

By contrast to the entire prevalence range above, the prevalence of X-linked ocular albinism (OA), generally speaking, is only about 1 in 50,000. OA makes up about 10% to 15% of all cases of albinism. We also briefly mentioned HPS above. This is a very uncommon type of albinism but in Puerto Rico where it is quite common, the incidence rate is 1 in 2,700.

We should also note that this increasingly accurate estimation of prevalence rates need not solely remain a purely scientific enquiry. It can lead to initiatives which will hopefully start to impact people's lives in a very positive way. Patricia Lund's (1996) research is a case in point. In the mid-1990s, Lund undertook a survey of 1.3 million children in Zimbabwe and from the results, was able to calculate an OCA prevalence rate of 1 in about 4,700. She also discovered a much higher rate (1 in 1,000) in the minority Tonga ethnic group who live in northern Zimbabwe (Lund et al, 1997). Affected subjects suffered many health and social problems.

However, later and from this new evidence base (Lund, 2001), she also got schoolchildren with albinism to complete a self-report questionnaire covering health, education and social situations. From these findings, she was then able to highlight the very great need in southern Africa to counter the major health problems of the people as well as the prevailing myths, misconceptions and fear within their communities. A management programme should promote the health and education of these children and encourage them to manage their own practical situations to do with low vision and lack of pigmentation. Over the last few years, Lund has been working with the Albinism Fellowship and Positive Exposure in southern Africa on a number of school-based initiatives to this end.

Skin Issues

People with albinism tend not to tan and so they burn very easily when they are exposed to the sun. They must take care of their skin to avoid the risk of burning and this applies whatever the weather. Most people with albinism are already aware of this propensity to burn in the sun but are recommended to use a high factor ultraviolet block sunscreen on all exposed areas of skin. Prolonged unprotected sun exposure should be avoided and people should keep in mind that most ultraviolet rays are present between 10a.m. and 2p.m. or between 11a.m. and 3p.m. British Summer Time.

There is an increased risk of developing skin cancer so a good skin care regime needs to be applied from an early age. Children can be encouraged to wear hats which are fashionable and attractive. Hats with peaks can also shade from bright light and glare. For a list of skin care products such as UV deflective swim/ action wear, sun hats and 'sun smart' products as well as main suppliers, why not have a look at the useful addresses section of the Albinism Fellowship's 'Sun and Skin Protection Factsheet', available on their website.

The Albinism Fellowship in the UK is not aware of any cases of people with albinism experiencing any form of skin cancer. This is undoubtedly because most people have taken care in the sun over many years. In fact, insurance companies in the UK are increasingly recognising this by lowering their insurance premiums. It is very regrettable that people with albinism in developing countries often have complete lack of access to affordable skin care products.

Maximising vision, maximising inclusion

As an introduction to maximising vision, we recommend that readers consider Barbara Käsmann-Kellner's recent paper available on the Albinism Fellowship's website. This paper describes in detail the kind of corrections to low vision readily achievable by people with albinism if they obtain the right prescriptions and apply them in the use of glasses or contact lenses. Retaining for the moment her use of the German system for describing visual acuity, one of the examples she gives is of two people with short-sightedness or myopia, one with "healthy" eyes and without albinism, and one with albinism. The same degree of myopia leads in her particular comparison to a visual acuity of 10% in the former and 5% in the latter. With correction though, the person without albinism sees at 100% (i.e. 6/6 vision) while the person with albinism sees at 20%. This is important in itself just from a functional perspective but lenses can also include further adjustments such as 80% absorption (tint) for outdoors use to reduce sensitivity to light and glare. So it is essential that adults and children with albinism see an ophthalmologist (eye specialist) regularly to obtain the right lens and tint prescription.

