Introduction

My name is Dr Brian Evans. I am 64 years of age, and have albinism. My corrected eyesight is about 6 18 I have spent most of my working life in scientific research. My retirement hobby is gaining a better understanding of my condition and communicating that information to people with albinism (and their families) and to eye care professionals.

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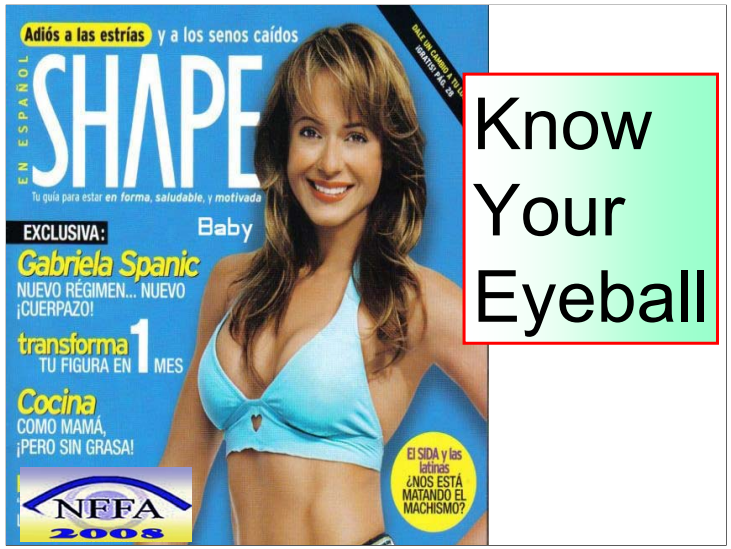
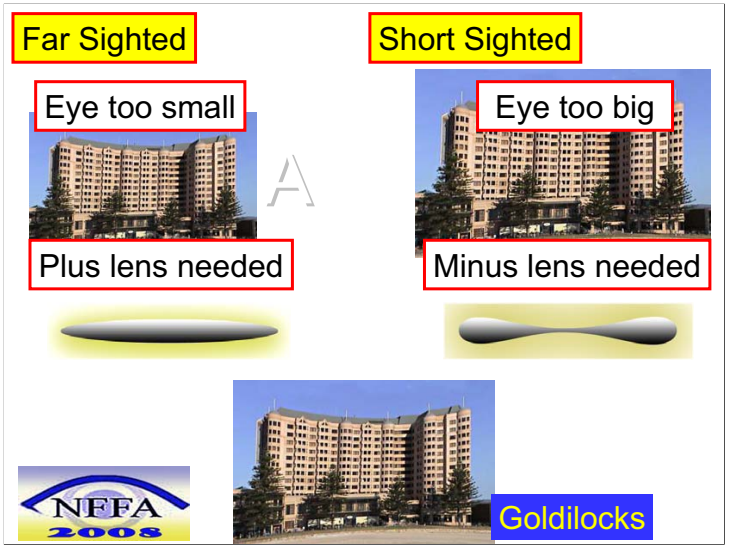


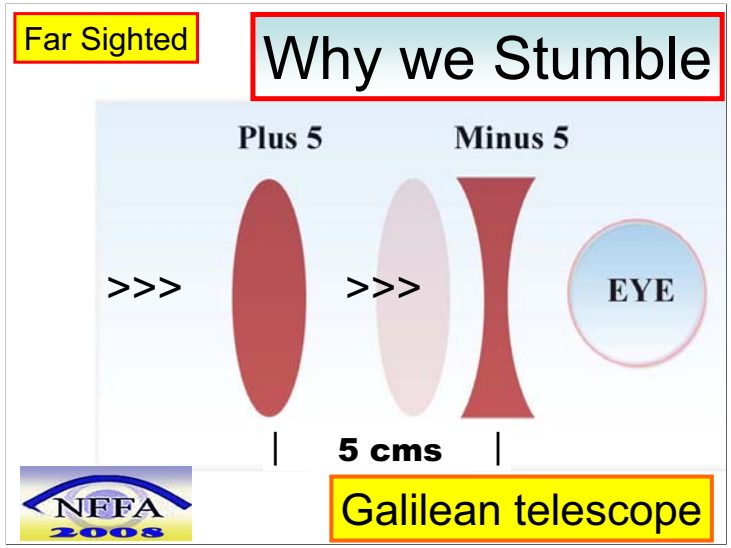
The next part of the presentation will discuss the size and shape of the eye.



The normal adult eye measures about 25 mm from front to back. The front surface cornea and the internal crystalline lens usually have sufficient power to focus a far away object onto the retina – approx 22 mm behind the front surface.

If the eyeball is too small then an extra external glasses or contact lens can be used to add extra focusing power. If the eyeball is too big then a minus lens can be chosen to weaken the focusing power of the cornea.

Most albinos are far sighted – as the result of a small eyeball size.



Far sighted people are prescribed a plus lens to add extra power to their smaller than normal eyeball.

The eye is short of power by say 5 dioptres so a plus 5 dioptre glasses lens makes up the difference.

This forms a simple 2-lens Galilean telescope which provides some magnification (Good News) The Bad News is that there is a trade off between magnification and field of view. Someone wearing high plus correcting glasses will not be able to see where his feet are going – so may stumble on descending flights of stairs.

