



Navigating **NYSTAGMUS** *with your Doctor*

what you need to know
Plus: *how to plan for surgery*

by
Edie Glaser

Foreword by
Richard W. Hertle, M.D.

Table of Contents

Table of Contents	iii
List of Figures	v
Foreword	vii
Acknowledgments and Contributions	ix
Author's Preface	xi
Disclaimer	xiv
Chapter 1—Nystag...what?	1
• What nystagmus really means	1
• Prevalence of nystagmus	2
• Forms of nystagmus in everyone	3
Chapter 2—How Did I Get It?	9
• Causes	10
• Consequences	15
Chapter 3—What Do I Have Exactly?	23
• Diagnosis	23
• Descriptions	28
• Doctors	34
Chapter 4—What Can I Do About It?	39
• Optical aids	39
• Vision therapy	50
• Non-Traditional treatments	53
• Drug treatments	55
• Surgical Treatments	57
Chapter 5—How Do I Prepare for Surgery? A Personal Planner	83
• Insurance matters	85
• Scheduling	88
• Emotional preparation	91
• Surgery day: What to expect	96
• Recovery: Frequently asked questions finally answered	98

Glossary	107
Appendix A: Acuity Conversion	123
Appendix B: Resources	124
Index	135
About the Author	141

List of Tables and Figures

Chapter 1—Nystag...*what?*

- Table 1: Estimated Population of People With Infantile Nystagmus 3

Chapter 2—How Did I Get It?

- Figure 2-1: Common Vision Defects That Often Accompany Nystagmus and Can Cause Low Vision..... 14
- Figure 2-2: Simple Jerk Left Nystagmus Waveform 18
- Table 2-1: Life Events That Affect Nystagmus and Foveation 20

Chapter 3—What Do I Have Exactly?

- Figure 3-1: Electrocardiogram (EKG) Waveform 25
- Figure 3-2: Common Nystagmus Waveforms Showing Direction and Speed of Eye Movement 27
- Table 3-1: CEMAS Excerpt 30

Chapter 4—What Can I Do About It?

- Figure 4-1: Functions of Eye Muscles 58
- Table 4-1: Effects of the First Tenotomy Clinical Trial: Acuity Change 65
- Table 4-2: Effects of the First Tenotomy Clinical Trial: National Eye Institute Visual Function Questionnaire (VFQ) 65
- Table 4-3: Effects of Tenotomy on Patients with Oculo-Cutaneous Albinism (OCA) and INS: Log Mar Acuity and Head Posture 67
- Table 4-4: Effects of Tenotomy on Patients with Oculo-Cutaneous Albinism (OCA) and INS: Null Zone Width and Null Position 69
- Table 4-5: Effects of Tenotomy on Patients with Oculo-Cutaneous Albinism (OCA) and INS: Change in Foveation Time (measured in milliseconds) 70
- Table 4-6: Treatment Options for Nystagmus: Brief Summary 74

Foreword

It is my pleasure to introduce this work by Ms. Edie Glaser. In the over 20 years that I have been practicing medicine and medical research, I have been fortunate to have the opportunity to establish a physician/patient relationship with countless patients and their families. It is the personal part of these interactions and the possibility of providing hope that has been most rewarding for me. I believe that the next large step in the physician/patient relationship is the combined efforts of both physician and patient in improving the health and quality of the patient's life in the absence of a total "cure" of chronic conditions. It is not now, and will no longer be, the role of the patient or family to be a passive participant in their health care. The patient and family will have an increasing role in investigation, evaluation, treatment planning, and selection of their altered health. The role of the patient as a participant in healthcare, health investigation, and distribution of information is also increasing. It is within this context and modern environment that Ms. Glaser's work is ahead of its time. I believe the research effort and personal experience from which this manuscript was drawn provide a unique view of the disease of infantile nystagmus. The work will provide patients and their families with a resource from which to more expertly discuss their condition with a chosen health care professional. I commend Ms. Glaser on her work and believe it will contribute to providing hope to patients and families with nystagmus.

—Richard W. Hertle MD, FAAO, FACS, FAAP
Chief of Pediatric Ophthalmology
Director of the Laboratory of Visual and Ocular Motor Physiology
Children's Hospital of Pittsburgh
Director of Pediatric Ophthalmology & Strabismus
UPMC Eye Center, Eye & Ear Institute
Professor of Ophthalmology and Bioengineering
University of Pittsburgh School of Medicine
Pittsburgh, Pennsylvania

Acknowledgements and Contributions

My sincerest gratitude goes to my family and friends who have supported me in various ways during my life journey with nystagmus and throughout the intense research and writing phase of the *Navigating Nystagmus* series.

My deepest thanks also goes to the following experts in the medical and scientific community who reviewed the content of this guide and graciously contributed their expertise for the benefit of its readers. Without their participation, this guide would not be possible. In alphabetical order, these contributors are:

Louis F. Dell’Osso, Ph.D. at www.omlab.org

Dr. Louis F. Dell’Osso is the father of the tenotomy procedure for treating nystagmus. Over his 40 year career as a biomedical engineer researching eye movement disorders, he has held many distinguished positions. Currently, he is the Director and Principal Investigator of the Daroff-Dell’Osso Ocular Motility Laboratory at the Louis Stokes Cleveland Department of Veterans Affairs Medical Center and CASE Medical School. He is also a Professor of Neurology and Biomedical Engineering at the Case Western Reserve University School of Medicine in Cleveland, Ohio.

Jennifer Galbraith, O.D., M.S.

Dr. Jennifer Galbraith graduated from Westminster College in New Wilmington, Pennsylvania in 1996 with a B.S. in Biology. She then went on to Pennsylvania College of Optometry where she earned both a Masters in Low-vision Rehabilitation and Doctor of Optometry degrees in 2000. Dr. Galbraith is in private practice in Harrisburg, Pennsylvania with *Leading Edge Eyecare* where she specializes in treating patients who have all forms of vision impairment, including nystagmus. She often speaks on low-vision rehabilitation issues to Lions Clubs, local blind associations, nursing homes, doctors offices, and at conferences. Dr. Galbraith is currently on the board of directors of the Tri-County Association for the Blind.