Most people with albinism can benefit from using hand-held low visual aids (LVAs) such as magnifiers, monoculars and small telescopes. There is also an impressive range of electronic

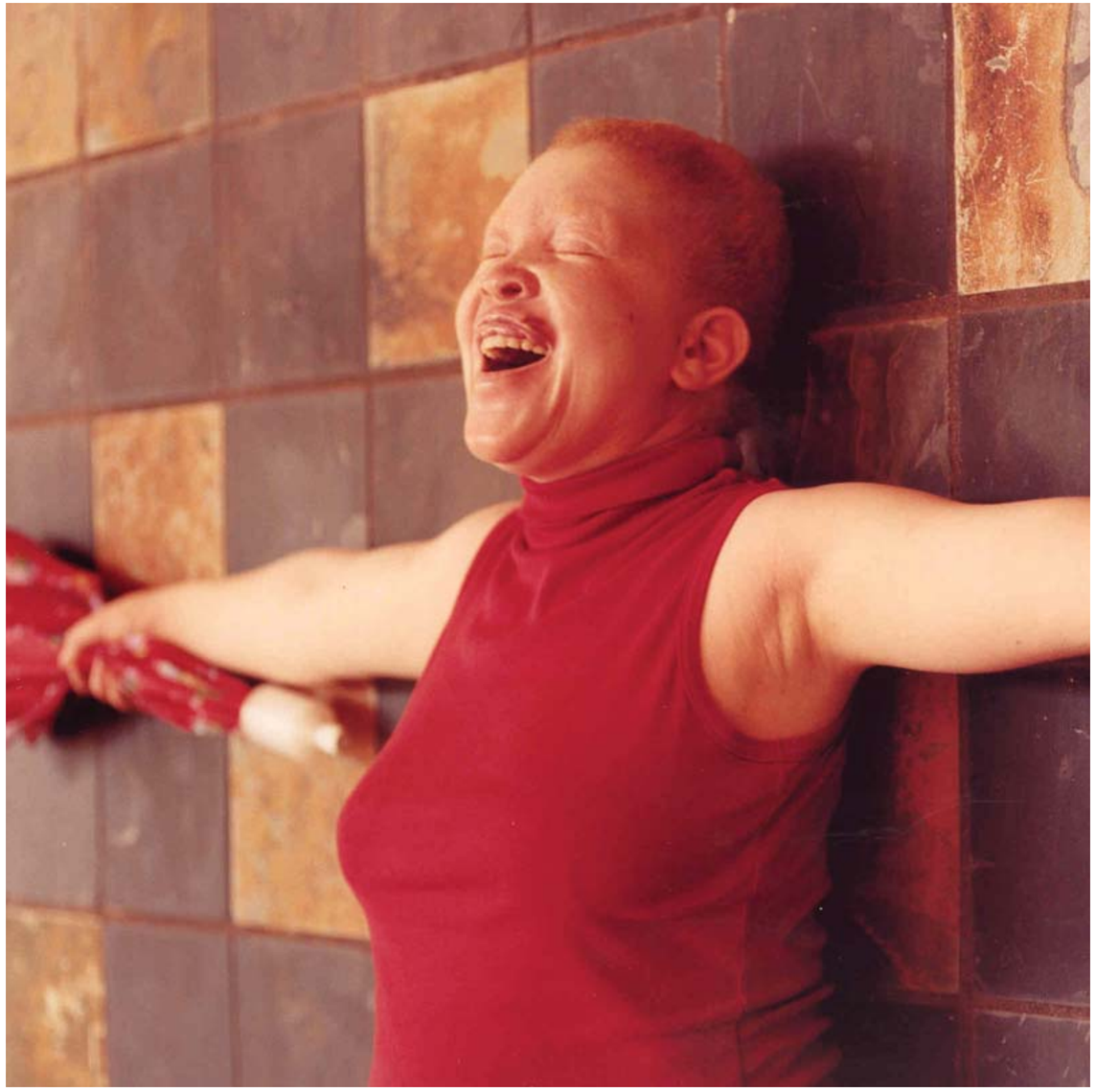
aids available such as video magnifiers, also known as CCTVs. Many people with albinism use mainstream computers with adaptive technology such as a large monitor and/or software to enlarge the display (software such as Zoomtext) or convert it into speech output. High contrast print material will also help, along with an increased size of font.

Children and young people with albinism should be helped to understand their condition and to be open about it. It is also helpful to them if they can meet others of a similar age with the condition since this can help them develop a healthy self esteem. They can also be encouraged to think about and experiment with wearing different colours of clothes. Certain colours can enhance skin tone and hair colour. They therefore enable people to make the most of their appearance and feel good about themselves. All these things can be combined to achieve a feel good look.