Short Sighted

Eye too big

Myopia Research

Chinese students are known to be studious – and they are also known to be short sighted.

This is a big problem for the Chinese –

Why does short sight (myopia) happen and how many eye Doc's will be needed to prescribe glasses for maybe 300 million people ?

The photograph shows a school gathering in Hong Kong. Many of the students are wearing glasses. Some are also wearing masks – the photo was taken in 2003 at the height of the SARS outbreak in the Far East.

Close Focus needs a bigger distance between the lens and the film

NEAR

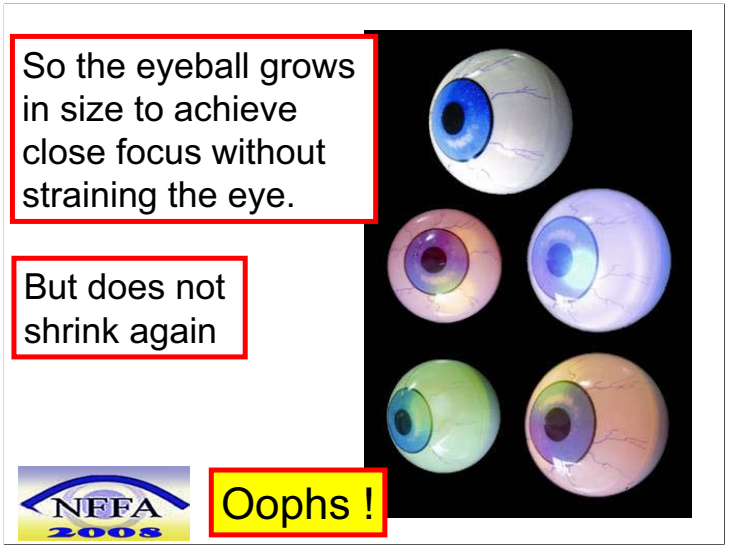
FAR

Focus Ring

A good quality camera (film or digital) may have a chunky lens with a focus ring. Turning the focus ring makes the front of the lens move in and out – thereby placing the lens closer or further away from the film or digital sensor at the back of the camera.

When we focus the camera on something close the lens moves forward so as to increase the distance between the lens and the film.

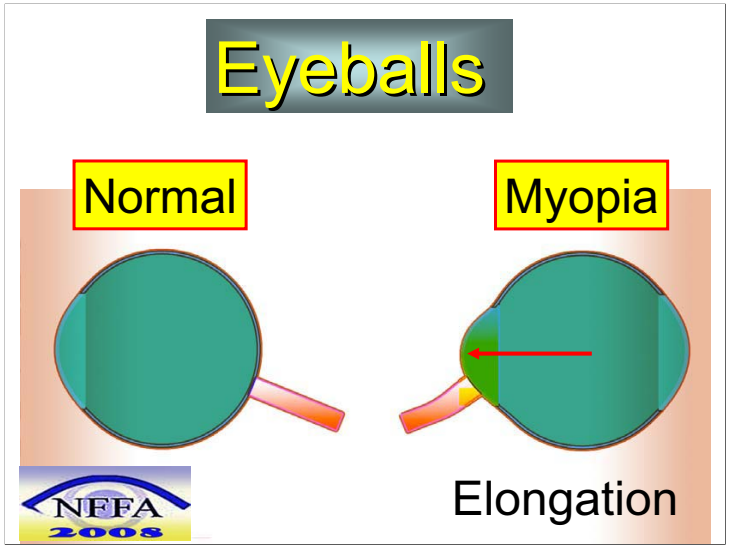
They eye wants to try the same trick.



To read something close up the muscles in the eye have to control the internal crystalline lens that is set about a 6 mm back from the front of the eye.

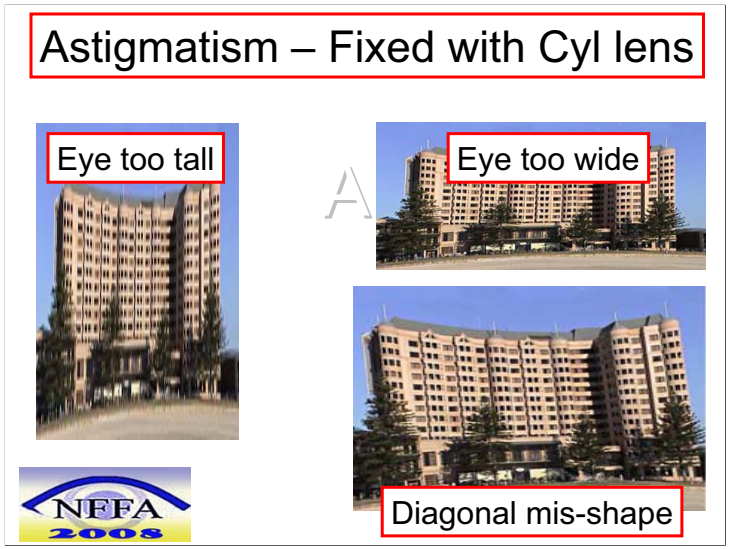
After a while the muscles get tired of all this work. They say to themselves – if the eye was a bit bigger – so the distance from the lens to the retina at the back of the eye was a bit longer - then we wouldn't have to work so hard.

