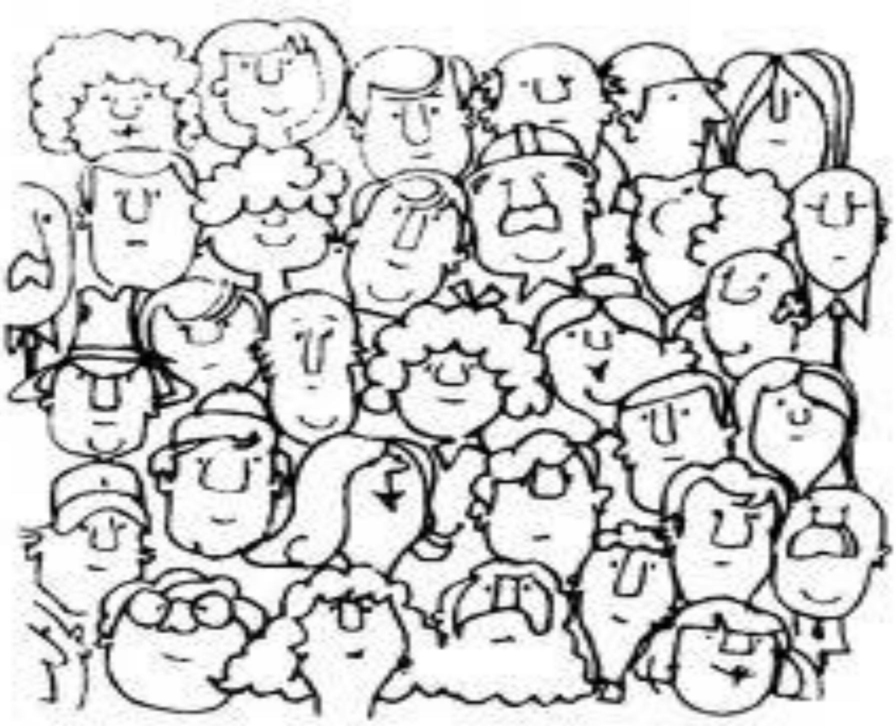
“Eyes Right”

An introduction to living with Albinism in New Zealand…..

By Allen Little



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Contents –

For more up to date information about current happenings visit www.albinism.nz where there is an electronic copy of this booklet
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Interested people are invited to register for and join our monthly SKYPE forum help on the last Monday of each month at 7pm.

Why produce this booklet?

Over the years many hours have been spent talking with and reassuring parents who are concerned at having a new infant with Albinism.

There is so much negative misinformation about that the Albinism Trust feels a need to publish this booklet in an effort to allay anxieties.

We echo the intention of the Children’s Commissioner that "the interests and rights of every child or young person are recognised so each enjoys a safe and secure family life, good health, education, economic and socio-cultural wellbeing plus opportunities to actively participate in matters which affect them.

Albinism Trust wants all Mums, Dads, Siblings, Grand Parents, Uncles and Aunties together with the wider community to enable every success and enjoyment of life for youngsters with Albinism. We believe the priorities are:-

- Nurturing by loving caring parents
- Maximum opportunities to play and learn
- Peer group socialisation
- Environmental Safety and Personal health
- Individual rights to just be a child

Success

- ,Anyone can become more successful in life.
- Individuals can overcome, or work-through, barriers to success.
- Individual success and happiness does not depend on other people.
- Every situation can be improved with stronger personal relationship and work strengths / skills.
- Success is built one skill at a time, from the inside out.
- Albinism should not prevent personal success, achievement or enjoyment of life.

First words:

Often the first words a young parent hears goes something like this.. **’I’m sorry to tell you your child has a condition called Albinism…’ or ‘gee your baby has such pale features I think he/she is an Albino..!’** There’s hypersensitivity around words like “Albino” which does little to the understanding of “Albinism”. People get tied up in what they think is a derogatory description.

Albinism is not something to be ashamed of or embarrassed about but sadly many people are uncomfortable and develop negative thoughts or feelings about this unavoidable condition.

Research has confirmed very few doctors, nurses and other health professionals have had training about Albinism. Many health professionals feel awkward and uncomfortable because they have little knowledge and experience dealing with variations from the norm. One of the most intimidating things young parents encounter are the words used to describe what others think or feel about an infant. Whether it’s a well-meaning friend, neighbour, relative or a health professional their utterances are probably based on scant knowledge or experience. The reality is there is little which can be done about the fact. A child with Albinism is simply that ‘a child’ and should be treated as any of their peers or siblings.

- **If you have an Albino baby – love them**
- **If you know an Albino child – include them**
- **If you meet an Albino teen – befriend them**
- **If you see an Albino adult – engage them**
- **If you are an Albino person – be yourself**

In the kaleidoscope of emotion, identity, hormones and maturation, the added concern of Albinism may be over whelming to some. Adults need considerable sensitivity to a young Albino’s individual hopes and aspirations in order to positively support development and self esteem.

What is Albinism?

Albinism is an inherited condition where normal pigmentation is absent. It’s seen across all living species. People with albinism have little or no pigment in their eyes, skin and hair. Apart from this they have the same physiology as others and are usually happy healthy people.

There are two main types of albinism:

> **Oculocutaneous Albinism "OCA"** (pronounced ok-you-low-kew-tain-ee-us) is where melanin pigment is missing or in very small amounts in the skin, hair and the eyes.
>
> **Ocular Albinism "OA"** (pronounced ock-you-lahr) is where melanin is mainly missing in the eyes with the hair and skin appearing normal. Possibly regarded as “just very blond” Albinism genetics are both complex and varied. It’s not a case of having done or not done something which determines an individual’s status as a person with Albinism.