Richard W. Hertle, M.D. www.chp.edu/bio2/hertle_r.php

Dr. Richard Hertle is the Director of The Laboratory of Visual and Ocular Motor Physiology at Children's Hospital of Pittsburgh specializing in treating eye movement disorders in adults and children. He is also Chief of Pediatric Ophthalmology and Visiting Professor of Ophthalmology at the University of Pittsburgh School of Medicine in Pittsburgh, Pennsylvania. Hertle performed the first clinical trials on the tenotomy procedure for treating nystagmus and is considered by many to be a leading expert on eye movement disorders.

Vicki Leung, O.D. www.eyedocs.org

Dr. Vicki Leung received her Doctorate of Optometry in 1989 and completed her residency in Vision Therapy and Pediatrics in 1990. She is currently in private practice in Woodland Hills, California, where she specializes in treating patients with nystagmus and other functional vision disorders utilizing vision therapy, visual aids, and medications. She has also received certification in the treatment and management of ocular diseases (TMOD) from the National Board of Examiners in Optometry (NBEO). Dr. Leung also serves as a senior and supervisory examiner for the NBEO. She has lectured in the areas of pediatric vision development, children born at risk, and nystagmus.

Zhong Wang, M.S. www.omlab.org/OMLAB_page/Personnel/zw/zw.html

Zhong Wang is a Ph.D. candidate at the Department of Biomedical Engineering, Case Western Reserve University. She graduated from Zhejiang University in 2003 and came to the U.S. to study nystagmus. She is currently working as a research assistant with Dr. Louis F. Dell'Osso at the Daroff-Dell'Osso Ocular Motility Laboratory. Her Ph.D. thesis is focused on utilizing eye-movement data analysis to assist the clinical treatment planning of nystagmus, and also on control-systems modeling to explore the organizing principles of the ocular motor system. She has been actively involved in the OMLAB patient recording, patient consultation and treatment planning. She has published several peer-reviewed scientific journal papers on the application and evaluation of the tenotomy procedure. She has also been invited to write for and speak at multiple international conferences on important research findings on infantile nystagmus syndrome.

Author's Preface

Navigating My Own Medical Journey Through Nystagmus

My eyes have been wobbling since I was a few months old (a condition known as **nystagmus**) and 35 years later, doctors were still telling me that nothing could be done about it. I had crossed eyes, too, but was never offered surgery to straighten them—a surgery that has been performed regularly since the mid 1800s. Doctors said it was too late and I should leave well enough alone. For as long as I can remember, I responded with “Okay, thank you” as I left their offices and continued on with life.

Throughout those years, whenever people asked me why my eyes moved, my answer was always the same: “It’s just something I was born with.” Then at age 35, I started seeking answers to my own questions. I attended a conference on living with nystagmus and after doing much of my own research, I learned many things, including the fact that there were treatment options not being offered to me, both old treatments and a new procedure called *tenotomy*. I also read about a doctor in Pennsylvania who specialized in nystagmus and performed the first tenotomy clinical trials, but I didn’t want to travel to Pennsylvania when there were state-of-the-art eye hospitals in my own home town of Los Angeles. So I made an appointment with a local neuro-ophthalmologist.

After a routine eye exam given by an intern, the doctor advised me that everything was as good as it would get. He said nothing could be done to improve my nystagmus or to straighten my strabismus (crossed eyes). In fact, he said that I had no strabismus. In other words, it was the same diagnosis and prognosis as usual.

By now, I heard about the importance of eye-movement recordings in the diagnosis of nystagmus, so I asked if I could have a recording done. He said, “It’s not necessary. I know why you have nystagmus.”

“Well, what are these recordings for, then?” I asked.

“For research,” he said.

So I asked about surgery, but he refused again. “It’s not that I don’t want the business. We do surgeries here all the time, but surgery won’t have any benefit for you.”

I was not as informed then as I am today and so I could not intelligently discuss the matter with him. I instead made one last effort for my cause. I told him I heard of a specialist in Pittsburgh, Pennsylvania and asked if I could be referred to him. His answer was, "If this doctor were a few hours away, I'd say go ahead, but I wouldn't travel across the country."

I must digress here for a moment and say that this doctor/patient exchange is commonly heard throughout the United States and around the world today. The fact is that many eye doctors treat common disorders affecting the majority of patients. They cannot specialize in rare conditions, such as nystagmus. In addition, it was only in 2001 that the clinical trials for the tenotomy procedure to treat nystagmus had concluded. That is not a lot of time to convince thousands of eye doctors to support a new surgery that claims to improve nystagmus and visual acuity. In my case, though, I was not offered the tenotomy procedure, or strabismus surgery to straighten my crossed eyes, or null point surgery to move my null point to center (the point where my nystagmus slows down and I see the best). These latter two surgeries have been performed for several decades now.

I couldn't accept another "*nothing can be done for you*" diagnosis when my own research told me that something was being done for some people. So the next day, I made arrangements to fly to Pittsburgh.

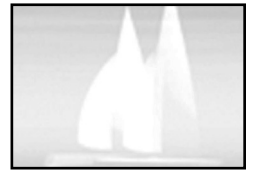
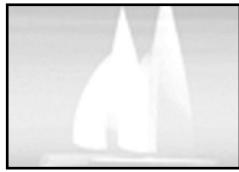
Immediately upon arriving at the University of Pittsburgh Children's Hospital, I was led into a room to do an eye-movement recording. There, I sat and watched a red dot move up and down and across a screen while sensors inside the goggles that I wore recorded every eye movement. These recordings were graphed into a waveform, which meant nothing to me, but it was easily translated by Hertle who examined me and told me things about my particular condition that no one had explained to me before.

After completing several more tests, the specialist advised that surgery would likely benefit me for a variety of reasons. That was good to know, but after so many years of hearing that nothing could be done, I was very skeptical. I needed to know more. Over the next several months, I read peer-reviewed studies in medical journals, talked to experts, and listened to personal experiences. That intensive research helped me make the very personal decision to have surgery and it formed the groundwork for the *Navigating Nystagmus* series.