So the eye starts to elongate itself in order to take the load off the focusing muscles.



Short sight (Myopia) often develops between the ages of 5 to 15 years. The eyeball grows in length by up to 3 mm. The growth is usually seen as an extension bulge at the back of the eye rather than an increase in the overall size of the eyeball.

The retina lies within this growth area and may therefore experience more bending than in a normal eye. This extra flexing can lead to problems in later life. People who are very short sighted (more than -10 Dioptres) should monitor periodically the internal health of the eye.

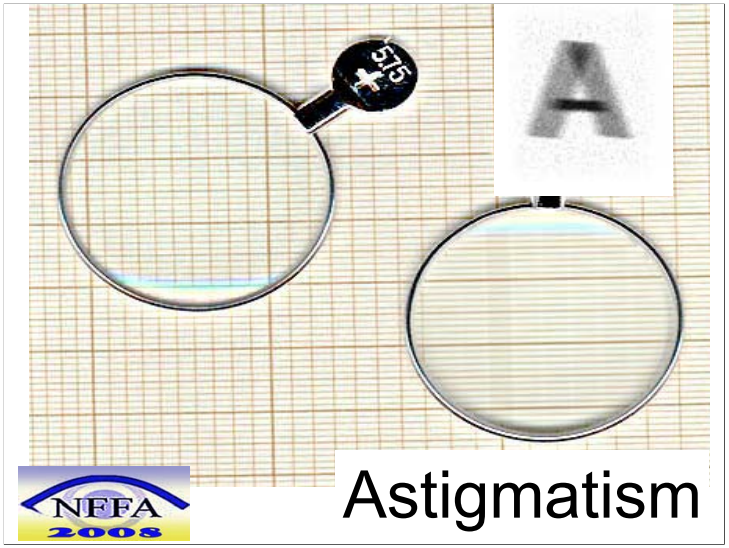


If eyeballs are generally too big or two small then short sight or long sight will result. There is also a chance, however, that the eyeball might be a little bigger or smaller in one direction compared to another.

Such irregularities are not unusual. Focus can be restored by using cylinder lenses as part of the overall glasses or contact lens script.

Most albinos have eyes that are a bit wider than taller. This is termed “with the rule” astigmatism.

When some of you were children perhaps you used a magnifying glass to start a fire or burn your friend’s arm. Do you remember how difficult it was to get the size of the spot really small. Tipping the lens made the spot change shape from a dot to a line.



If the eyeball does not have a round shape then the front of the eye – the cornea – cannot act as a perfect front lens.

Deviations from a perfect shape mean that the lens cannot manage a good focus in all directions at the same time.

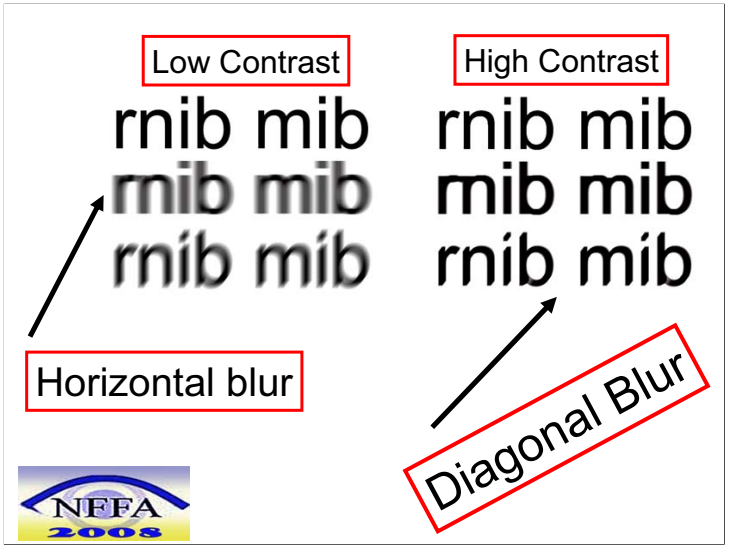
What it can do, however, is to get a good horizontal focus but miss out on a good vertical focus. Or vica versa.

In the left hand part of the slide you can see both horizontal and vertical lines of the graph paper. On the right hand side the horizontal lines are still OK but the vertical lines have blurred and have almost disappeared.

I use a “Star Chart” to check for astigmatism. It consists of 40 spokes of a wheel that each get thicker as they move from the centre.

Someone with good eyesight – no astigmatism – will be able to see all the spokes equally well. For a person with albinism, however, he will probably see the 3 and 9 o’clock areas of the chart fairly well but will find the 12 and 6 o’clock axes a blur.

The eye Doc can (mostly) correct this blurring by prescribing cylinder lenses (cyl lenses) as part of the glasses script.