Most people with albinism live sociable, productive lives and participate in a normal range of interests and activities. Although following a fast moving ball can be difficult for children, they should be encouraged to try as many sports and activities as possible so that they can find out which they enjoy most. Even the use of the right LVA will enable people with albinism to follow team sports while using a brightly coloured ball will often allow them to actually take part. Some people with albinism go on to become good and very competitive athletes.

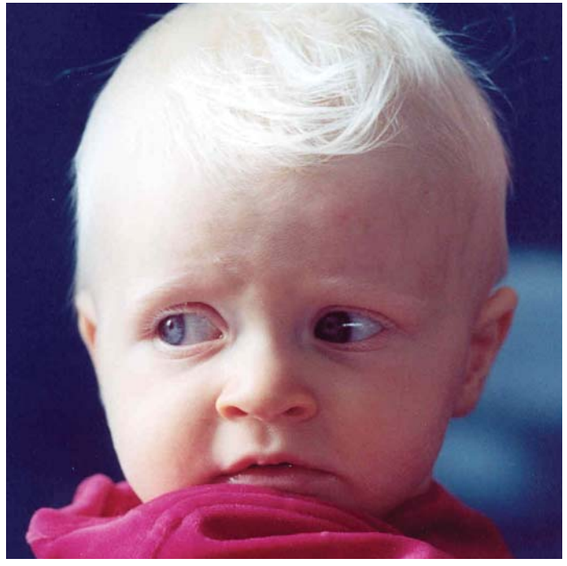
It is also important to remember that melanin only occurs in specific parts and 'tissues' of the body such as hair, skin, eyes and internal tissues and that the skin is normal in all respects other than pigmentation and a greater tendency to be more sensitive to irritations and infections. The absence of melanin in the body does not usually affect parts of the body and physical and other functions which do not involve melanin anyway - such as heart, liver, brain, immune system, intelligence and general well being. Albinism does not cause an intellectual disability or a mental health condition. The incidence of these in people with albinism is the same as for anyone else. However, albinism can cause social difficulties and isolation, particularly in childhood and adolescence and particularly within non-Caucasian populations where distinctive appearance least resembles the norm.

These are some of the basic facts about albinism but what does it actually mean for someone born with and living with albinism? This book seeks to go well beyond issues to do with genetics and inheritance and explore instead the reality of living with the condition. As we will see, there are challenges which people with albinism must face and overcome, some to do with a visual impairment which cannot be completely corrected and some to do with different characteristics in appearance caused by a lack of pigmentation.



Chapter 2

A Chapter for Parents



The purpose of this chapter is to bring together much of the information aimed at parents of children with albinism. Most of it derives from and recognises the two authors Sheila Brown (1999) and Averil Legg (1987) but some derives from organisational websites such as the sites maintained by The Albinism Fellowship and the American society, The National Organisation for Albinism and Hypopigmentation (NOAH).

What Albinism Is Not

One common myth is that "your child is or will be blind". There are other myths about albinism of course but this is certainly one of the most potentially destructive to morale. One of the factors which can perpetuate it is the fact that the majority of people with albinism can be registered in the UK as partially sighted and sometimes as blind. This merely means that people with albinism have low vision, usually correctable to a limited extent. In most circumstances, registration as blind can follow assessed low vision of less than 3/60 against the Snellen chart. That is, at 3 metres they can read what someone with 6/6 vision can read at 60 metres. Registration as partially sighted entails visual acuity of roughly between 3/60 and 6/60. Total blindness or no useful vision is not caused by albinism.

Whether to seek registration as partially sighted is a personal choice. Registration is voluntary and, in the UK, is with social services after an assessment by an eye specialist; usually registration is arranged so that people can obtain entitlement to additional benefits and services. Some people, particularly young people with various types of low vision, not just low vision caused by albinism, choose not to pursue registration because they want to avoid possible labelling or stigma. Many others though are aware that registration can confer certain advantages, including access to benefits and services. Some of these apply to additional expenses incurred simply through daily living and also give entitlement to free or discounted public transport. Other benefits and services can apply in educational settings such as mainstream schools and tertiary education. It can sometimes be easier to access educational support measures once a disability is assessed and properly recognised by the education and funding providers.

