5. MISCELLANEOUS QUESTIONS ON INFANTILE NYSTAGMUS

- In some cases, even if Infantile Nystagmus Syndrome (INS) is reduced to a very small amount, people will still not see 20/20. Why?

  Remember, while the nystagmus [ni-STAG-muss] waveforms can affect the visual acuity, any other visual deficits accompanying INS can also reduce visual acuity. For example, a retinal underdevelopment can reduce the visual acuity from 20/20 to 20/80, and the nystagmus further reduces it to 20/100. In this case, even if we could get rid of all the nystagmus (which is not achievable), the highest possible visual acuity would still be 20/80, not 20/20. We can’t easily treat the sensory defects in the visual system, because they are located in the brain; all the growth and development of the visual system occurred when you were an infant, while the nervous system was still developing.

- What can you do to minimize the effects of INS during a driver’s license vision test?

  Nystagmus tends to really get worse when you are nervous. If you are on the borderline of qualifying on the vision test, being nervous might make your nystagmus worse and make your acuity worse, although you can see much better when you are not stressed. So do your best to relax!

  There are some other things you can do to ensure you get an optimal result. (We are not suggesting here that you should be “sneaky” and attempt to fool the DMV staff; we are offering some suggestions that can make your vision test results closer to how well you actually can see in your daily life. You should always know your limits when it comes to driving.)

  Try to use both eyes to look at the chart. If the staff insists on covering one eye and testing each eye individually, explain to them that covering one eye might make your nystagmus worse. This is because you probably have a preferred eye with a better acuity. The non-preferred eye, more than likely, will have a worse acuity. When you are walking or driving, you are using the preferred eye and the better acuity. A poor test result in the non-preferred eye should not be the reason to deny your driver’s license. Also, the latent component in INS, if you have it, will generally be larger if one eye is covered than with both eyes open.
Ask for a regular eye chart if you feel uncomfortable with the testing machine that has small scopes to look into. Having a larger field of view might help you get one more line. Also, if you have a “null” point to the side, you cannot use it if you are looking into the machine.

- **Why do some people with INS feel more sensitive to light? Why can’t some people see 3D movie effects?**

Some INS patients have varying degrees of symptoms of “ocular albinism”. It means that light can come through the pupil, iris and the white part of the eyeball. In people without “ocular albinism”, light only comes through the pupil and the pupil can adjust its size according to the strength of the light. In ocular albinism, although the pupil might still work on changing its size, it does not help much, because light is coming in from everywhere! What you need in bright sunlight are large wrap-around sunglasses to reduce the total amount of light coming in.

“Stereovision” enables you to see 3D movies. It is developed very early in infancy. It relies on two eyes well lined up and working together. About half INS patients do have 3D vision. However, others do not because of their strabismus [stra-BIZZ-muss] (their eyes are not aligned). Even if you have them aligned later in life, you still probably can’t get much better 3D vision, because you have missed a critical stage in visual system development. Stereovision and nystagmus are two separate things. Nystagmus by itself does not cause the loss of stereovision. Loss of 3D vision does not mean you can’t identify what’s close and what’s far away. You can still use visual cues: for example, you know a pigeon in the sky as small as a black dot is actually not a black dot, it is small because it is far away. When you go to the 3D movies, however, the images are manipulated to have a 3D effect, so you probably won’t see it if you don’t have stereovision.

- **What’s the difference between a nystagmus surgery and a strabismus surgery? Are they performed separately?**

In a nystagmus surgery, the “good” eye (viewing eye) is what determines the operation, that is, moving the eye muscles so that the null point is in a straight-ahead position. Tenotomy & reattachment (T&R) operates on 4 muscles (2 per eye) of both eyes to achieve both damping and broadening effects. In T&R, no muscles are moved, so it does not change the alignment. In a strabismus surgery, the “bad” eye (non-viewing eye) is the biggest concern, since every effort is made to correct its misalignment. In the case of nystagmus plus strabismus surgery, the ophthalmologist must be sure that the viewing eye is moved to wherever the nystagmus has the best waveform, and then correct the strabismus by aligning the other eye with the viewing eye. All these are performed in one outpatient surgery. Testing should be done to decide if you need a strabismus correction, and how that could be combined with the nystagmus surgery.

T&R is a nystagmus surgery, not a strabismus surgery, because it does not move the muscles. Some doctors do not yet believe in or fully understand the beneficial effects of tenotomy because they say, it does not “move” any muscles. It is not meant to. T&R was not designed to correct strabismus, but to reduce the nystagmus, which is a more important, functional result, once the 3D development critical period is past.