Albinism involves a group of inherited conditions. People affected by albinism have little to no pigmentation in their hair, eyes, or skin and have inherited genes which have been altered and do not produce the average amounts of a pigment known as, 'melanin.'

Approximately 1: 17,000 New Zealanders have a form of albinism, which affects people of all racial backgrounds.

Many parents feel a mixture of emotions when they are told their new infant has Albinism. There is often an unnecessary cycle of shame, blame and guilt associated with the diagnosis of Albinism. It’s worth noting children with albinism are usually born to parents who have average eye and hair colour.

A new baby with Albinism can cause real upset amongst some Pacific and other ethnic populations. Many people are not aware they have albinism until it is diagnosed. A real myth about albinism is everyone with it has red eyes; the fact is there are different forms of albinism and the amount of pigmentation in the person's eyes varies from individual to individual.

While some people with albinism do have violet or reddish eyes, the majority are more bluish. Some people with albinism even have brown or hazel eyes. Unfortunately; every form of albinism is associated with vision issues.

Not everyone with albinism has white hair and fair complexion; although most do.

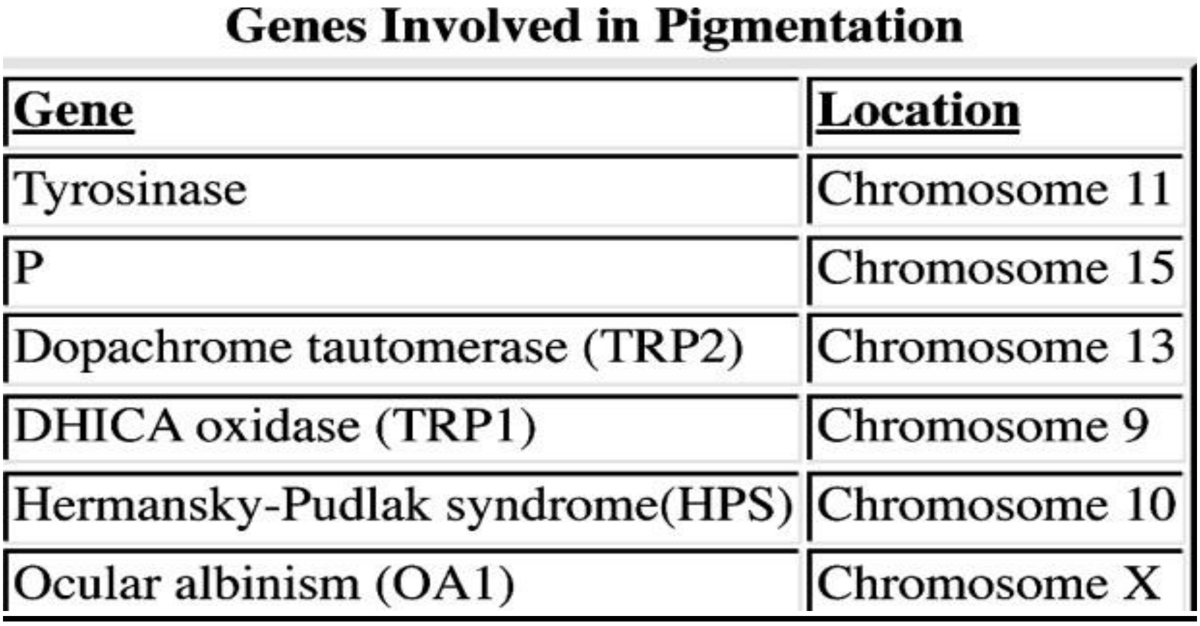
A person with Albinism may have different characteristics in Polynesians or Asian people. They can have dark complexion and ginger hair.

Albinism is caused by inheriting altered genes from parents and these genes do not allow the body to make usual amounts of a pigment called melanin. Melanin is a compound that protects our skin from Ultraviolet (UV) light which causes our skin to tan.

A person is born an Albino and this cannot be changed. They are not sick or inflicted with a disease as some people think. In some countries people with Albinism are shunned and treated quite inhumanely because they are thought to have strange powers. Such extreme prejudice does not exist in New Zealand but is in Oceania. There are many false notions around colour.

The human eye normally produces enough pigment to colour the iris blue, green or brown and lend opacity to the eye. In photographs, those with albinism are more likely to demonstrate "red eye," due to the red of retina being visible through the iris. Lack of pigment in the eyes also results in problems with vision, both related and unrelated to photosensitivity.

People afflicted with albinism are generally as healthy as the rest of the population, with growth and development occurring normally. Albinism by itself does not cause mortality, although the lack of pigment which blocks ultraviolet radiation increases the risk of melanomas and other problems. This Chart shows the Genes of the pigment melanin which is lacking in people with Albinism.



