

American Nystagmus Network
Editor
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Newsletter of the
**American
Nystagmus
Network**

July 2001



Nystagmus is an involuntary eye movement 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. The American Nystagmus Network, Inc., is a nonprofit organization established in February, 1999 to serve the needs and interests of those affected by Nystagmus.

be used to minimize adverse effects of nystagmus. Coping challenges and adjustments are prevalent throughout life for those with nystagmus and their families. It can be especially challenging after initial diagnosis, and throughout early childhood development and primary education. It is commonly troublesome to social development during adolescence, when dating and obtaining a driver's license can be so important. The challenge of coping with nystagmus continues through adulthood. Preparing for careers and finding jobs involve choices which may be strongly influenced and determined by functional vision and appearance. Lifestyle and personal adjustments, beyond earning a livelihood, impose a never ending need for coping skills.

ANN not only seeks to serve those affected by nystagmus, but also to provide useful information to persons with a professional or personal interest as well. These include health care providers, educators, researchers, and other relevant private and public institutional personnel.

In following its mission, ANN will utilize all media, publish and distribute materials to specific audiences, maintain an Internet website, and hold periodic conferences. ANN will pursue funding from its members and friends and from organizations, agencies, and institutions, public and private, sensitive to its mission.

ANN, Inc. Caveat: Though discussions on specific problems are permissible and expected, remember that nothing here shall constitute professional health care or medical advice, and you should never rely on any contribution to this bulletin on important medical or professional health care questions. No publication is a substitute for the careful advice and treatment of a competent professional health care provider or doctor. ANN, Inc. is a volunteer, nonprofit organization for persons and families involved with nystagmus. ANN, Inc. does not diagnose or treat, or provide professional counseling. It is involved in self-help, while trying to promote research and education, among other goals contained in its mission statement.

Mission Statement

The American Nystagmus Network, Inc. is a nonprofit organization founded in 1999 to serve the needs and interests of those affected by nystagmus. It is an outgrowth of the Nystagmus E-Mail List introduced on the Internet two years earlier to provide information on a wide variety of topics pertaining to nystagmus.

Although nystagmus takes several forms and is associated with a wide variety of different conditions and sometimes with no other condition, nystagmus generally refers to involuntary eye movement 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.

ANN seeks to provide technical and experiential information about nystagmus and its manifestations, but not medical advice. Information relates to a wide range of concerns including without limit, diagnosis, type, visual effects, non-visual effects, tests and available treatment. It also covers heredity, research, and known statistical data on nystagmus.

ANN also seeks to provide help in coping with nystagmus through the exchange of information and ideas, guidance and counseling. ANN seeks to respond to specific problems and concerns and provide feedback which may

Contents of this Issue

From the Editor	2
2001 Conference	5
Profile: Sister Patricia Ann Preston	8
Nystagmus E-Mail Discussion List	15
LASIK and Nystagmus	16
<i>by Jen Hensil, O.D.</i>	
Benjamin's Story	18
<i>by Kerri Johnson</i>	
Nystagmus Support Activities in the United Kingdom	24
<i>by Chris McMillan</i>	
Letter from the ANN Board	26
ANN Mission Statement	28



This bulletin is an occasional publication of the American Nystagmus Network, Inc.

From the Editor

Since this is my first issue as editor of this newsletter, I do feel a need to introduce myself. I'm David Garrett of Newport, Tennessee, a member of the Nystagmus e-mail list for several years (though not a frequent poster).

After Alan Burstein put out a call for a newsletter editor, I put myself forward and the Board was gracious enough to accept my offer to put out the newsletter.

My experience with newsletters goes back to 1971, when my wife Virginia and I were part of the crew who helped put together the newsletter for our tropical fish club. I've put out the monthly newsletter for our church since 1979. I've done newsletters on mimeo, using stencils and tons of

correction fluid, and on Xerox. I've used desktop publishing programs on a Commodore 64, in DOS, and now in Windows. I don't want the "good old days" back - they weren't that good!

One of the new and interesting challenges of doing this particular newsletter for me is working out the best compromise between fitting all the material in and making the newsletter as readable as possible for a number of people with vision difficulties ranging from mild to severe. I know, in a community as large as the ANN, the design won't be the best it could be for everyone. However I hope it works well for most of you.

Our experience with nystagmus goes back to 1977, when our son

the coming year, however, it is our hope to reach out beyond the internet to a wider audience. To borrow a phrase from recent popular politics, let our ultimate goal be to leave no child with nystagmus behind! Whether you can join us in Minnesota or not, we'll invite you to join us in pursuing this goal in any way you can. We appreciate your ongoing support and look forward to our all continuing to work together.