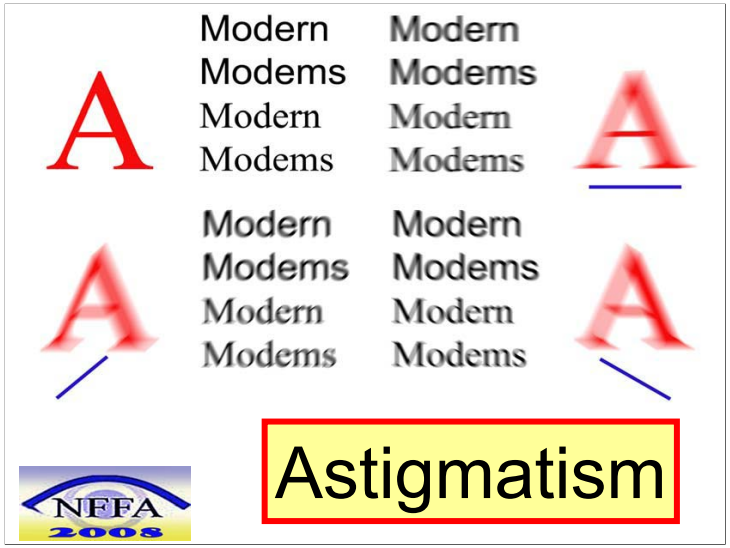


RNIB is the abbreviation for the UK Royal National Institute for the Blind. A few years ago I visited their exhibition and was surprised to see MIB written on some of their posters.

It took me a moment to realise my mistake.

My less than perfectly corrected astigmatism allows the R to merge into the adjoining N so as to from the letter M.

This is a big problem for albinos in which their astigmatism blur is East West. Diagonal astigmatism blur is not so bad – that is why albinos tip their heads to read more clearly.

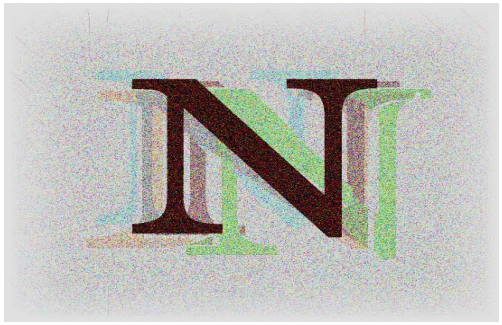


The effect of uncorrected astigmatism is very apparent when trying to read. A poor vertical focus allows the r and the n in the word

M o d e r n to run into one another and form the word M o d e m.

If the astigmatism were to produce a diagonal defocus rather than a vertical defocus then the blurring of the letters would be different/better. If you see a PWA reading with his head on the side you will know that he has uncorrected astigmatism!

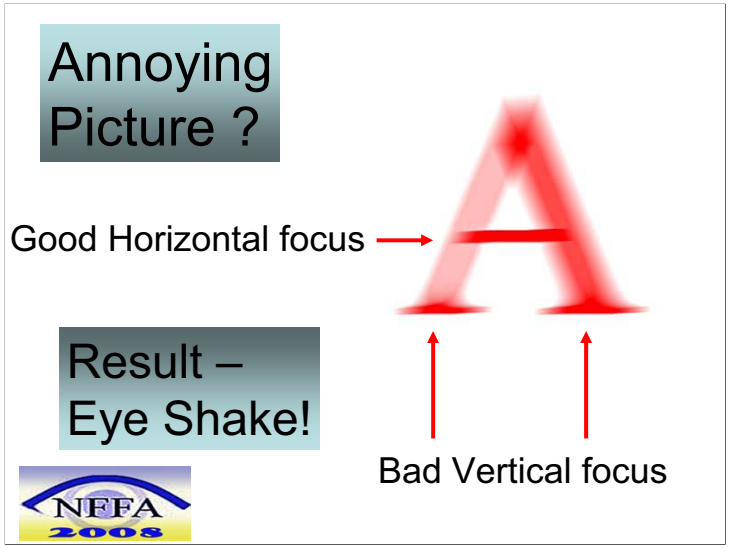
Try to get it fixed with glasses.



Nystagmus

Nystagmus is eye wobble.

Nystagmus can be acquired early in life or later on. There is a big difference in how the brain can handle Early and Late Nystagmus.



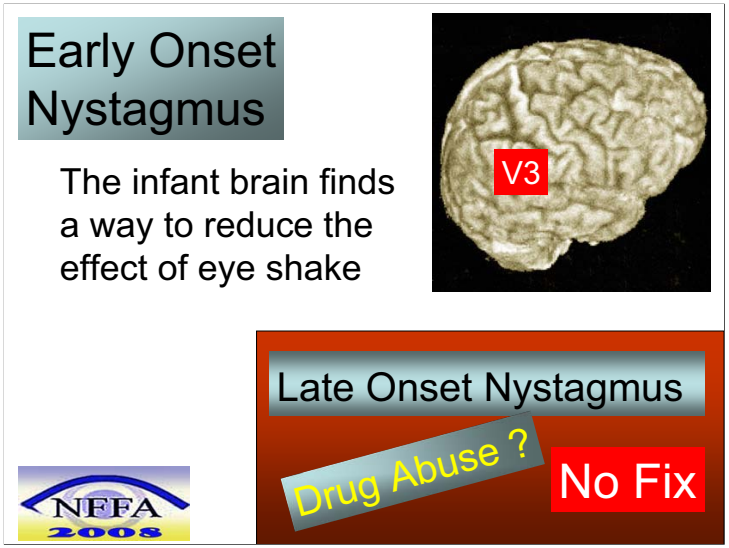
Look at the Capital A.