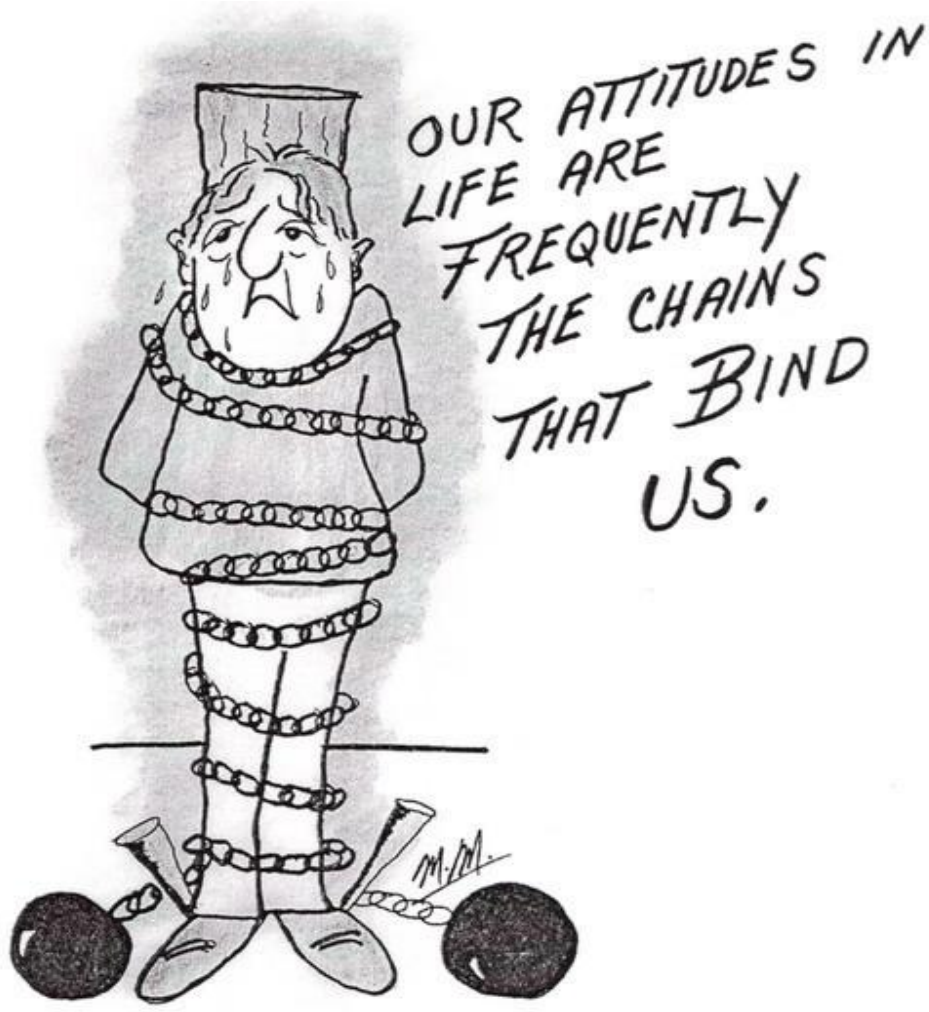
Genes Involved in Pigmentation

Gene	Location
Tyrosinase	Chromosome 11
P	Chromosome 15
Dopachrome tautomerase (TRP2)	Chromosome 13
DHICA oxidase (TRP1)	Chromosome 9
Hermansky-Pudlak syndrome(HPS)	Chromosome 10
Ocular albinism (OA1)	Chromosome X

Most forms of albinism are recessive, which means a child inherits one abnormal gene from each parent. Most children with albinism are born to parents with normal pigmentation. One in every 75 people are carriers for albinism.   A carrier is someone who has one abnormal gene and one which functions normally.

Because the functional gene overrides the abnormal one, these people do not have albinism themselves. However, they are still able to pass the abnormal gene on to their child. This type of inheritance is called “autosomal recessive”. When two people are carriers of the albinism gene, they have a one in four chance that the child will have albinism, one in two chance that the child will not have albinism but be a carrier and a one in four chance that the child will neither be a carrier nor have albinism. Simply put, DNA is a molecule which carries genetic information or instructions telling our bodies how to function and develop.

Albinism does not prevent success but attitude does



Albinism does not affect physical or mental development. All the ages and stages of living follow the usual pattern. People with albinism don’t have developmental or cognitive problems. Many albinos mature to live successful family lives with numerous and diverse personal or professional accomplishments. They are the same as everyone else raising families, enjoying hobbies, and interests, laughing, crying just as their friends, neighbours or acquaintances do.

In general many people can come up with all sorts of reasons why they should not do something. The three keys to enjoyment are energy, imagination and opportunity not ones Albinism.

With a bit of common sense, ingenuity and lateral thinking most people with Albinism can, and do, enjoy many recreational activities. Albinism should not prevent full participation and equal opportunities in the pleasures of living.

Some people with Albinism do manage to pass the Drivers' Licence Test and own motor vehicles but many others are legally blind because their visual acuity is not great. Transport and getting about is one of the big challenges for people with Albinism who are sight impaired.

Effects of Albinism:

There are four ways in which albinism affects people:-

1. Vision impairment
2. Skin protection
3. Hair colour
4. Social stigma

Often new parents worry when they can't contact a competent health professional for reassurance and advice. There is a **Nationwide Helpline** available and calls to it are free within New Zealand from a cell phone or landline. Call **0800 611-116** if either a child or yourself is feeling unwell and you're not sure whether you need to see a doctor when your own medical practitioner is not available. A person with Albinism is not a "sick" individual or in need of other than normal everyday medical care or attention. Because there is no cure for Albinism, all that can be done to help is to enable living, recognizing the broad spectrum of individual differences, options and choices which everyone has.

Vision Impairment:

Depending on the type of Albinism a person has and how well eyes have been cared for determines the level of vision impairment. Regular eye care assessments will help determine general health of the eyes.

As with any other person, it needs to be understood a wide variety of conditions can develop and affect eyesight over and above Albinism. For example the person who is Diabetic would want to be aware how that condition can affect the eyes.