Navigating Nystagmus with Your Doctor is not a recommendation for surgery or for any one doctor. It is my hope that through this work, families, caregivers, and adult patients will finally understand what nystagmus is, how it develops, and the many ways it can be treated. With this knowledge, parents and patients will be able to make informed decisions with their vision specialists and become more responsible for the direction of their own vision care.

This guide is written in non-technical prose so that it can be accessible to the widest possible audience. It has also been reviewed and endorsed by leaders in the field as noted previously. In that light, this guide also offers a useful introduction for those in the medical community who have not yet been exposed to the fascinating eye movement disorder known as **nystagmus**.

Chapter



Nystag...what?

The thing about nystagmus is that most people don't know it exists. There are no actors doing TV spots for it. No athletes are visiting children with it. No rock stars are doing benefit concerts for it. To most people, it is just an alien word to them....My spell checker does not even recognize it.

—Marcus (Q1)

Marcus is not alone in his frustrations. Most of us who have nystagmus—also referred to as “**N**”—are just as clueless as the general public, our spell checkers, and even most physicians. We know we can't control it and we know there is no cure, but that's about all we know. By the end of this guide, you will be able to answer many questions that you've wondered about for so long. Our journey begins here with understanding what nystagmus really is and who has it.

What kind of word is nystagmus anyway?

Kids in school gave me a nickname. They called me 'sleepy' because my eyes seemed to be half-closed most of the time.

– Tommy (Q2)

Tommy's sixth grade classmates seem to know the same thing that etymologists have already known for years:

The word *nystagmus* is of uncertain origin and most probably is derived from the Greek verb *nystazo* "to feel sleepy," which comes from the verbs *nefstazo* or *nevo* "to nod" or, according to Homer, "to bend the head." It was much later, during the eighteenth century, that the word *nystagmos* acquired its current medical meaning as involuntary eyeball oscillations **(1)**.

One eighteenth century medical dictionary described nystagmus as:

Nystagmus, a twinkling of the eyes, such as happens when a person is very sleepy. -- Authors also define nystagmus to be an involuntary agitation of the ocular bulb **(2)**.

Today, the American Nystagmus Network (the only non-profit group in America dedicated to supporting people with nystagmus) defines nystagmus very simply as "...an involuntary eye movement, which usually results in some degree of visual loss." **(3)**

How many people have nystagmus?

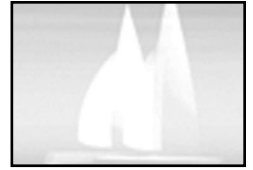
The numbers vary widely throughout the medical literature, but there are two surveys that provide an educated guess. In 1989, Howard Stang, M.D. reviewed the records of 70,000 young patients (age 1-16) from Group Health Incorporated and found a 1 in 2,850 occurrence of (what was known then as) Congenital Nystagmus **(4)**.

In 2001, the University of Leicester in the United Kingdom sent surveys to over one million people within the Leicester area. Initial results suggest an occurrence of 1 in 1,000 to 1 in 3,000.

Table 1 gives worldwide estimates of pathological (see **page 31**) occurrences of nystagmus based on the more conservative occurrence of 1 in 3,000.

- If you spin yourself dizzy at a local carnival or in an office chair, you will get a good dose of **rotational nystagmus**. While your head is rotating, the fluid in the inner ear bounces around causing your eyes to jerk back and forth as they try to keep up with the movement. **Post-rotational nystagmus** continues after the spinning stops until the visual system gradually adjusts the eye movement back to normal.
- Imagine riding in a fast-moving train. As you look out the window, you notice a series of windmills lining the route. Your eyes track one windmill. As it passes out of sight, your eyes quickly jerk back to another windmill, and then another, and another. This type of eye jerking is sometimes called **railway nystagmus** or more technically, **optokinetic nystagmus (OKN)**. Doctors sometimes try to produce OKN in infants just to see if their visual system is responding normally.
- **Caloric stimulation** can initiate another kind of nystagmus that doctors try to reproduce. By pouring warm or cold water into each ear, the eyes should move quickly away from the direction of the water and then slowly back again. If nystagmus does not occur, then the inner ear is probably not functioning properly and further testing is needed.
- The drug, PCP (phencyclidine), and very high levels of alcohol affect the central nervous system and produce a **vertical nystagmus**, causing the eyes to jerk up and down instead of the more common side-to-side (horizontal) motion. Some over-the-counter medications can also cause vertical nystagmus.
- **Miner's nystagmus** was considered one of many occupational hazards of working in the mines during the nineteenth and early twentieth centuries. After working underground for long periods of time, some miners seemed to exhibit involuntary eye movements, thus the name *miner's nystagmus*. No one reason has been accepted for why it developed. There are, however, four theories discussed in an article entitled "The Rise and Fall of Coal Miner's Nystagmus." These theories are 1) a lack of adequate lighting, 2) looking up or to the side for long periods of time, 3) inhaling noxious fumes over long periods, and 4) stress and neurosis. Some medical experts think that miner's

Chapter



How Did I Get It?

When I was in 6th grade, my teacher...stopped in mid sentence, stared and asked me, "How do you do that?" "Do what?" I asked. I really had no idea what he was talking about. "How do you make one eye move around while the other stays still?" I shrugged.

—Tommy (Q3)

We should be able to explain to our teachers, doctors, friends, and strangers why our eyes move. But the fact is that even most ophthalmologists know very little about nystagmus, so it's easy to see why most of us don't understand it either. Okay, let's start getting some answers.

CAUSES

A disorder waiting to happen

Inside our brain is a motor that controls normal eye movements, called the ocular motor system. Every mechanism within that motor must be functioning at peak performance in order for our eyes to move as they were designed.

Normal eye movements are designed to make every effort in keeping the eyes "on target." In other words, they move slowly or quickly according to the target movement, such as during normal saccades (see page 6). But with so many high-frequency mechanisms at work within the ocular motor system, nystagmus is really a disorder waiting to happen, says Louis F. Dell'Osso, Ph.D. the Director of the Daraff-Dell'Osso Ocular Motility Laboratory in Cleveland, Ohio. Dell'Osso has nystagmus and has been researching eye-movement disorders for almost 40 years. His work has led him to the conclusion that miscalibration of the ocular motor system is the root cause of nystagmus (8).