In her paper on The Albinism Fellowship's website, Barbara Käsmann-Kellner points out that too many children with albinism wear no lenses at all while others receive them relatively too late. Children with albinism need access to corrective lenses since apart from improved visual acuity with all its practical benefits, refractive errors corrected early on in life may improve visual acuity much later on in life. Using the German classification, she summarises the general partial sight of people with albinism as roughly between 10% and 20% of "perfect" vision, 6/6 vision using the UK term. Exceptions do occur though and can be as high as 50% for OCA1 and 80% for OCA2. Because all children develop their visual acuity through their first six years of life and especially the first two years of life, early use of corrective lenses even for babies and toddlers with albinism can significantly improve final acuity throughout childhood and adult years. Seeing, she asserts, is partly a learning process of the developing brain. Käsmann-Kellner uses a fairly standard scenario of maybe 10% final visual acuity for an older child with albinism who did not access early correction with 30% for an older child who did.

She also stresses the value of contact lenses, producing a good retinal image in all cases. But what if you want to go down the route of contact lenses early in life but the toddler with albinism objects? Käsmann-Kellner puts it like this: "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!" As she says, specifically to the parents of young children, "Enable your 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".

Pat Lund and others have also been working in this area. In their recent study, they worked with 153 black South African children with OCA to establish the degree of improvement in their functional vision achievable through optical correction. They note that optical corrections led to significant improvements in visual acuity across their OCA group (see Oduntan et al, 2002).

Sun and Skin Protection

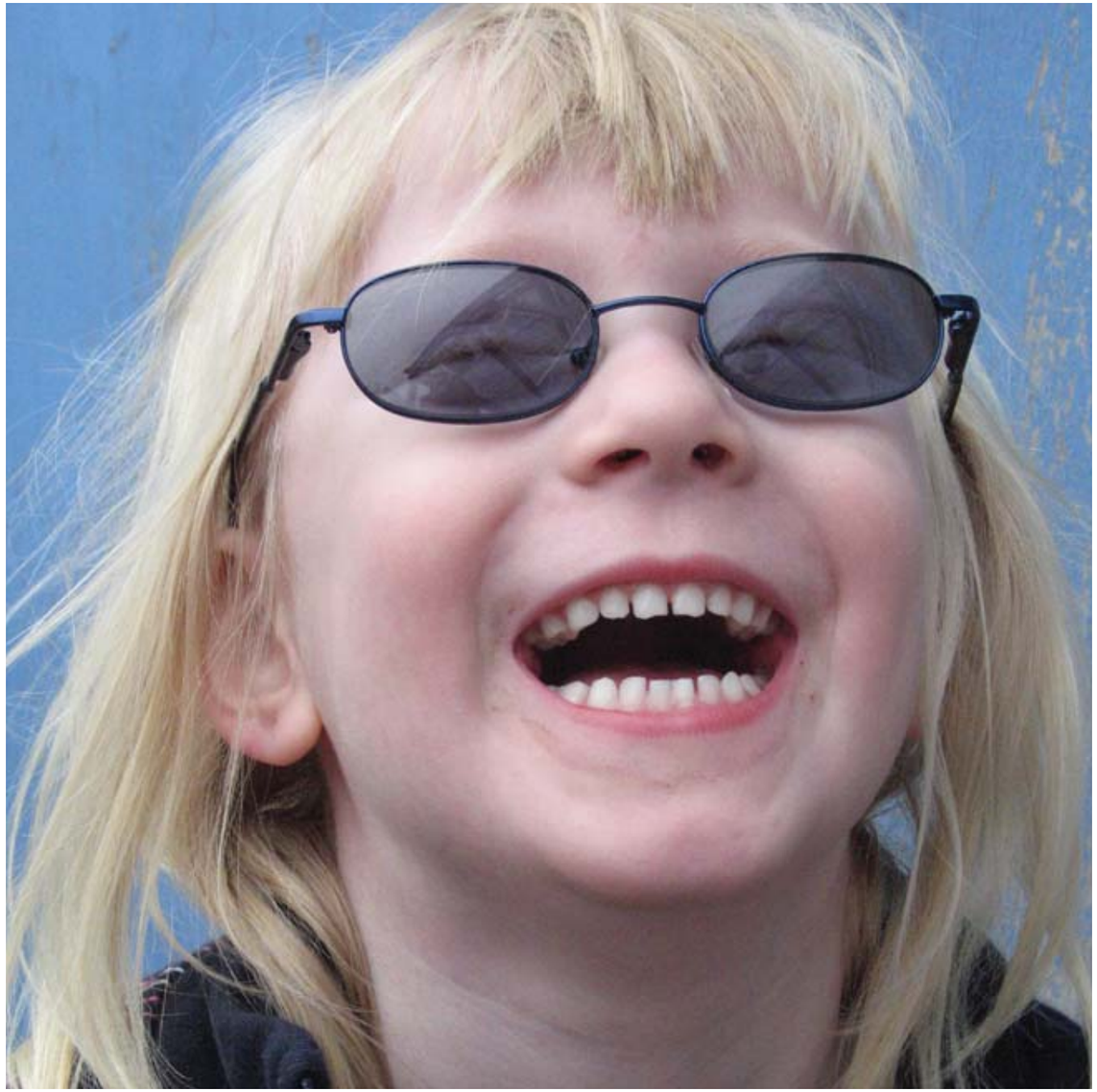
Because melanin is lacking or absent in people with albinism, so too is their natural protection from sun damage. The Albinism Fellowship website and similar sites provide useful, practical information on issues such as Sun Protection Factor (SPF) and Sheila Brown's (1999) book also goes into some detail. Parents should take advice from their GP and/or a dermatologist but generally, the following principles should be applied.