NOTE: There are many causes of headache and it's important to ensure all options are considered by a competent medical professional

Many people with Albinism have "low vision" and hold things up close to see them better. Low vision is when, even after interventions like glasses, people have difficulty distinguishing objects and / or distances.

People with low vision can be helped by simple inexpensive changes to their environment or using specially made devices. Eye-care professionals measure eyesight against recognised standards based on what most people are able to see on a standard eye-test chart. The person with Albinism is affected by how much melanin is present during the development of the eyes and their tolerance of light or glare. Many people with Albinism squint their eyes and peer in order to see. This can cause stress and headache discomfort or fatigue. Headaches are not uncommon amongst people with Albinism and should be discussed with a Registered Medical Practitioner. Headaches are a physical response to light and glare, not simply stress and anxiety. The importance of having a long term involvement with a competent eye-care professional who understands and equips for success can not be over stated.

People with Albinism should ask questions and be given the information they want and can understand. With competently prescribed low vision aids and appliances the person with Albinism will usually perform daily tasks with comfort and competence.

A low vision assessment is an important consideration and can result in provision of aids or appliances which greatly enhance enjoyment of life. Real care should be taken to avoid being over supplied with sophisticated technologies which are underutilised and soon outdated. Some electronic technologies can be very expensive and may prove to be unnecessary in the big picture.

Responsibility for looking after the eyes is the onus of the individual. For comfort's sake it's wise to wear "transition" lenses which filter glare. Most people with Albinism are quite significantly visually impaired but manage every day and familiar things because they learn to live with what they have rather than the converse. Most people with sight loss do the best they can where they are at.

Much of what a person does and achieves depends on attitude and expectation. If the environment is poor and disorganised then personal comfort and productivity may be affected.

It's hard to understand or explain what is seen as it's not simply about blurry vision, big or small, distance or proximity. They see colours just like usual vision but find small detail hard to make out. The eyesight of a person with Albinism is hard to explain and equally hard to conceptualise. Unless you have had it there is no way of knowing what 'normal' vision is like. The person with Albinism just gets on with living and doing what's needed to be done. This may seem like repetition but the key to getting on in life is having competent on-going assessments aimed at realistically equipping the individual for success and safety.

Assessment by Low Vision specialists will involve discussions around your lifestyle, hopes, dreams and aspirations while matching optics to enable and help in diverse situations.

Promotion of accessible and affordable Low Vision services is a priority for the Albinism Trust.

For help with or information about **Low Vision** please contact our colleagues at **Sight Loss Services New Zealand** www.sightloss-services.com Phone 0800 555 546_or the **Blind Foundation** www.blindfoundation.org.nz on 0800 24 33 33.

Looking at Low Vision

Most people with Albinism have an awareness of living with Low Vision. The early assessment of everyday living and how enjoyment of life is impacted by Low Vision are matters which require realistic assessment by a competent Professional. An extensive functional history looking at what is required in order to enable best use of residual vision will be taken.

The assessment will take into account such matters as vision to read, functioning in the kitchen, glare problems, travel vision, the workplace, television viewing, school requirements, etc. It will also include a careful review of your ocular and medical history.

Preliminary test may include assessment of ocular functions such as depth perception, colour vision, contrast sensitivity, curvature of the front of the eye. It will involve careful measurement of the visual acuity using low vision test charts followed by low vision refraction. Many members of the **NZ Association of Optometrists** take a special interest in 'Low Vision' and have a commitment to high quality eye health care for New Zealanders.

Contact NZAO

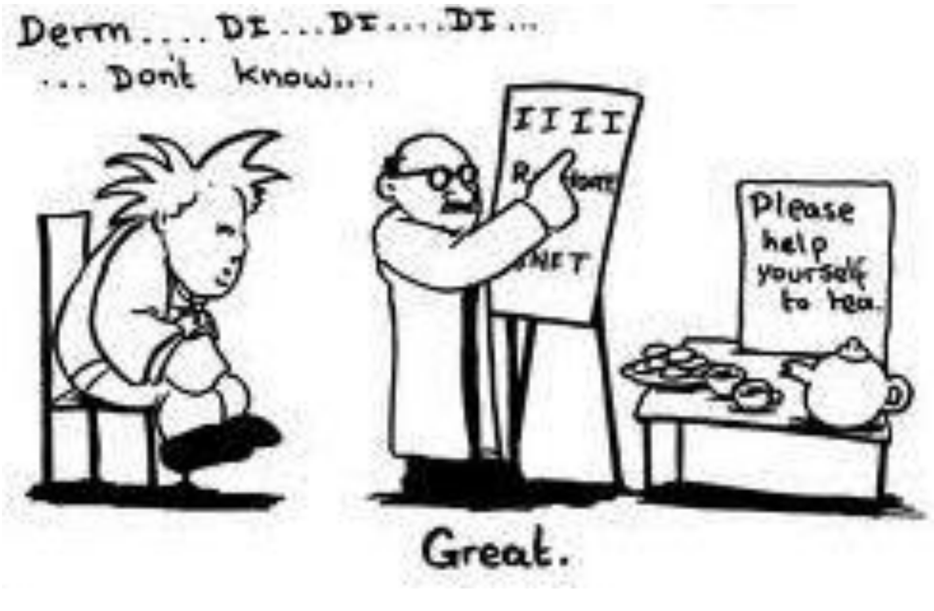
New Zealand Association of Optometrists
PO Box 1978, Wellington 6140, NZ
Telephone: 0800 439 322 WEB: www.nzao.co.nz

The NZAO membership comprises some 94% of the practising Optometrists and are usually accessible in local communities. Opticians and Ophthalmologists with an interest in Low Vision will have an awareness of the whole of life implications for Albinos living with vision limitations.