As Dell'Osso explains to people with nystagmus, imagine a technician inside your brain adjusting various knobs that control the ocular motor. If one or more of these knobs are turned up too high, there will be too much 'gain' and your eyes will start to shake. Think of it also like a loudspeaker system. When there is too much gain, the audio becomes unstable and that results in the loud squealing we have all heard at one time.

While technicians know how to adjust the gain in amplifiers and microphones to create stable sound quality, the exact process and location that causes the instability of the ocular motor system isn't known yet. In fact, there could be various processes and locations for any one kind of nystagmus or any underlying disorder. Fortunately, we are learning more every year thanks to a handful of scientists throughout the world who have dedicated their careers to understanding how the the control system to the eyes is calibrated and how it becomes miscalibrated. With independent research and collaboration, these scientists are slowly unraveling the manufacturer's design specs of the entire visual system.

Chapter



What Do I Have Exactly?

*Nystagmus is like a thumbprint.
No two people have the same.*

DIAGNOSIS

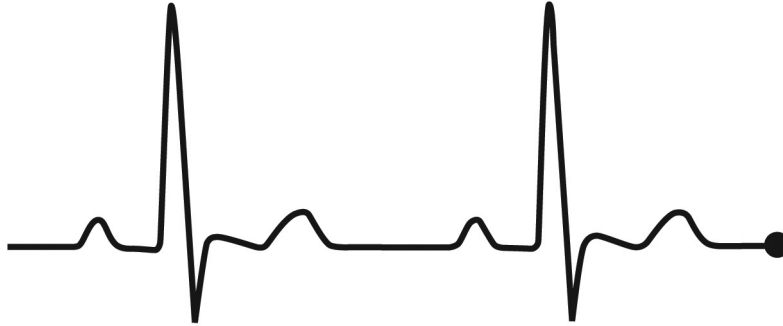
As we discovered in Chapter Two, nystagmus can be caused by a number of potentially life-threatening conditions. To rule out that possibility and determine a true diagnosis, an eye doctor skilled in treating eye-movement disorders will want to perform a variety of tests:

- **Magnetic resonance imaging (MRI)** is one of the first and most important diagnostic tests. It will capture an image of the brain that indicates the location of any tumors or other physical defects around the optic nerve, brainstem, or elsewhere.
- **Diagnostic tests** routinely performed at an eye exam (visual field, color, stereopsis, and eye pressure) give an overall picture of any visual defects and can help identify underlying conditions.
- **Full ocular examination** includes looking into dilated eyes using an ophthalmoscope or using a fundus camera to take pictures of the inside, rear surface of the eye. With these images, a doctor can see if there are any noticeable abnormalities in the retina and optic nerve area.

- **Electroretinograph (ERG)** tests how well the rod and cone receptors are operating in the retina. This is helpful for understanding why vision may be poorer at night or why glare is such a significant problem. For example, an ERG will show that people with albinism have almost no cones.
- **Electronystagmograph (ENG)** is an impressive word that even has *nystagmo* right in the middle of it, but this exam is not really testing nystagmus. The ENG is testing for problems in the vestibular system (the area of the inner ear that maintains body balance). Defects in the vestibular system can sometimes cause nystagmus, but an ENG is only one limited test among many.
- **Eye-movement recording (EMR)** (preferably using infrared or high-speed digital video technology) creates accurate waveform recordings of the speed and direction of the nystagmus, null point, and other gaze angles. This recording is graphed as a waveform such as the ones shown in Figures 2-3 and 2-4.

Eye-movement recording (EMR)

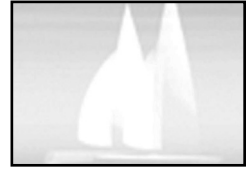
Eye-movement recordings have been performed for almost 50 years; but for most of that time, they were primarily utilized for psychological testing and various forms of research. It wasn't until the 1970s that Dell'Osso (who was trained as a biomedical engineer) began using eye-movement recordings to diagnose the various forms and characteristics of nystagmus (**15**), (**16**). Today, some specialists in eye-movement disorders routinely perform eye-movement recordings before making any diagnosis or treatment plan. Dr Hertle is one such specialist. He sees the EMR serving the same purpose as the electrocardiogram of the 1940s and 1950s. At that time, people often visited two or three heart centers to have their arrhythmia (irregular heartbeat) recorded. That recording would lead to a diagnosis, which would then form the basis of a treatment plan. Today, the electrocardiogram (EKG) is the accepted practice for observing the rhythm of the heart, diagnosing defects, and helps to form a treatment plan. The waveform that an EKG generates (see Figure 3-1) is easily recognized even by children and is not too different from an eye-movement recording.

Figure 3-1: Electrocardiogram (EKG) Waveform

Dell'Osso believes that only an eye-movement recording can identify an accurate treatment plan because only an EMR can accurately record a variety of factors that is unique to each person's nystagmus (**17**). He cites the following important characteristics of the waveform:

- First, only the waveform type positively identifies the nystagmus as either infantile nystagmus or one of the many forms of acquired nystagmus. Different types of nystagmus respond differently to the same surgery, so it is critical to know which kind of nystagmus a patient has.
- Second, if the nystagmus is infantile nystagmus syndrome, the waveform will help the surgeon to accurately calculate the following features:
 - The direction and speed of the waveform over time. Knowing exactly which direction the nystagmus is moving is critical to knowing which muscles to cut. Periodic alternating nystagmus, for instance, isn't helped much by the muscle-moving surgeries that help non-alternating forms of nystagmus. See Figure 3-2 on page 27 for an example of how eye movement variations appear on a waveform.

Chapter



What Can I Do About It?

It is no longer acceptable for any eye specialist to say to a patient with nystagmus, "Nothing can be done for you."

There are a wide range of treatment options available for people with nystagmus (22). Let's review what is available as of this printing.

OPTICAL AIDS

Correction of significant refractive errors in both children and adults with nystagmus is the single most powerful therapeutic intervention for improving vision and visual function in these patients (23).

—Richard Hertle, M.D.

Millions of people have experienced remarkable visual acuity improvement with ordinary glasses and that includes people with nystagmus. If this kind of improvement happened with any other treatment, Dr. Hertle says that it would be hailed as a new 'wonder treatment' for nystagmus; yet, that is exactly what accurate prescriptions of glasses and contacts are doing for people with nystagmus every day.