Sincerely,

ANN Board of Directors

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(those with active e-mail addresses)

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Letter from the ANN Board of Directors

Nearly two years have passed since our first conference in Cleveland. For many of us, it was our first opportunity to meet others with nystagmus. It was a wonderful learning experience, teaching us not only about low vision and nystagmus itself, but also giving us with nystagmus something of an opportunity "to see ourselves as others see us." We with nystagmus came away from the conference feeling better about ourselves, and nystagmus parents came away feeling better about their children's future.

We've kept up with the friendships we made in Cleveland, and now we're looking forward to seeing old friends and making new

ones at our upcoming conference in Bloomington, Minnesota, on June 22-24. We'll hear from legal experts, other professionals, old friends of the mailing list including Drs. Newman and Hensil, and keynote speaker Dr. Hertle, a leading expert in Nystagmus. We'll share our own experiences with one another, and on Sunday morning, we'll have our annual membership meeting to discuss ANN's activities and elect a new board of directors. It's not too late to plan on joining us in Bloomington, so we hope to see you there!

Increasingly, ANN is growing to serve the nystagmus community as a source of information through the mailing list, conference, newsletter, and soon to be released informational brochure. In

Geoffrey was born. Both Geoffrey and our daughter Arwen (born in 1980) were born with albinism and severe nystagmus, as well as the other vision difficulties associated with albinism. Geoffrey graduated from Tennessee Technological University with a degree in chemistry in 2000 and is living at home now; Arwen will be a junior at Rhodes College in Memphis this fall, working toward a professional career in music.

While they don't drive - which is a real hassle in this society - , they **have** been able to be incredibly active and productive people. Both were honor students in high school (Arwen was a valedictorian), and both won scholarships to college. Geoffrey ran varsity cross country in high school. Arwen marched in the

marching band. Both of them have some years experience working at DollyWood, a local theme park, including running cash registers.

I guess if we have one message we would like to give to parents of children with nystagmus, it's this - trust your children. Get the accommodations they need, but don't do too much. Their ability to work around their vision and achieve their goals is greater than you think. In retrospect, the two or three most important interventions we made in the school system during their childhood were not getting services that they needed - though we did that - but intervening to **stop** the system from giving them inappropriate services which would have fostered dependence rather than independence.

But enough editorializing, and enough bragging - if you'd like to meet us in more depth, our personal website is:

www.planetc.com/users/garrett

Has anyone got a good idea for a name for the newsletter? It would need to be approved by the Board, of course. I would also recommend that it be simple - complex and humorous names don't tend to wear well over a long period of time. So far the best thing I've thought of has simply been **Vision**. Let me know any other ideas.

Remember that your personal submissions of articles are welcome. They may not be printed immediately; every editor's dream is a backlog of good material for future issues. Hopefully we'll have a balance of organizational

news, articles by professionals, international news, and personal stories from both adults with nystagmus and parents of children with nystagmus.

If you write letters, we could even have a "letters to the editor" column.

Please address all letters and articles to:

David Garrett

515 5th Street

Newport, TN 37821

You can also send material to our e-mail address:

garrett@planetc.com

However, please don't send any pictures or other large attachments to that address - our formerly state-of-the-art computer is now ancient and it's a daily fight to keep enough hard drive space open to keep it going!

Hope you enjoy this issue.

laws.

We meet for an 'annual general meeting' and conference each May. Our membership runs to around 700 from the UK and Europe.

With the exception of our paid Development Worker, all the committee are volunteers, receiving only expenses.

Many people contact us first of all either via our national helpline, or via the web site:

<http://www.btinternet.com>

NN UK has a quarterly newsletter available in large print or on cassette, and monthly 'web letter' entitled *Focus*. Parents may 'link up' via this forum, and all ages contribute their views on living with Nystagmus. It is also where we share information and ask for help.

Literature plays a big

part in our 'education'.

'Wobbly Eyes' for the newly diagnosed has been written by eye specialists, and a booklet written by one of our younger members, 8 at the time, tells how 'she sees it'. In addition there is a 'yellow card' for parents to give to teachers.

NN UK does not have any medical personnel on its committee, but we are very fortunate indeed to have the support of several ophthalmologists.

Whenever possible we raise money which pays for research projects. Fund raising events range from the simple 'coffee morning' or car boot sale to more adventurous sponsored sports events. We occasionally have been able to gain governmental funds too - but it is the hard work of our members which has made us what we are today.

Nystagmus Support Activities in the United Kingdom

by Chris McMillan

Hi, I'm Chris from the UK. My Nystagmus was present from birth. My husband has a visual impairment and we have a fully sighted daughter aged 17. I have been a *noisy* chatterer on the Nystagmus mail list for most of its life.