The eye care Professional will have an ongoing conversation around how your condition might affect your vision and what can be done to enhance or protect your vision. Independent living aids may be suggested to fit specific problems. Effective Low Vision care is not just about providing some device or apparatus which looks impressive. For the person with Albinism It’s about enabling functionality.

The low vision examination is quite different from the basic eye health and refractive examination routinely performed by primary care optometrists and ophthalmologists. It involves some coaching around what to do if and when…!

The Low Vision assessment is very personal and aimed at enhancing daily living. The examination begins with an extended case history including a chief complaint, any current problems, and treatments of their condition. Additionally, it includes a careful medical and social history. The emphasis of this history is to understand how the individual is functioning and what needs they have.



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Sight and eyesight:

It’s important from earliest years to have a competent eye assessment and examination. Not everyone who makes or prescribes glasses is experienced in assessment and care of patients with Albinism. There are some excellent eye-care professionals and we encourage a long term relationship with such professionals.

Your family doctor should be able to advise on the availability of, and access to, competent eye-care professionals.

There is a lot of misinformation around and it’s important to have reliable, trustworthy advice from someone who knows both the patient’s needs and market availability.

Albinism and Vision Issues:

Many people can be helped to use their limited vision with properly designed and inexpensive optical aids. A portion of the population with albinism is Legally Blind although they still have the ability to read. The term "legally blind" is one which many ask for an explanation of. Blindness does not mean a total black out.

To be eligible to receive services from the **Blind Foundation,** an assessment is made by a medical professional such as an optometrist or ophthalmologist (eye- specialist).

Llegal blindness means a person has less than 3/60 sight in the best eye, with corrective aids, or horizontal fields of less than 20 degrees. This means you would only be able to see an object at 3 metres where a person with normal vision could see from a distance of 60 metres. Normal vision is 6/6.

No one is too young or too old to become a Blind Foundation client. It’s something which should be considered and is not an admission of defeat. Many clients are not completely blind and have some useful vision; however all must meet the registration criteria.

Albinism Trust is happy to support and advise any person with Albinism interested in being a client of the **Blind Foundation**. New Zealand residents who, in the opinion of a registered ophthalmologist or optometrist, have a visual acuity not exceeding 6/24 in the better eye with corrective lenses, or serious limitations in the field of vision, generally not greater than 20 degrees in the widest diameter in the better eye, is eligible for registration. Paper work needs to be completed and this includes a report on visual acuity.

Children and young adults must also have a referral from an ophthalmologist or optometrist.

All children and young adults (21 years of age and under) who are currently registered with Visual Resource Centres, regardless of their degree of vision loss, may apply to become a **Blind Foundation** client.

For further advice or assistance around issues to do with blindness, please feel free to telephone **0800-243333** where Blind Foundation staff are pleased to help.

There are a variety of other diagnoses which may be attributed to a person with Albinism including :-

- ~ Astigmatism.
- ~ Far-sighted or near-sightedness.
- ~ An iris with little or no pigmentation.
- ~ Photophobia or sensitivity to bright light and glare.
- ~ Nystagmus, or regular horizontal back and forth movement of the eyes.
- ~ Foveal hypoplasia, under developed retina prior to birth and during infancy.
- ~ Strabismus, or muscle imbalance of the eyes (lazy eye).

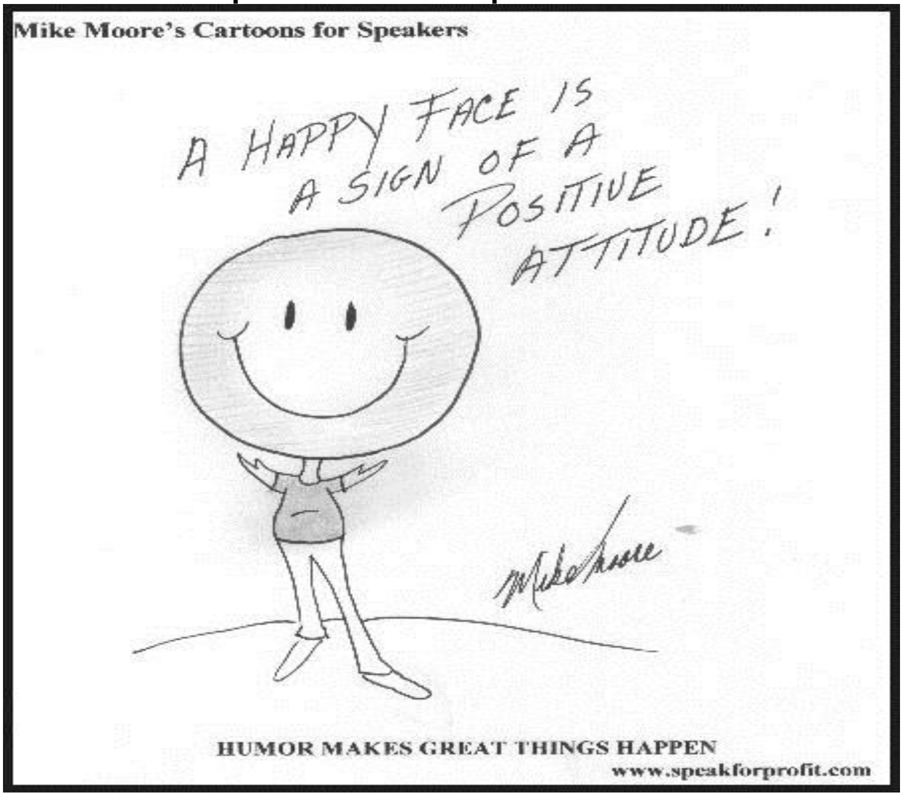
One of the best things that can be done for an infant with Albinism is to have the child comprehensively assessed by an ophthalmologist who is willing to commit to long-term care as the eyes mature.