Eyeglasses

it is not yet twenty years since there was found the art of making eyeglasses which make for good vision, one of the best arts and most necessary that the world has.

—Dominican monk Giordano da Rivalto
of Pisa in a sermon on February 23, 1306 (24)

For at least 1,000 years, humanity has been using glass magnification spheres known as *reading stones*. It wasn't until 700 years ago, though, that we began shaping those glass stones into lenses and holding them in front of our eyes. During the 14th and 15th centuries, the glass industry of Italy boomed. Italian crystal workers became the world's finest opticians, exporting their crafted eyewear throughout Europe and beyond. They were hand-held pieces for the most part until about 500 years ago when man found a way to attach a cord to the lens frame and loop it around the ears. That was a great day (24).

Optical technology and frame styles have matured over the past centuries, but their impact remains the same. Spectacle making is still one of the most useful arts on earth.

Do glasses treat nystagmus?

Glasses do not treat nystagmus at its source, but wearing the correct prescription focuses light rays accurately onto the retina, allowing the possibility of clear images to be received. Nystagmus tends to decrease as images become clearer. Without a corrective lens, images might be focused either in front of the retina (if you are nearsighted) or behind the retina (if you are farsighted) causing images to be very blurry. Watch someone with nystagmus take off their glasses and put them back on again. You will probably see a noticeable difference in the intensity of the nystagmus (higher with the glasses off and less with the glasses on).

Quotes Cited

- (Q5) Sheri. The American Nystagmus Network yahoo group message# 32869. Posted on May 21, 2006. Available at <http://health.groups.yahoo.com/group/ann-list/message/32869>

Works Cited

- (22) Larry A. Abel. **Infantile nystagmus: current concepts in diagnosis and management.** *Clinical & Experimental Optometry.* (2006) Volume 89, Issue 2, Page 57-65. PMID: 16494607.
- (23) Richard W. Hertle. **Chapter 9: Nystagmus and ocular oscillations.** *Handbook of Pediatric Neuro-Ophthalmology.* (2006) Page 316. Springer Science+Business Media, New York, New York.
- (24) **Eyeglasses through the ages.** *Antique Spectacles.* Available at http://www.antiquespectacles.com/history/ages/through_the_ages.htm. Accessed June 17, 2007
- (25) Vicki Leung, B. Wick, H. Bedell. **Multifaceted treatment of congenital nystagmus: a report of 6 cases.** *Optometry & Vision Science.* (1996) Volume 73, Issue 2, Pages 114-124. PMID: 8927312.
- (26) **Institute of Optometry Research Study** as reported on the Nystagmus Network UK research web page at <http://www.nystagmusnet.org/Research.htm>. Accessed March 7, 2007.
- (27) M. Mezawa, S. Ishikawa, K. Ukai. **Changes in waveform of congenital nystagmus associated with biofeedback treatment.** *British Journal of Ophthalmology.* (1990) Volume 74, Issue 8, Pages 472-476. PMID: 2390522.
- (28) D.G. Kirschen. **Auditory feedback in the control of congenital nystagmus.** *American Journal of Optometry and Physiological Optics.* (1983) Volume 60, Issue 5, Pages 364-368. PMID: 6881263.

- (29) P. Sharma, R. Tandon, S. Kumar, S. Anand, **Reduction of congenital nystagmus amplitude with auditory biofeedback.** *Journal of American Association for Pediatric Ophthalmology and Strabismus.* (2000) Volume 4, Issue 5, Pages 287-290. PMID: 11040478.
- (30) Kenneth J. Ciuffreda. **Eye movement auditory biofeedback therapy or nystagmus: past, present and future.** Proceedings - 19th International Conference - IEEE/EMBS. (1997) Volume 6, Pages 2766-2770. Available at <http://ieeexplore.ieee.org>. Digital Object Identifier: 10.1109/IEMBS.1997.756903.
- (31) N.V. Sheth, Dell'Osso LF. Leigh RJ. Van Doren CL. Peckham HP. **The effects of afferent stimulation on congenital nystagmus foveation periods.** *Vision Research.* (1995) Volume 35, Issue 16, Pages 2371-2382. PMID: 7571472.
- (32) S. Ishikawa, H. Ozawa, Y. Fujiyama. **Treatment of nystagmus by acupuncture.** *Highlights in Neuro-Ophthalmology. Proceedings of the Sixth Meeting of the International Neuro-Ophthalmology Society (INOS).* (1987) B.F. Boyd, Editor: Pages 227-232. Aeolus Press, Amsterdam.
- (33) Tanya Blekher, T. Yamada, R.D. Yee, L.A. Abel. **Effects of acupuncture on foveation characteristics in congenital nystagmus.** *British Journal of Ophthalmology.* (1998) Volume 82, Issue 2, Pages 115-120. PMID: 9613375.
- (34) Eric Petterson. **Earring auriculotherapy for congenital nystagmus,** *Medical Acupuncture, A Journal for physicians by physicians.* (2004) Volume 16, Issue 1. Pages 43-45. Full text available at http://www.medicalacupuncture.org/aama_marf/journal/vol16_1/case3.html Accessed January 3, 2007.
- (35) B. Seif. **Nystagmus/Liver-wind affecting the eyes.** *Qi: The Journal of Traditional Eastern Health and Fitness.* (2002) Volume 12, Issue 2, Pages 8-11. Full text available at



How Do I Prepare for Surgery?

Deciding to have surgery is an emotional and intellectually exhausting experience. Some people take years to make a decision. While adults may have this luxury of time, parents need to consider that visual development is forming during the first six months of life and continues for the next several years. The earlier treatment begins (surgical and non-surgical), the better the chance that the visual system will develop in normal ways. Studies also show that the best results of surgery are more likely to occur in children under the age of eight. Realize that it's never too late, though. Significant results are still possible, even in adults.

Once the decision to have surgery has been made, it's time to prepare.