The horizontal bar of the A is in good focus but the legs of the A are fuzzy.

The eye says to itself – the horizontal is OK so I must be doing something right. Perhaps the verticals will improve if I hunt around a little.

Hence the eye wobble.

Nystagmus is a bad habit – learned early in life. Just like a stammer it takes a lot of un-learning.

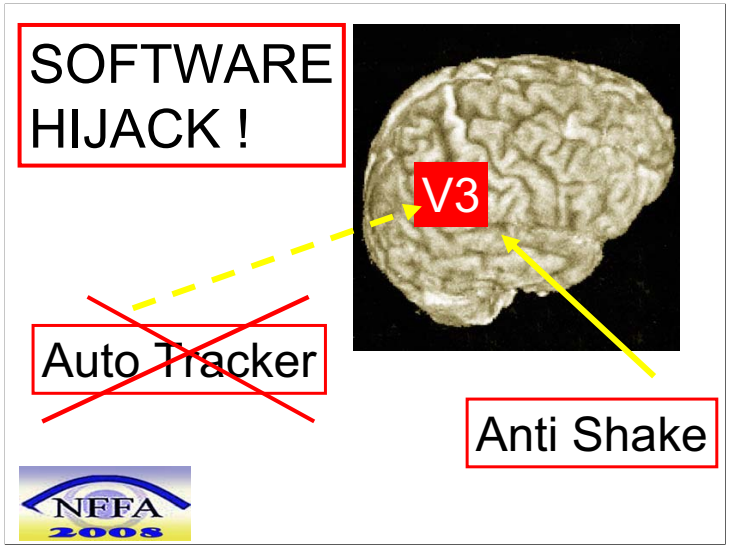


Visual images are processed in the back of the brain in an area described as the visual cortex. Studies have shown that a sub-area – termed V3 - is used to track fast motion – without us even thinking about it.

However, If nystagmus is present something amazing happens.

Within a few months of birth this auto-track function is reassigned to take the shake out of the images arriving from the wobbly eye.

Once assigned to anti-shake duties the "software" cannot be re-assigned to its original auto-track function.



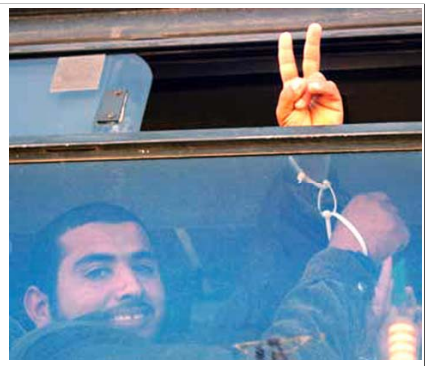
This loss of the auto-track functionality means that the albino eye can now only track moving objects under "manual" control.

Response time is much slower because it requires a conscious effort to track a fast moving object.

Under manual control It takes a split second to first recognise that the object is moving – then a lot of conscious effort to track its movement.

Without the regular fast auto-track function in place it is therefore extremely hard to catch a ball or follow a fast moving sport.

Was he going on vacation?



"Seeing" people in a moving car is very difficult

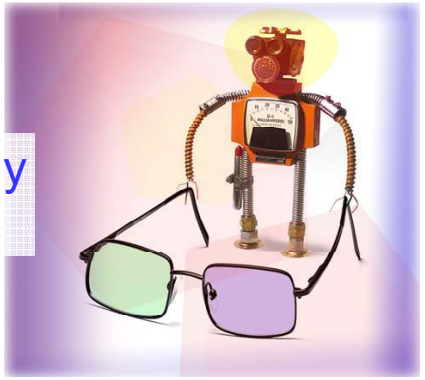
Albinos cannot "lock on" to low contrast & fast motion

Albino eyes take a long time to "lock onto" someone going past in a car – and mostly do not bother to do so.

By the time your friends in a passing car have shouted at you – and you have manually locked onto their presence – they are gone !

Refractive Correction -

Are we really in Control?



Up to now we have followed conventional optometry teaching – Glasses, contact lenses etc.

But - Why is it that most albinos do not wear the glasses that have been prescribed for them?

Why do they have a drawer full of glasses – none of which they like?

Why does EVERY eye Doc get it wrong – surely they can't ALL be bad?

Are WE to blame ?

266 Lenses - but none of them work for me !!

For many albinos a trip to the eye Doc has proved to be a waste of time and money.

Why is it that there are no lenses that can fix their eyesight ?

Irregular Astigmatism

Most eyes enjoy a regular contour – but some do not.

Imagine a construction company who built most of the hotel to the correct dimensions on the plan – but who got some of the dimensions wrong. Most rooms were the correct size – but some were bigger or smaller than expected.

