



**American Nystagmus Network**

## **My Child Has Nystagmus - What I Should Know**

**by Evelyn Gonzalez, ANN Vice-President**

First know your child can live a full and happy life. I remember the fear and pain when I learned that my oldest son had nystagmus at the age of 4 months. No one in our extended family had the condition. The stories I read on the internet were all very depressing. I wish I could go back and tell myself not to worry; it would be OK.

I have four children, my oldest and youngest children have infantile or congenital nystagmus. My third child developed acquired nystagmus temporarily as a result of a concussion. (This handout is focused on congenital or infantile nystagmus)

My oldest son is a computer engineer for an internet startup company. He was active in sports and played ultimate frisbee in college. His vision was 20/200 when he was in grade school. Today his vision is 20/50 to 20/70.

My youngest son has a B.S. in biomolecular engineering. He is a Ph.D. student at U. Penn. He was also active in sports. His vision in grade school was 20/90 and today it is 20/30 or 20/40.

There are good stories of very successful people with nystagmus.

### **Overview of Nystagmus**

Nystagmus is a condition characterized by an involuntary shaking or jerking of the eyes which usually results in some degree of visual loss. The degree and direction of eye movement, amount of visual loss, and resulting impairment varies greatly from person to person.

It is a very complex ocular condition that is well recognized, but not yet well understood. There are many different types of nystagmus. Some researchers list 49 different subtypes. Each of the subtypes has very different characteristics. Be aware that on social media one person may be talking about one subtype and another person a different subtype. It is possible for a person to have more than one subtype.

Nystagmus results in a decreased visual acuity or low vision that cannot be corrected to 20/20. While the eyes may move your child does not notice this movement. They just

lose some of the details. They can see shapes and colors but they may not be able to see the fine details - picture is not as crisp. The image is not blurry, just less details.

There are two main types of nystagmus: infantile or acquired. Infantile nystagmus syndrome (INS) is also referred to as congenital nystagmus and appears during infancy. Acquired nystagmus (also called acute nystagmus) can develop at any stage of life. It often occurs due to injury or disease.

### **Null point**

The null point is the head position at which your child has the most eye control. People with nystagmus often hold their heads in a seemingly abnormal position, in an effort to maintain a null point - a position whereby eye movement is minimized.

The null point may change over time as your child grows. Your doctor may suggest surgery to move the null point. Since the null point can shift as your child develops your doctor may want to wait until your child is older before correcting the null point to avoid multiple surgeries. A decision to have nystagmus related surgery will be one of those tough parental decisions. Do your research, listen to your doctors, and stand firm with your decision. There will be lots of opportunity for self doubt and what ifs. Remember, whatever decision you make, your child will be fine.

### **Fluctuation in Vision**

Some research suggests that an increase in the speed or magnitude of the eye movements results in decreased visual acuity. Other research suggests the causal link is reversed and the eye moves in response to decreased visual acuity. Regardless of the causation, you will notice that your child's eyes move more rapidly at times. This rapid movement and the additional decrease in visual acuity can be caused by stress, emotional state, fatigue, or the direction of view. Your child's vision will fluctuate. You may find them increasingly using their null point more when they are tired or stressed. Eye fatigue also causes decrease in visual acuity. Your child's best vision is generally early in the day.

### **Glasses**

Glasses will not help with nystagmus. Your child may be prescribed glasses for other eye conditions (astigmatism/myopia/hyperopia). The doctors want to provide your child with the best vision to help with your child's vision development.

### **Lazy Eye or Strabismus**

This is a separate condition that may also affect your child. Your child may develop a strong eye and a weak eye. This is often treated with physical or chemical patching.

This patching is not a treatment for nystagmus, but does help with strabismus. Your doctor wants your child to have the best vision possible as they continue to develop and it is important to have both eyes working together. Surgery is also an option for strabismus. Strabismus surgery is different from the null point surgery or other nystagmus surgeries.

### **When and How to Tell Your Child About Nystagmus**

This is a personal decision. We decided to tell them both from an early age. Nystagmus was just a part of their lives. When adults and children asked why their eyes moved they could answer, "I have nystagmus, which is an eye condition." We were very open about the condition and treated it as one of the characteristics that made them special. Giving them knowledge and practicing answers to questions will help prepare them for the possible bullying situations.

### **Driving with Nystagmus**

Whether my children would drive consumed so much of my mental energy. What would their life be like if they could not drive? This really was more my issue and not their issue. Both were able to get their permits. My oldest son did not like driving and chose not to get his license. My fully sighted daughter decided she did not like driving and also did not get her driver's license, for many years. My youngest son with nystagmus, got his driver's license, but he prefers to be a passenger. Living without a license today is very different from when I was a teenager. There is better public transportation, and options like UBER and LYFT.

Driving with nystagmus is often possible. Each state has different rules and requirements. Some people with nystagmus will never drive, others will be able to drive. Whether your child drives should not define who they are and what they do.

### **What Can I Do To Help My Child Prepare for Life with Nystagmus**

I remember sitting in the Pediatric Ophthalmologist office after he told us that our son had nystagmus. and asking this question. He turned to us and gave us some wise advice, "Don't limit what your son does." Let him try whatever he wants to try. As parents, we want to protect our children. It is difficult to allow them to fail, especially when the failure is based on a physical challenge. My sons both wanted to participate in sports and that required them to practice more than their peers. The persistence and commitment to additional practice proved to be valuable life skills especially as adults.

The doctor also said to work on building his confidence. Many studies confirm the importance of building resilience and confidence in children. I think that this was the most important advice that I received. Instead of focusing on what he could not do, instead we focused on all the things he could do.

I would add humor to the list. All the successful people I know with nystagmus are able to laugh at situations, instead of letting the situation get them down.

At the last ANN conference, my son was on the teen panel. One of the parents in the crowd asked, "If you could go back and not have nystagmus, would you?" My son answered, "No, nystagmus has made me who I am."