It’s important to **enable** Children at every stage of development beginning with their first eye examination.

Modern lenses can be custom designed to help with daily living requirements. Glare is an issue for people with Albinism and this can often be managed without inconveniencing others. It’s important that an adequately lit and comfortable environment becomes a priority for everyone. People with Albinism live within the community and not apart from it. There will be times when common sense ‘give and take’ needs to be the underlying principle in shared settings.

The use of tinted contact lenses or sunglasses can help outside and shades or curtains will make things more comfortable indoors.

Letting the person with Albinism organise their own work area settings is useful. Never make assumptions about what is or is not useful. Someone with Albinism may have particular personal preferences which suit in some circumstances and not in others. A light source shining over the person's shoulder instead of in front of them for example, is often preferable.



Optical Aids:

There are a number of different optical aids a person with Albinism can use depending upon how they use their eyes at work or during other activities.

Do not be tempted to use the sophisticated and expensive applications which many commercial enterprises want to sell you. Often their only interest is in how much they can make from customers being sold sophisticated technologies.

Bifocals with strong reading lenses or prescription glasses as well as contact lenses, might help.

There are also hand-held magnifying devices, or even small specially-constructed telescopes that some people with albinism prefer to use.

Screen magnification software or hardware can help while using a computer. To complement magnification software there is also available an inexpensive Kiwi innovation in the form of an illuminated **“Big Print keyboard”** which makes word processing more comfortable. This LED-illuminated ‘Big Print Keyboard’ is available in New Zealand at **www.bigprintkeyboard.co.nz**

Bi-optics are glasses with small telescopes mounted on, in or behind a person's regular lenses so they may look through either their glasses or the telescope. Newer bi-optic designs use lenses that are both smaller and lighter in weight.

Ophthalmologists and optometrists who have experience in working with people who have low vision might recommend different optical aids.

Vision Clinics should provide a person with Albinism with any vision aids on a trial or loan basis, as well as any instructions for using them.

Fixed light examination should be kept to a minimum so to avoid stressful discomfort.

A competent eye professional will be aware of astigmatism and nystagmus plus pathologies associated with Albinism. The objective of any eye examination would be to find a patient’s maximum usable vision to enable safe and successful living.

Never hesitate to ask your doctor questions and to get answers you understand. This is a basic Health and Disability right in New Zealand to receive this information.

As a parent it’s important to observe the wide variety of function and limitations without drawing unnecessary negative attention to differences. At all times safety and welfare are paramount as children recognise their own capabilities and explore their world.

Simple things help:

Most people with Albinism:-

- wear a cap or sunhat to shade their eyes
- use small hand monocular lenses for mobility
- have discrete hand magnifiers to read
- prefer to write with black ball pens
- benefit from large print and clear fonts
- look closely at their work
- have close personal body space
- like curtains to reduce or shade glare and excess light
- use the telephone as a tool
- need to be driven rather than drive vehicles
- enjoy diverse interests and hobbies
- have thoughts, feelings and ambitions

Expensive adaptive technology is not always the best or most suitable for the individual. There is ‘no one size for all’ rule when equipping for success or enjoyment. As with everything you buy ask the question, “is it fit for the intended purpose” !

Dangers of Sun:

A person with Albinism does not tan and is prone to rapid sun burn. People with albinism are highly sensitive to UV exposure and have to be very careful not to get sun-burnt as they burn very easily and are therefore at a very high risk of skin cancers. Besides the “Slip, Slop and Slap” regime to reduce sun damage, regular visits to a Dermatologist are wise.

Sun-burn lasts for life

People with albinism have significant impairment of their vision and can be very sensitive to bright light (photosensitive).

Skin Protection: Without melanin to help protect skin from the sun's harmful ultraviolet (UV) light, it burns very easily.

People with Albinism who do not use appropriate skin protection have the potential to develop life-threatening forms of skin cancers..

Use of sunscreen lotions with a rating of 30+ SPF and protective clothing allows people with Albinism to enjoy outdoor activities in the summer.