YOUR PERSONAL SURGERY PLANNER

The planning offered in this chapter is based largely on this author's own journey of diagnosis and treatment during three trips from Los Angeles, California to Pittsburgh, Pennsylvania: one for diagnosis, one for treatment, and a follow-up to determine the clinical effects of surgery. However, this chapter is just as applicable for patients having surgery locally. Keep in mind that your surgeon and hospital may have requirements throughout the preparation phase that will affect your own planning strategies. Don't be shy to ask your health care professionals about their procedures and allow for some flexibility as you create your own personal surgery planner. Let's begin that plan with getting organized.

Get Organized

You need to be able to find essential information and create a paper trail between you and the various people involved with your surgery. For some of us, there's nothing like a brand new file holder in a cool color with nifty pockets to motivate us to get organized. But even if your file system is only a shoebox, it's better than leaving papers piled on a table, in the glove compartment, and on the floor. Get organized:

- Keep all insurance papers and medical documents (test results, doctor reports, prescription info, etc.) in one place, no matter how trivial the paper may seem.
- Whenever possible, handle conversations with hospital and insurance staff by email and snail mail and file those written responses in your organizer.
- Keep notes from phone conversations and write your to-do lists in one notebook designated only for surgery matters. Keep that notebook with your organizer.

JANUARY				
S	M	T	W	T
		1	2	3
6	7	8	9	10
13	14	15	16	17
20	21	22	23	24
27	28	29	30	31

6

Months Before Surgery

Insurance Matters

The first step in planning for surgery is to find out how much of it will be covered by your insurance policy. This is not an easy answer. There are hundreds of public and private health plans and just as many policies regarding what kinds of medical procedures they approve, how much they pay for those procedures, and under what conditions. You could read the policy, but it may not clearly say what you want to know. Translate that policy to user-friendly language by speaking to the benefits department at your insurance company and get their answers to these questions in writing, if possible:

- **Are my physician, hospital, and anesthesiologist approved providers?** This is important because each provider will bill separately for their services.
- **What percentage of the fees charged by the hospital, the surgeon, and the anesthesiologist will be paid through the insurance plan?** In other words, what fees, co-pay, or deductible will I be personally responsible for paying?
- **What are the procedures for qualifying for this coverage?** For example, do I have to get a second opinion? Who requests the pre-authorization and when?

Insurance companies usually require the surgeon's office to submit a Pre-Authorization form within 30 days of the surgery. But don't be fooled by the name of this form. It does not *pre-authorize* payment. In fact, the form should really be called *Pre-Notification* because all it really does for most insurance companies is put them on notice that you are about to have surgery. It doesn't guarantee payment.

Start Scheduling

Schedule a visit with your local eye doctor

If your local eye doctor does not see you before surgery, it will be difficult for him or her to evaluate how the procedure affected your nystagmus and your vision. It will also make it more difficult for him or her to discuss your care with your surgeon.

Schedule the hotel

If surgery is scheduled during a busy vacation season, arrange for the hotel and flight well in advance. Try to make a reservation at a hotel that is within 15 minutes of the hospital where you will have surgery. You and your eyes will appreciate the short journey.

Schedule the flight

Consider arriving at least one day before the pre-op appointment to get settled in and maybe do some sightseeing. Consider leaving two days after surgery. This will let you rest and stay close to the surgeon, if needed.

If you are not able to afford the costs of the flight for surgery try contacting the following organizations and airlines. For qualifications and guidelines, visit each website or call the numbers listed below:

Air Care All is a central resource for free air transportation provided by volunteer pilots and charitable aviation groups.
Website: www.aircareall.org

Angel Flight America arranges flights with volunteer pilots who use their own private aircraft at their own expense.
Phone: 888-426-2643 Website: www.angelflightamerica.org

National Patient Air Transport Hotline helps people in financial need find free or reduced rates for air travel for medical purposes.
Phone: (800) 296-1217 Website: www.mercymedical.org

Glossary

Listed here is vocabulary commonly heard at eye care offices and throughout medical research literature. The terms are defined as they relate to nystagmus.

abduction (ab-DUK-shun)

Normal movement of the eye away from straight ahead position to an outward direction.

accommodation (uh-kah-muh-DAY-shun)

The process in which the lens of the eye increases in power in order to keep objects in focus as they move closer to the eyes.

acuity

See visual acuity.

albinism (AL-bi-niz-i m)

Portuguese: *albo*, meaning *white*, also Latin: *albus*, meaning *white*.

Oculocutaneous albinism is the absence of normal pigmentation or coloration in the hair, skin, and eyes. **Ocular albinism** is the absence of pigment only in the eyes. Albinism is often accompanied by vision problems, such as nystagmus, sensitivity to light, and retinal defects that cause low vision.

adduction (ad-DUK-shun)

Normal inward movement of the eye toward the nose.

adjustable sutures See *sutures*.

amblyopia (am-blee-OH-pee-uh)

Greek: *amblys* meaning *dull* + *ops* meaning *eye*.

Also known as **lazy eye**. Decreased vision in an eye that is otherwise physically normal. Usually occurs when the brain stops seeing out of an eye that is not aligned correctly due to strabismus. Vision therapy, optical aids, and sometimes surgery can reverse amblyopia.

amplitude

Distance of eye movement (in any direction), usually measured in millimeters. Decreasing the amplitude of nystagmus improves cosmetic appearance, but *does not*, in and of itself, affect visual acuity.

anirida (an-uh-RID-ee-uh)

Greek: *an*, prefix meaning *without* + Latin: *iridis* meaning *rainbow*

Literally means “without iris.” Also known as **iris hypoplasia**. A congenital defect where the iris does not develop completely. Often associated with nystagmus, sensitivity to light, and poor vision.

aphakia (ay-FAY-kee-uh)

Condition where the eye has no lens, usually due to removal during cataract surgery.

Anderson-Kestenbaum (A-K)

Surgery that moves an eccentric null point to the center position by moving two muscles in each eye. If only one muscle in each eye is moved, the surgery is only referred to as **Anderson**.

astigmatism (uh-STIG-muh-tiz-um)

Greek: *a* prefix meaning *without* + *stigma*, *stigmat* meaning *point*.