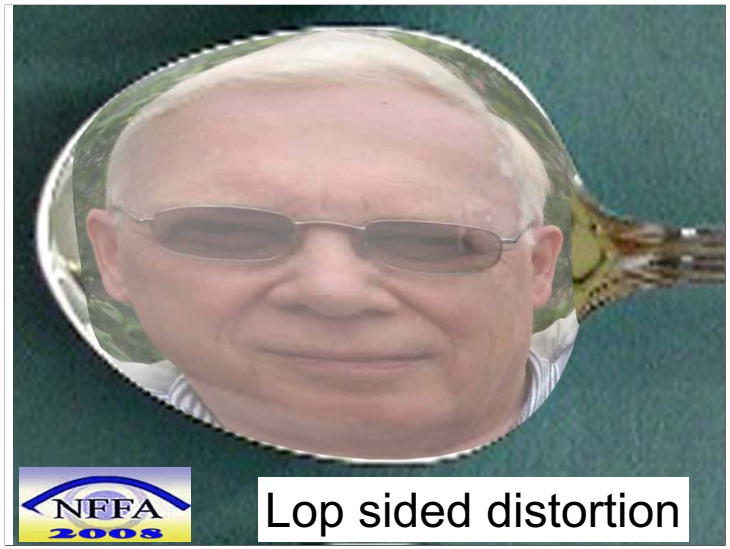
A standard lens can correct an eye that is too big or small overall – but cannot correct localised variations

Know Your Spoons

The slide shows table spoons on the left and soup spoons on the right.

The soup spoon is symmetrical but the table spoon is not.

If the spoons are new and shiny then you can see your face in their “mirror”.



If I look into a table spoon the reflection of my face is distorted.

If the shape of my eyeball has a sag then the mis-shape in the lenses in the eye will distort and defocus the image reaching the retina.

Irregular Astigmatism

- Cataract Surgery
- Keratoconus
- Albinism

Top of the list is the adverse effect of cataract surgery

Irregular Astigmatism

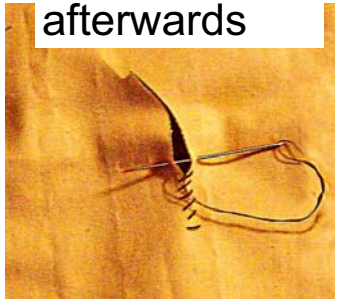
- Cataract Surgery
- Keratoconus
- Albinism

Common problem

Cataract surgery requires a cut to be made in the eye, The crystalline lens – which has become opaque with age is replaced with a synthetic one.

Cataract Surgery

The surface of the cornea is never quite the same afterwards



The swapping out of the old lens for a new one has been done successfully millions of times.

Most surgeons make a small cut in the corner of the eye in order to swap the lens. Some surgeons, however, prefer to make a cut further away from the iris so that the resulting dimple in the surface of the cornea is further away from the pupil / iris area.

This procedure, however, does cause more bleeding and a longer recovery time.

Irregular Astigmatism

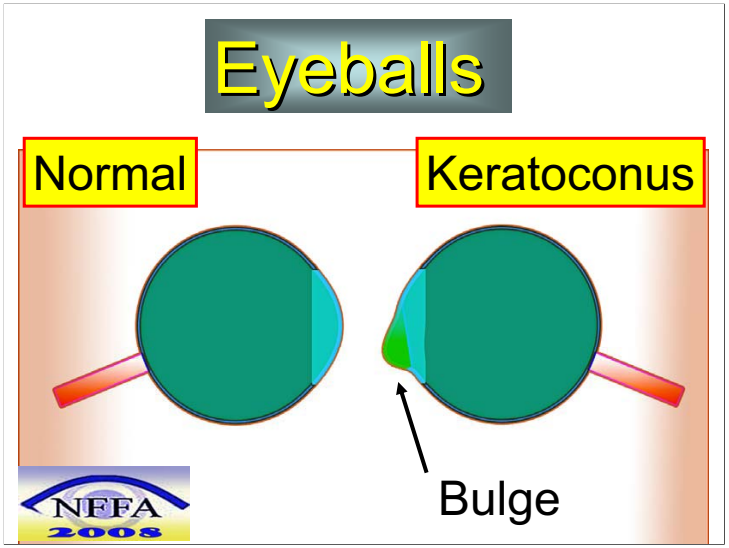
> Cataract Surgery

> Keratoconus

> Albinism

Incidence - 1 in 2,000

About 1 in 2,000 people suffer a distortion of the front of the eye termed keracotonus. This typically can occur between teenage and 40 years of age.



The bulge has a big impact on the ability to see clearly.

In the past the treatment has been a special contact lens or a corneal graft (from a donor)

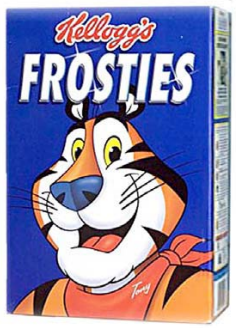
What follows is still experimental. To date the number of eyes that have been treated with the corneal linking technique amount to tens of thousands rather than millions.

Rind-stone cheese-boy ?

Tough Smooth Surface

Keracotonus is being treated in a new way. It is believed that the bulge in the cornea is a result of a mechanical weakness in the front of the eye. This technique aims to produce a transparent tough coating on the front of the eye – just like the rind on a cheese.