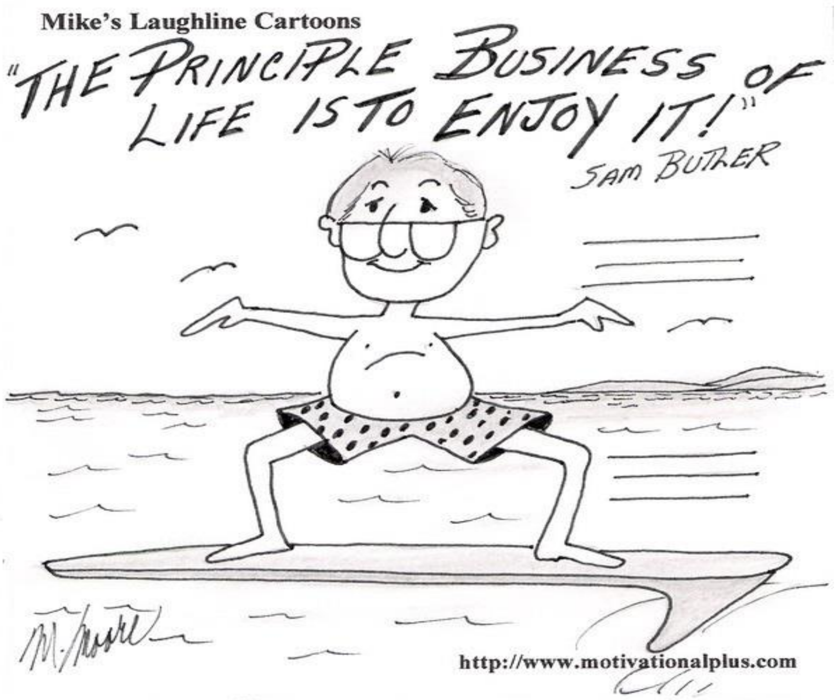
We encourage people to talk to their family Doctor about the best sunscreen to meet individual needs.

There is information on our web site www.albinism.nz about getting sunscreens on prescription.

CAUTION: Not all lotions with high SPF give safe sun protection. Consult your pharmacist. Certain sunscreens are now on the pharmaceutical's list. Your general practitioner simply gives you a prescription which is filled at the local pharmacy.

Common sense is of utmost importance when it comes to protection from the sun's harmful rays.

The old maternal habit of leaving an infant to lay exposed to the sun for a kick and fresh air should be avoided for a youngster with Albinism. Skin damage starts when the skin is first exposed to harmful rays. The sun's rays often penetrate fabrics that garments are made from, but this should not prevent the wearing of attractive and fashionable attire. In common with every other Kiwi, albinos should practise good 'Sun Sense' doing the standard 'Slip, Slop, Slap' (Slip on a shirt, Slop on sunscreen and Slap on a hat!) and stay out of the sun during the times when UV is most intense.



Some people with Albinism enjoy the surf but just not at the time of day when there is the danger of being sunburnt.

Hair Colour:

White hair sure makes a person with Albinism stand out in a crowd. It’s a real issue for many who simply want to blend in as naturally as possible.

Sadly some people take to colouring their hair so they don’t look like a person with Albinism. Large amounts of money can be spent on this vanity trip but it is everyone’s right to be the person they want and to colour their hair if it makes them feel better.

White hair is said to be a real conversation starter and hard not to notice. In their ignorance some people turn and stare at individuals of fair complexion and white hair. This can cause embarrassment and discomfort for the individual.

Whilst elderly people are accustomed to greying and white hair, its usually not something, seen on a child or teenager. Younger people just want to hang out with their friends and not be noticed. Having white hair can cause all sorts of complications for teenagers, particularly when they are sensitive to peer pressure. There are things which go on in the adolescent world which defy interpretation by many adults.

These young women feel good about themselves in spite of their Albinism. They each attest to growing up with supportive parents who made them feel like they could do anything.

As with any cosmetic or image altering process such as hair colouring, these are personal decisions which should be made with informed advice. Professional hair colouring can be expensive and time consuming. In general most people just accept us as we are, complete with pale complexion and eyesight issues.

Social Stigma

What your peers think and feel about you is always of importance. Albinism and it’s features can generate horrendous bias and be disabling.

At one extreme over recent years there have been very sad reports of inhumane treatment of people with Albinism in some African countries. Fortunately we don’t have this horrid extreme in New Zealand, but we still have prejudice and exclusion because of difference.

Some people act quite insensitively towards others who look different, but in reality this says more about them than it does about the focus of their attention.

Thankfully we have laws about discrimination in New Zealand and the vast majority of Kiwis have a healthy and positive attitude toward others who look different.

If discrimination occurs don’t draw attention to it but share issues and concerns with family, trusted friends or the Albinism Trust. Social stigma is based on ignorance and the Albinism Trust is proactive in fostering awareness and positive attitudes concerning Albinism.

Overcoming stigma is one thing, preventing it is another. Stigmatising is a form of bullying and does not belong in a fair, just and inclusive society. It’s a disabling attitude shown toward anyone who looks different or has an affliction where they stand out from what is stereotyped as 'normal’.

Bullying:

Sadly we need to highlight this issue which affects some people with Albinism at various ages and stages of life. It can be subtle and seemingly not of importance but it does need to be taken seriously. The cumulative effect can have a lasting impact on an individual’s esteem and self worth,

Bullying is when someone keeps doing or saying things to have power over another person. It might happen that a person with Albinism can become the victim of unwanted attention. Being called names, saying or writing nasty things about them, side-lining from activities and not talking to them can lead to uncomfortable feelings.

No matter what form bullying takes it is a wrong behaviour which makes the victim feel afraid or uncomfortable.

It's always best to treat others the way you would like to be treated. People with Albinism have the right to feel safe and secure. If bullying is an issue:-

- Move into a well-populated safe area
- Don't retaliate or escalate
- Connect with trusted friends or family
- Seek support and advice from a teacher colleague or family member
- Remain confident and don't be intimidated.

On the right track:

From earliest stages children with Albinism should be encouraged to enjoy living and participate in the educational system. As a baby develops parents will see natural occurrences through their play and exploration.

It is important to know educational support is available right from the start for children who are blind or have low vision.

