



Note: Information from this page contains no medical advice.

You should always consult your doctor about INS treatments.

This document was created by Z. I. Wang and edited by Dr. L.F. Dell'Osso.

Note: In this document, we have presented very complex scientific information in laymen's terms.

DD_OMLAB Patient Information Series:

1. INFANTILE NYSTAGMUS SYNDROME

❖ What is Infantile Nystagmus Syndrome (INS)? How common is INS in newborns?

Infantile Nystagmus [nĭ-STAG-muss] Syndrome (INS) is characterized by the constant movements of the eyes, even when you don't mean for them to. The eye movement is usually horizontal (left and right). INS is also known as congenital nystagmus. The incidence is reported to be about 1 in 3000 births (1 in 2000 males and 1 in 4000 females). We also see INS in dogs, cats, goats and cows.

❖ What caused INS?

INS can appear when a baby is born, but is usually discovered a few months after. INS is not directly caused by any sensory visual problems (for example, optic nerve or retina problems), although it can happen together with these problems. INS itself is caused by an unstable eye-movement control system. Scientists have reported a gene (Xp11.4 – p11.3) to be related to some forms of INS. INS can be a family disorder; the “nystagmus gene” is usually carried from the mother to the son.

❖ Do all the people with INS have bad vision?

No. INS by itself does not always reduce vision very much and many people with INS lead normal, active lives. Those with very poor vision usually have other sensory visual problems. These other problems are responsible for their relatively bad vision.

❖ Why do some INS patients have a head turn? Why do some have head nodding?

A consistent head turn indicates the patient can see best at a certain angle. You can sometimes confirm the head turn by checking old photos (especially photos that were not posed). If the head turn is always in one direction, that's an indication of a possible treatment to improve INS. If you have a big head turn, you should consider surgery because sometimes a big head turn or tilt may cause neck muscle problems. Surgery can be done on the eyes so that you may see as well without turning your head.

The nystagmus signal from the brain drives the eyes, it can also affect the neck muscles. This causes the head nodding. Head nodding usually happens when you are concentrating and trying really hard to see.

❖ **What should the parents of children with INS do?**

Parents should bear in mind that INS will not prevent children from doing well in school and becoming successful. Nothing is impossible with motivation and support. This is not the end of the world. James Galway, the famous flautist, also has INS. If your child has visual problems, make sure you let the teacher know and ask the teacher to arrange a seat in the middle front row for your child (a letter from your doctor may help).

❖ **What is Asymmetric (a)Periodic Alternating Nystagmus (APAN)?**

APAN is one type of INS. It means the INS characteristics change with time. If you have APAN, you may not have a preferred head turn position because your nystagmus always changes. A large percentage of INS patients have APAN. The tenotomy and reattachment (T&R) procedure can help APAN patients see better over a wider visual range.

❖ **What is Fusional Maldevelopment Nystagmus Syndrome (FMNS)?**

FMNS is also known as latent/manifest latent nystagmus. It is usually noticed right after birth. Latent nystagmus occurs when one eye is covered; it beats in the direction of the open eye and disappears when both eyes are open. Pure latent nystagmus is rare. Manifest latent nystagmus occurs when both eyes are open; it beats in the direction of the fixating eye (the eye you use to see). The waveforms of latent nystagmus are different from those of INS. Right now there is no surgical treatment proven to be effective for FMNS. However, if a strabismus [stra-BIZZ-muss] procedure is performed, T&R of the unoperated horizontal muscles may reduce FMNS.

❖ **Why do people with INS see worse when they are nervous?**

INS gets worse when you are nervous, angry or excited. When you are in an emotional state, you will have increased nystagmus. INS is present whenever you attempt to see, even in the dark. INS goes away when you are asleep or daydreaming.

❖ **Why can't I see my eyes wiggling in the mirror, if I have INS? How can I see it?**

You can't see your eyes move, because the wiggling eye image in the mirror is moving at the same speed as the image you see at the back of your eye (your retina). To see your nystagmus, you should have someone videotape you.

❖ **With wiggling eyes, why do most INS patients still see the world as being stable?**

Since INS happens at birth, the brain somehow knows early in life that the "dancing" image on the retina is not a true image. The brain is clever enough to eliminate the wiggling signal, and you can see the world as being stable. However, it is normal that sometimes you see things jumping, especially when you are tired, or when the object you are trying to see has a high contrast against the background (for example, your digital clock in a dark room).

❖ **What is Acquired Nystagmus (AN)?**

AN happens later in life; it is a different type of nystagmus from INS. AN can happen after accidents, strokes or drugs. The major complaint from AN patients is that they see the world as jumping around, because their brain cannot subtract the movement of the eyes from the total visual information that it processes.