A condition in which the curvature of the cornea is irregular, causing light rays to bend unevenly as they enter the eye. The rays then land on the retina at different points instead of one focal point. Slight uncorrected astigmatism may not be noticeable, but a large amount may result in blurring and headaches. Special contacts and glasses to correct astigmatism can be prescribed.

atrophy (AT-troh-pee)

Deterioration or loss of function in cells, tissues, or an organ, such as with *optic nerve atrophy*.

binocular vision

Latin: *bini* meaning *two* + *oculus* meaning *eye*.

Also known as **fusion**. The ability to see one image out of both eyes at the same time.

Bioptic (bi-AHP-tik)

A small, single telescope that is mounted to the top portion of an eyeglass lens to help people with low vision see or read distant objects, such as names on street signs or fast-food menus.

biofeedback

During vision therapy, biofeedback provides visual or auditory information about how the eye is functioning so that through trial and error, a person learns to consciously control and improve these functions.

Index

A

accessibility software 49

acquired nystagmus.
See nystagmus: types of (pathologic): acquired (AN)

acuity 17, 18, 19, 20, 21, 26, 28, 37, 41, 47, 48, 49, 50, 52, 53, 54, 56, 57, 63, 64, 65, 66, 68, 69, 70, 73, 74, 75, 77, 83, 109, 114, 115, 116, 117, 121, 123, 125

adduction null 16

age, effects of 54

albinism 11, 24, 31, 33, 34, 42, 47, 56, 66, 67, 69, 70

alcohol, effects of 4, 5, 6

alternating gaze angles 17

amblyopia 31, 59, 68, 71, 109, 122, 123

amplitude 33, 57

Anderson-Kestenbaum (A-K).
See treatments: surgical

anomalous head posture. See null point

B

Baclofen 56

Botox 55

C

cataract 31, 110, 111, 112, 114, 119

CEMAS, Classification of Eye Movement Abnormalities and Strabismus 29, 31, 32, 37, 111

closed-circuit television (CCTV) 48

congenital nystagmus 2, 30, 32, 81

convergence 16, 48, 61, 75

convergence damping 16, 26, 71

crossed eyes. See strabismus

cysts 105

D

Dell'Osso, Louis F. XI, 8, 10, 11, 15, 21, 22, 28, 37, 54, 61, 62, 63, 71, 75, 76, 80, 82, 83, 117, 122, 127

Dell'Osso Procedure.
See tenotomy

doctor, finding one 34–36

E

electronystagmograph 24

electroretinograph 24

eye drops 103

eye movement recording (EMR) 24, 28, 37, 59, 61
types of 28

eye muscle anatomy VII, 58

F

fovea 18, 20, 57, 77, 114, 115, 116, 122

foveation VII, 17, 18, 19, 20, 21, 26, 37, 49, 50, 51, 52, 53, 57, 68, 69, 70, 72, 77, 80, 106, 114, 117, 122

fusion maldevelopment
nystagmus syndrome (FMNS).
See nystagmus: types of
(pathologic)

G

gabapentin 56

Galbraith, Jennifer XI

gaze null 16. See also null point

gene transfer therapy 76–77

glasses
bifocal 44
effects on nystagmus 40–41
keeping on children 42–43
reading glasses 44

H

head bobbing 15, 31, 114

head nodding 15

Hertle, Richard W. III, IX, XII, 14, 21, 22, 24, 29, 37, 39, 63, 76, 79, 82, 83, 101

horizontal gaze nystagmus
test 5–6, 115

I

infantile nystagmus syndrome
(INS). See nystagmus: types of
(pathologic)

International Classification of
Diseases (ICD) 28

J

jerk nystagmus. See nystagmus:
descriptions

L

Leber's congenital
amaurosis 76–77

Leung, Vicki XII, 50, 51, 79

M

macula 18, 112, 114, 115, 116,
117, 121

magnetic resonance imaging 23

memantine 56

N

NAFX 26, 117

neurontin 56

null point XIV, 16, 21, 24, 27,
43, 44, 45, 48, 57, 58, 59, 61,
62, 64, 66, 72, 75, 88, 105,
110, 112, 113, 117, 122. See
also treatments: surgical:
Anderson-Kestenbaum

null zone 66, 68, 69, 77, 117,
122

nystagmus*causes of*

- genetics **11**
- idiopathic **14**
- neurological & physiological Disorders **12**
- visual system defects **12**
- cataracts **13**
- cone or rod dystrophy **13**
- myopia **13, 43, 114, 117, 120**
- optic nerve hypoplasia (ONH) **13**

cure **76–77***descriptions* **28–34**

- (a)Periodic **32, 33, 34**
- asymmetric (a)periodic alternating nystagmus (APAN) **33–34**
- circular/elliptical **33**
- congenital **32**
- downbeat **33**
- early/infantile/late onset **32**
- horizontal **33**
- jerk **32**
- motor **31**
- oblique/diagonal **33**
- pathologic **31**
- pendular **32**
- periodic alternating nystagmus **33**
- sensory **31**
- torsional/rotary **33**
- upbeat **33**
- vertical **33**

diagnosis of **23***etymology of* **1–3***prevalence of* **2–3***seeing 20/20 with* **20***types of (in everyone)* **4**

- caloric stimulation **4**
- end-point **5, 6**
- optokinetic **4**
- physiological **3**
- (post) rotational **4**
- railway **4**
- saccades **6**
- vertical **4, 28, 31, 33, 50, 63, 113, 115**

*types of (pathologic)*acquired (AN) **12, 17, 21, 26, 32, 54, 56**fusion maldevelopment nystagmus syndrome (FMNS) **29, 30, 31, 110, 117**. See **Fusion Maldevelopment Nystagmus Syndrome**infantile nystagmus syndrome (INS) **11, 15, 16, 22, 29, 32, 55, 56, 62, 66, 68, 83, 117**. See **infantile nystagmus syndrome (INS)**spasmus nutans syndrome (SNS) **31****O****ocular examination** **23****ocular motor system** , **10, 11, 13, 14, 22, 57, 63, 111, 118***miscalibration of* **10, 11, 13, 15, 57, 63**

oculocutaneous albinism.

See albinism

optic nerve hypoplasia 31, 68, 118

oscillopsia 8, 17, 22, 119

P

pendular nystagmus.