Firstly, you need to take account of the weather and determine the extent to which you'll need to use an appropriate sunscreen. Brown's advice is that you needn't use it every day in the UK but that you need to use it if the weather is sunny, likely to be sunny or even in conditions when there is a lot of cloud but still bright. UV rays can easily penetrate clouds. You should also apply sunscreen if you're likely to be outdoors for a lengthy period of time. Legg (1987) advocates a more rigorous application of sunscreen every day "as a matter of course", reapplying it once an hour and preferably more frequently when outdoors. This more thorough approach is probably influenced by living in Australia in a much more constant, hotter climate. In any event, parents should take advice from a number of sources, develop a sun care regime which is sensible and apply it as diligently as possible.

When you apply the sunscreen, ensure that a baby's or child's skin is covered well, and particularly the areas which burn most easily such as face, ears, neck, and the backs of legs and hands. Be aware though that young children may wipe their eyes with the backs of their hands. Also be aware that babies with albinism under six months in age should not be exposed to the sun since if sunscreen is applied, their relatively permeable skin may absorb too much of the cream's chemicals. If sunscreen is not applied, they will burn.

For older children though, you need to ensure that the cream is applied initially about half an hour before going out in the sun. Some sunscreens take that time for absorption and becoming protective. The sunscreen should be applied evenly across all exposed areas and enough must be applied. The Albinism Fellowship estimates that most people apply only about half the amount needed to protect the skin adequately. You will then need to be diligent and re-apply the sunscreen from time to time, more frequently than usual in hotter climates. But even in the UK and Ireland, some re-application will often be necessary. It depends on the weather and also on the time of year! It is best though to keep children with albinism out of the sun during the highest risk times of day between about 11a.m. and 3p.m. Therefore, it is really important to plan outdoor activities to occur earlier in the morning or after mid afternoon.

You also need to remember that sand, snow and water can all reflect back the sun's ultraviolet rays. These rays can also penetrate water, glass and lightweight clothing used for swimming. Sunlight is also more intense at



higher altitudes. Even in shade or at cloudy times, ultraviolet rays may be reflected or be penetrating through the clouds. Of course, rubbing with towels can remove the protection so sunscreen will need to be reapplied. Another point: if your child or teenager with albinism wants to use a sun-bed, you need to veto that as strongly as possible!