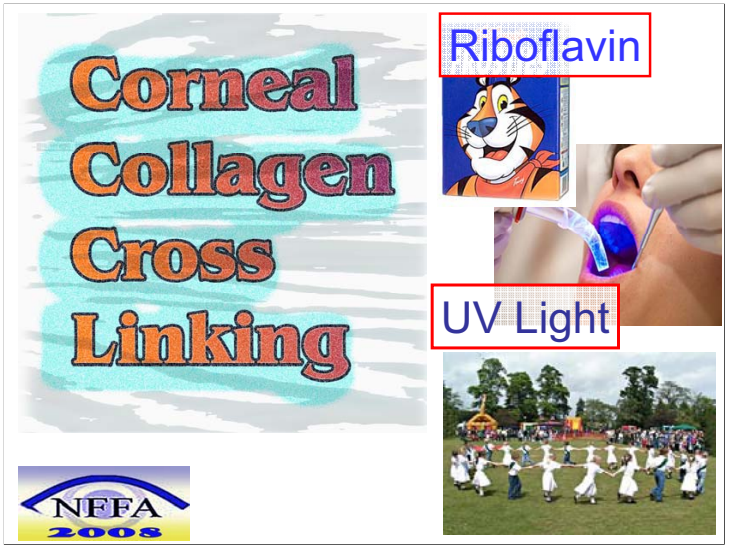
Quiz Time --



What's the connection ?

Quiz Time.

What is the connection between a breakfast cereal and a group of dancers holding hands?



Researchers have discovered that the front surface of the cornea can be strengthened by increasing the number of cross links between the cells of collagen. This can be achieved by painting the eye with Riboflavin – Vitamin B – and fusing it into the surface of the eye by means of low energy UV light. Unlike the high energy dental filling procedure - exposure time is 30 rather than 3 minutes .

This produces the required collagen cross linking.

If the number of unused pairs of glasses is anything to go by – albinos have irregular as well as regular astigmatism.

Quiz Time --

Bake a Cake

Deflate a Balloon

Every good cook knows that they must not open the oven door while the cake is baking – otherwise the cake does not rise properly.

Perhaps the same interruption occurs in the growth of the albino eye.

The albino eye seems to have an irregular front surface and an imperfect (often small) shape - just like a balloon which has been inflated but is now going down.

Quiz Time --

Pigmento

Albino

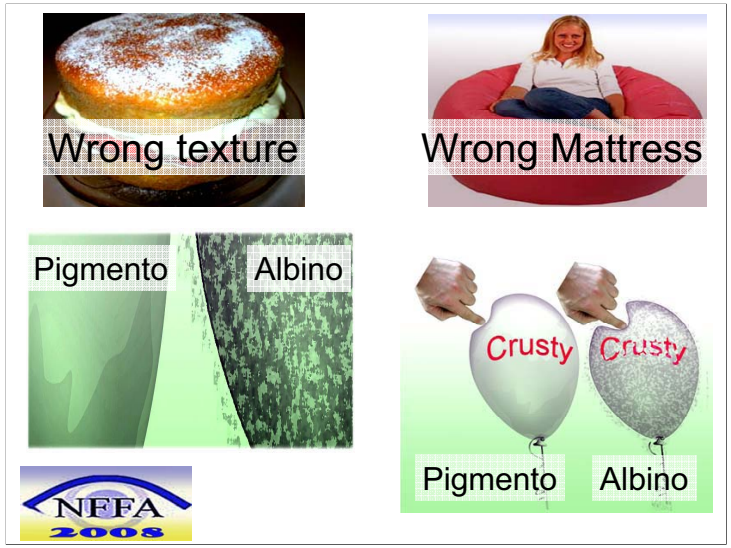
Two Quizzes –

Quiz 1

What is the connection between the man and woman enjoying a champagne breakfast and the girl who is sitting on a bean bag ?

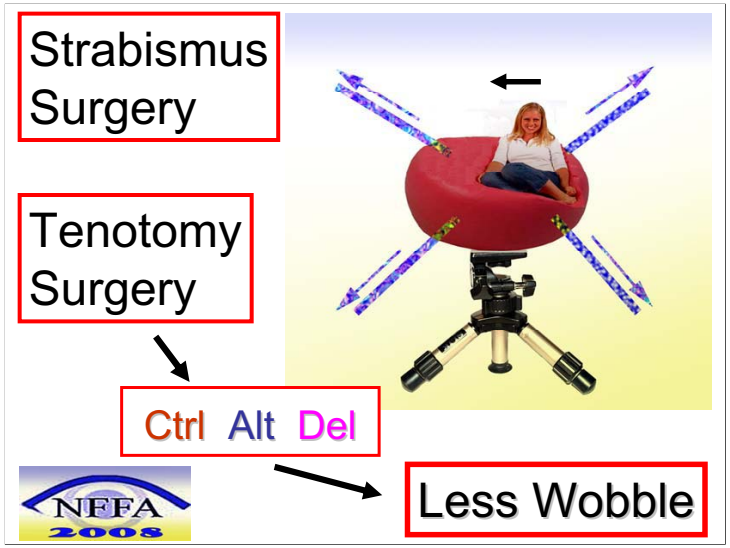
Quiz 2

Who is safer in bed – the couple on the hard mattress or the girl on the soft mattress ?