See nystagmus: descriptions

periodic alternating nystagmus 33. See also nystagmus: types of (pathologic)

R

research, staying current 76–77

S

saccades / saccadic oscillations 6, 10, 29, 121

Snellen eye chart 66, 68, 121, 123, 125

spasmus nutans. See nystagmus: types of (pathologic)

stitches 102

strabismus XIII, 11, 26, 27, 31, 35, 51, 55, 59, 60, 61, 66, 68, 71, 72, 81, 88, 100, 105, 109, 113, 119, 122, 130
surgery for 59–61

stress, effects of 19, 53, 54, 75

surgery options. See treatments: surgical

surgery, planning for

free airfare 92

get organized 86, 97

insurance matters 87, 87–90

physical exam 94, 97

pre-op appointment 97

prepare a recovery kit 95–96

scheduling considerations 90–92

surgery day 98–100

what to bring/wear 98

surgery, recovery from

complications 105

driving after surgery 104

follow-up

appointments 105–106

pain management 101–102

post-op appointment 100

using eye drops 103

vision therapy 105

wearing contacts 104

T

tenotomy 62–73

results of 64–70

treatments

acupuncture and chinese medicine 53

biofeedback 52

drugs 55–56

neck and forehead stimulation 53

optical aids 39–49

contacts 45–47

eyeglasses 40–45. See also glasses

magnification **48**
 prisms **47–48**
summary **74–75**
surgical **57–77**
 Anderson-Kestenbaum **57,**
 57–59, 62, 64, 75, 81,
 110, 117
 convergence / bi-medial
 recession **61**. See
 also **convergence damping**
 risks of surgery **73–74, 105**
 strabismus correction **59–61**
 tenotomy **62–73**
vision therapy. See also **vision**
 therapy

V

vision therapy, XII, 50, 51, 52,
59, 73, 105, 110, 119, 123, 130

W

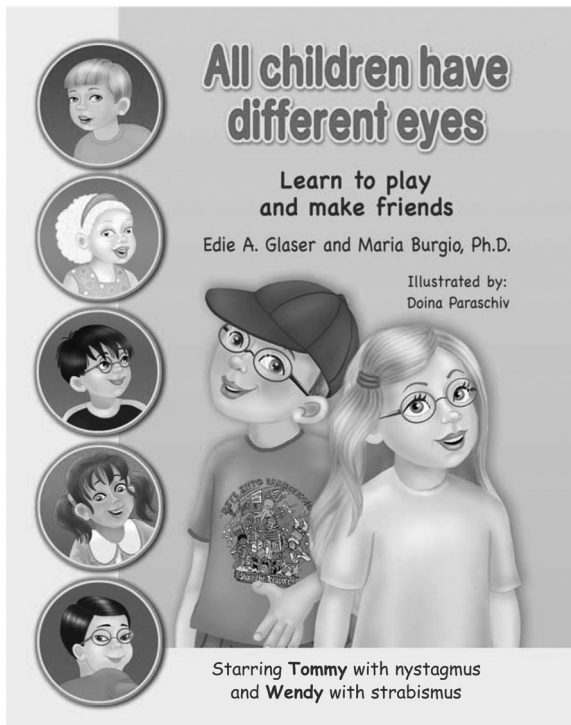
waveform XIII, XIV, XVII, 18,
24, 25, 26, 28, 30, 32, 34, 50,
53, 54, 64, 72, 79, 113, 117,
123
illustration of **18**

About the Author

Eddie Ann Glaser is a Southern California writer and business owner who has lived with nystagmus, strabismus, and low vision since she was an infant. Through her writing, she is proud to help children and adults understand their vision conditions in new ways. Her first work in this endeavor, co-written with a child psychologist, is entitled *All Children Have Different Eyes*, a picture book that models how children can learn to play and make friends while competently dealing with the social challenges of living with their visual impairment.

Eddie is pursuing a Master of Professional Writing degree at the University of Southern California and offers freelance nonfiction writing services to organizations and budding authors. Eddie is happy to speak at schools, libraries, and special events about being an author or about living with nystagmus and visual impairment. She can be contacted through her website at **www.lowvisionkids.com**.

All Children Have Different Eyes



All Children Have Different Eyes is a beautifully illustrated storybook starring Tommy with nystagmus, Wendy with strabismus, and children with a variety of visual impairments. The diverse characters model how to confidently and competently play and make friends while facing difficult social challenges, such as answering questions about their condition, entering play groups, or handling their limitations responsibly. Over 40 examples and activities transform the engaging stories into an interactive workbook for parents and teachers. Classmates will also learn to become better friends and

playmates when they discover why children with visual impairment see and play differently. A glossary for kids and resources for adults complete this valuable resource in every child's social development.

I wish my teachers had this book when I was growing up as a child with low vision. Today, it will help explain to my nieces and nephews why I don't see like they do.

-- Michael Stone, Resort Developer

"I love it!...especially how confident the kids are, their persistence to make friends, and their explanations for why they do what they do."

-- Cindy, mom to son with low vision

Visit the LowVisionKids.com website for excerpts, games, events, and more.

Available direct from the publisher at

www.lowvisionkids.com

also at Amazon.com and library wholesalers

Fax and Mail Order Form

Your Order

Quantity	Book title	Price	Total
_____	All Children Have Different Eyes	\$16.95	\$ _____
_____	Navigating Nystagmus With Your Doctor	\$22.95	\$ _____
		Subtotal	\$ _____
	Shipping & Handling (\$4.00/1st book + \$1.00 each additional book)		\$ _____
	Tax (8.25% for California Delivery)		\$ _____
		Grand Total	\$ _____

Shipping Information

Name: _____
Address: _____
City: _____ State: _____ Zip: _____
E-Mail Address: _____ Phone: _____

Billing Information (Purchase Order, Check, or Credit Card)

Purchase Order Number: _____ Check Number: _____
Credit Card Number: _____ Expiration Date: _____
Credit Card Type Visa MasterCard Discover Amex
Signature: _____

Fax this form to: 1-800-409-7170
Or make check/money order payable to:
Vidi Press
11721 Whittier Blvd. #203
Whittier, CA 90601



service@vidipress.com
www.vidipress.com