Regarding the best types of sunscreen to apply, ensure that an SPF (Sun Protection Factor) for "Type 1" skin is used if a child has any type of OCA and practically, that is an SPF of 25 or higher. This protects against UVB rays – B stands for Burning – and should have four stars. Also choose a product which gives protection against UVA rays – A stands for Ageing. Because sun care is so important for people with albinism, you should be able to get these creams on prescription. In the UK, if GPs look up "skin" in MIMS, they will find that sunscreen is prescribable for people with photosensitive skin. Also, sunscreens generally have a short shelf life so you need to check the use by date and ideally acquire it new each summer to take on holiday with you.

The above advice about using sunscreen needs to be applied alongside principles to do with use of clothes outdoors. The Albinism Fellowship recommends that adults help to set a trend for children outdoors in wearing hats since these are essential. The best ones are those with wide brims and/or a flap at the back to protect the neck and reduce glare. Peaked caps are also able to reduce glare. For clothing generally, closely woven fabrics offer better sun protection than loosely woven fabrics and some suppliers now sell densely woven 'breathable' synthetic fibre clothes which offer protection with long sleeves in hot weather. There are at least half a dozen specialist suppliers of UV deflective and 'sun smart' clothing within the UK. The Fellowship lists them on its site. Products also include UV protective buggy covers, sunshades for prams, and 'sun smart' beach shelters.

Sunglasses also need some thought. Of the off-the-shelf options, choose those which absorb at least 95% of UV radiation. The wrap-around types can be effective. Some lenses can be photochromic (react to light) and also come with a fixed tint. Due to the qualities in materials used, glass photochromic lenses seem to be able to go darker than their plastic equivalent. Children and adults with albinism can enjoy holidays and outdoor pursuits, even in warmer climates, as long as they take a variety of precautions and take sun protection seriously. There is a growing awareness in the wider population of the need for sun protection. If children with albinism can influence their friends to take more precautions, that's well and good.

Support in Schools

Disability charities in the UK are still unimpressed generally with the level of support in mainstream schools for pupils with disabilities. However, additional support is often available by means of visiting peripatetic teachers with a remit to work with visually impaired pupils. Mainstream schools should

also be willing to implement often straightforward classroom management approaches which maximise inclusion for any pupil with a sight loss. This includes the use of low vision aids (LVAs) and electronic technology often paid for from education authority budgets and made available by the authority. This presupposes that your child's needs regarding access to information are properly assessed and that the assessment is kept up to date.

Difficulties which often arise include accessing whiteboard or blackboard work in class, the small size of print in textbooks, lighting and the general pace of the teaching if any of these other issues are not addressed. For general guidelines, the self-help groups such as NOAH (The National Organisation for Albinism and Hypopigmentation) maintain relevant pages on their websites and Averil Legg (1987) also discusses school-based learning in some detail. Although the technology she mentions has been well overtaken by all the latest low-tech and high-tech solutions, the general points she makes are still good. Education providers and local authorities could also bear in mind that currently in the UK, the Albinism Fellowship offers an interactive training session framed around learning and living with albinism. This session is aimed at mainstream teachers, peripatetic support teachers, and others working in educational environments.

We recognise that much of the above really only applies in the developed countries.

We know that in many developing countries, children with albinism can lack the most basic solutions for school-based learning. Unfortunately, this is often combined with complete lack of access to skin care products. We know too that in many African countries, life spans are curtailed by as many as fourteen years for people with albinism compared to the overall population – because of the much higher prevalence of skin cancers. Although there are a small handful of papers and news reports on this (e.g. Lund, 2001; Lund et al, 1997; Machipisa, 1998; Zinhumwe, 1996), this is a story largely untold.

Because children with albinism appear significantly different to the norm, they are often the subjects of a variety of physical and verbal anti-social behaviours by other children, collectively termed bullying. And quite apart from children with albinism, research has shown repeatedly that this behaviour is common within schools in the Western World. Studies frequently report an incidence rate of roughly 50% of all school children when children are asked whether or not they have been bullied by other children at least once that term (Sharp and Cowie,1998). This level of incidence rises to 80% if children are asked if they have ever been bullied (BBC figures cited by Thomson, 2005). Yet it falls significantly below 50% in relation to more persistent patterns of bullying.

If bullying starts, it can escalate from verbal to physical and from infrequent to frequent until a child is regularly victimised by the