The Blind and Low Vision Education Network NZ (BLENNZ) has a network of educational services through ought the country and a main base at Homai Campus in Auckland. BLENNZ has specialist teachers called **Resource Teachers Vision** (RTV) who are based in Visual Resource Centres.

They provide educational support for babies through to young people up to leaving school. They visit you in the home for babies, and children up to the age of five at the early childhood facilities. For school age students RTVs will provide their support in whatever school the student is attending.

Their specialist support is to make sure that the educational needs of the child are being addressed, whether a new baby or a student sitting NCEA.

Parents can make a referral to a Visual Resource Centre. A referral will trigger a visit from an RTV who will come out to assess the educational needs of the child, always working in partnership with the family.

To find the contact details for BLENNZ services go to the BLENNZ website: **www.blennz.school.nz**

Tertiary Education:

A number of people with Albinism progress to and enjoy impressive academic careers. New Zealand Universities and vocational colleges are accustomed to helping students settle into higher learning opportunities which lead onto long and satisfying working lives.

Enjoy every opportunity

"Imagination is more important than knowledge. For knowledge is limited to all we now know and understand, while imagination embraces the entire world, and all there ever will be to know and understand."

Albert Einstein

Working:

People with Albinism have become well established and successful in many vocations:- Teachers; Doctors; Lecturers; Clergy; Mechanics; Broadcasters; Musicians; Householders; Clerical Workers; Cooks; Nurses; Storemen; Publishers; Astrophysicists; Lawyers; Psychologists; Bakers; Technicians; Publishers; IT Specialists; Farmers; Accountants; Counsellors and many other similar careers. **Given the right opportunities there is nothing which can prevent an individual from realising and excelling in their chosen work**.

Getting a job:

For a person with a visual disability, finding a job can be a challenge. It's worth remembering every employer is looking for a person who is a comfortable fit for their business. While blind and visually impaired people can do most things a person with full vision can, employers are often reluctant to take someone on who begins with a need for additional accommodation. An employer seeing their big picture needs to be assured that the person engaged will settle in and be productive. Albinism Trust is available to both advise employer's and assist Job Seekers with Albinism if required.

Our experience shows that being job ready is one thing getting a start in a work place is another. We know that if people with Albinism have three key component's they usually succeed in most work situations. Albinism Trust encourages our friends to :-

1. **Become thoroughly prepared with a sound skills related education.**
2. **Have the right attitude about yourself and accentuate capabilities.**
3. **Gather a portfolio evidencing current skills and aptitude.**

Assistive technology has been the cornerstone for pulling many visually impaired people into the job market, allowing them to overcome many obstacles, such as using computers which are considered a key piece of technology in the modern workplace. Employers are taking note how workers with impairments tend to be more loyal as they become familiar with their surroundings and the technology provided for them. All Job applicants must remember it's their role to make a strong, positive and engaging first impression. It’s important to act with integrity and demonstrate both realism and preparedness to work.

Adult life:

Having survived the early years it’s time to take on the adventure of establishing one’s own home and family life. People with Albinism can and do enjoy all aspects of family living. There is no reason why they should not have children. It would be worthwhile having a conversation around family planning matters to be aware about the possibility of having children with Albinism. There is nothing wrong in that. A family doctor should be able to give guidance on questions of genetics and probability. Many different genes can be mutated to cause Albinism. Our genes carry all the data from generation to generation.

Making melanin requires lots of special proteins called enzymes which bind our chemicals.

There is no reason why children with Albinism should not mature to enjoy life with all its rights and responsibilities including parenthood.

Albinism Trust aims to foster capability and enjoyment of life for people with Albinism, their families and friends. We want people with Albinism to feel good about who they are and thrive regardless of the thoughts and opinions of the uninformed.

There are a number of ways to make the world a better place and they all start with ourselves doing the best we can with what we have where we are.

If we approach daily life with positive, respectful and inclusive attitudes everyone will benefit and our shared world will be more congenial.

Many people with Albinism seem to have an ability to rise over adversity and thrive. There will always be those who don't believe in exploring possibilities.

Our world is a place which is rich in opportunities and we all have the responsibility for the choices we make. Encouraging a young person with Albinism to have confidence in their capabilities rather than a focus on their disabilities will help them to get on in life. Nurturing optimistic rather than pessimistic attitudes leads to a sense of enabling.

"Start by doing what's necessary; then do what's possible; and suddenly you are doing the impossible."

St. Francis of Assisi

Useful contacts:

Albinism Trust works in partnership with kindred groups around the world. There is a list on our website **www.albinism.nz**

Blind Foundation
http://blindfoundation.org.nz Phone 0800 243333

Parents Of Vision Impaired
www.pvi.org.nz

Blind & Low Vision Network (BLENNZ)
www.blennz.school.nz

Sight Loss Services Trust NZ
www.sightloss-services.com Phone 0800 555 546

Optometrist New Zealand Optometrist's
www.nzao.co.nz

Albinism Fellowship of Australia
http://albinismaustralia.org

British Albinism Fellowship
www.albinism.org.uk

Albinism US 'NOAH'
www.albinism.org

Pacific Albinism Project Pacific Albinism Project
www.pacificalbinismproject.com

The Vision for Tomorrow
www.visionfortomorrow.org/albinism

Can you help ?

Albinism Trust is a **Registered Charity CC22352** and financed by Donations, Grants or Bequests. All help would be gratefully received. If you would like to make a Donation please send it to:-

Albinism Trust
7 Earl Street
Levin 5510

For advice on estate planning and making a bequest contribution please email:-

albinism@inspire.net.nz