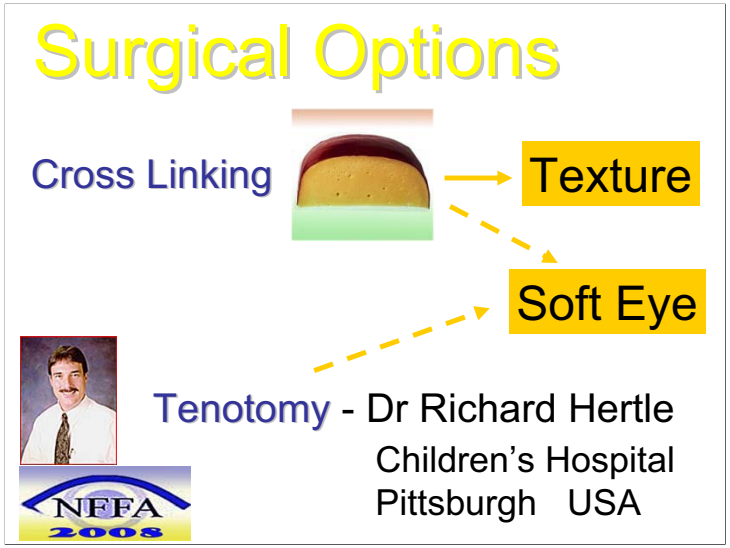
The albino eye has a less than perfect texture and a consequent tendency to irregular astigmatism.

It may also be “softer” than a normal eyeball with the result that the operation of the eye muscles might distort its shape.



If the mattress (eyeball) is soft then it is a good idea to sit the girl in the middle rather than on the side. Strabismus surgery makes the eye point forward rather than to the side by re-positioning the eye muscles.

However - Dr Richard Hertle discovered that doing no more than disconnecting then reconnecting the eye muscles seems to "relax" the eyeball and improved vision – just as though you had typed Ctrl Alt Del on your PC. He termed this technique tenotomy – because the eye muscle is more like the tendon in your ankle than a regular muscle.



There are two new techniques for albino eyes.

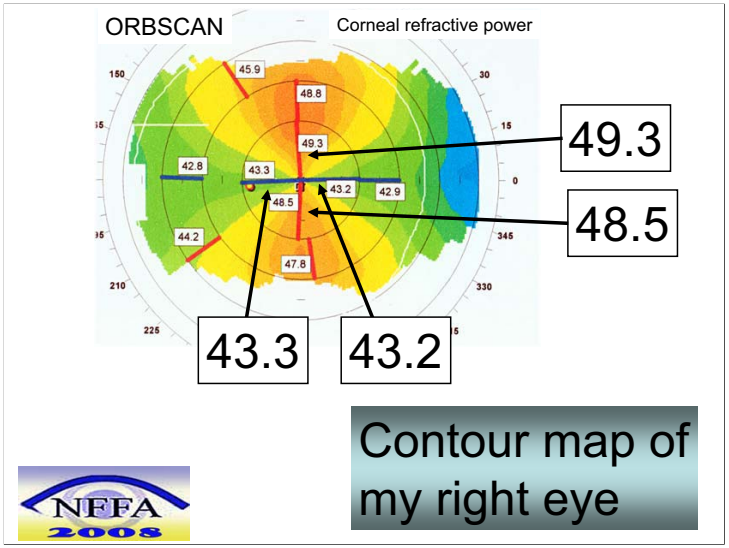
Collagen cross linking to take the bulges and dimples out of the front surface of the eye.

Tenotomy surgery to relax any possible internal twists or tensions within the eyeball.

Tenotomy typically improves albino eyesight from 6 60 to 6 24.

Collagen cross linking typically increases eyesight in non albino eyes from 6 36 to 6 12.

We do not know the effect of collagen linking on the albino eye.



This slide shows a contour map of my right eye. It shows that the top of my eye has a corneal surface power of 49.3 Dioptres whereas the bottom of my eye has a power of 48.5 Dioptres.

This shows that I have an irregular astigmatism of 0.8 of a Dioptre – which cannot be fixed with regular glasses but MIGHT be fixed with rigid contact lenses.

Progressive or varifocal lenses have been around for some time. The top of the lens is designed to give good distance vision whereas the bottom of the lens is designed to provide added power for reading.

The white area provides excellent vision (for pigmentos), the green area provides fair vision but the no-go red areas provide poor vision and are to be avoided.

It is the red areas that interest me – because they provide distortion. With trial and error (and a bit of luck) a number of albinos have noticed a distinct improvement in their vision when looking through the red no-go areas of a progressive lens.

Summary

Ten years ago the eye Doc took one look at the albino retina and said that nothing could be done to improve vision.

Today the emphasis is on eyeball shape, muscle tone and protein biochemistry

It has always been thought that the apparent poor state of the albino retina is the limiting factor of albino vision.

Recent research seems to indicate that the retina might not be quite as bad as was first thought – and that geometric distortions at the front of the eye might be a major factor.

At present we have no way of improving the retina – but we may be able to do something mechanical that will improve eyeball shape.

No promises --

But the next few years could yield some major advances in therapy

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Please contact me at the above email address if you have any queries or you require a further copy of this presentation.