Nystagmus Network UK was formed in 1984 by parents of children with Nystagmus to help them receive the best education possible through mainstream education, to spread the word about living with Nystagmus, and if possible to fund research



into its causes.

As time goes on, we are also able to work closely with other groups where Nystagmus is part of the condition and other national organisations for visually impaired children.

We are a registered charity under UK's charity

2001 Conference

ANN will hold its second conference in Bloomington, Minnesota (Twin Cities area) on June 22-24, 2001. Our keynote speaker will be Dr. Richard Hertle, M.D.

Hotel Registration

The conference will be held at the Holiday Inn Select Minneapolis/ St. Paul International Airport. Reservations can be made by calling the hotel directly (1-952-854-9000) or on-line at <http://www2.basshotels.com/holiday-inn>. The ANN rate for a hotel room is \$109.95 plus tax per day and for a suite is \$119.95 plus tax per day. These rates are available until June 1, 2001 and after that depending on space availability.

Conference Registration

To register for the ANN 2001 Conference, please fill out the registration form and mail it along with the appropriate registration fees to the address on the form. The form is available on the ANN website (www.nystagmus.org) and requires the Adobe Acrobat Reader program. If you need the program you can download it at no charge from www.adobe.com. If you have problems getting the form, send e-mail to webmaster@nystagmus.org.

PROFILE PROFILE



**Sister Patricia Ann
Preston, SSND**
Mount Mary College,
Milwaukee, WI

Science Finally Caught Up with Me

It was a March day at the height of the Depression, 1933. The nurse brought my parents' second child to them for their first view. They already knew that **she** wasn't the hoped-for **he**. They first saw a quite large head with lots of dark hair, so much in fact that a caring nurse had arranged the damp locks in a marcelled hairdo - in fashion at the time. However, to my poor parents it looked as if I had a corrugated skull. After hunting amid the blankets for two arms, two legs, they settled in to look at their bumpy-headed daughter and noticed that she had eyes that raced from side to side constantly.

Benjamin's nystagmus has dampened to the point that it is no longer noticeable, not by me, or even his Pediatrician! I attribute this to his young age at the time of the surgery. I think his brain was able to compensate much better than an older child or adult's brain would. We still go for yearly check-ups with Dr. Brodsky, and while he can still detect the Nystagmus, Benjamin's vision was pronounced perfectly normal for his age at our last visit! We are so thankful to Dr. Brodsky, the wonderful people on the ANN List, and for God's protection and direction through all of the difficult times.

For questions or comments, please email me, Kerri Johnson, at michaelj@nwaisp.com. I would be happy to help in any way that I can.



Benjamin at 4 years

Benjamin was born, he had the "Kestenbaum" surgery to correct his head tilt. The way it was explained to us, a muscle on the top and bottom of each eye would be cut, then reattached in a slightly different position. This would, in effect, tilt his eyes instead of his head. We went to Arkansas Children's Hospital early in the morning for the outpatient surgery. I think the hardest thing I have ever had to do was handing my baby over to the nurse. Then came the waiting. It seemed like time stopped, but it actually took 2-3 hours before we could see him again. After a short observation period, Benjamin was released around 1 p.m. He was very groggy and slept most of the day.

The recovery time was approximately six weeks. That was how long it took

for him to unlearn the habit of tilting his head. During the first few days after the surgery, the most difficult part was keeping Benjamin from rubbing his eyes. Apparently, his eyes were very itchy, and explaining to a 1 year old that he must not rub his eyes is not an easy task! But at least the itching went away during that first week; the redness and swelling took another 2-3 weeks to go away completely. And all of the heartache was worth it to hear the Dr. say, at his six week follow-up, that the surgery was a success and the head tilt was gone!

It has now been three years since the surgery. Even if the head tilt returned tomorrow, Benjamin has had at least three years of normal growth and development. The most miraculous part of the surgery, though, is that

(A famous Spanish novelist created a character, a beggar, that he described as having "dancing eyes." I prefer his words, but no one has ever used them for me.) Later my parents learned that I was born with a congenital nystagmus.

I was born into a not "politically correct" time in history, when neither physical oddities nor quick intelligence were at all desirable. My parents, however, had a superabundance of love and showered it on me, my older sister, and several years later my long-awaited two brothers. Their way of coping with my differences was basically to ignore them. Although there were to be some negative consequences for me in part of my emotional development, it was certainly the best choice given the times, and I am grateful to

them. And I certainly never lacked for love.

I somehow learned to crawl and walk, probably with a few more falls than most toddlers. In contrast to my extraordinarily active older sister, I loved to sit very quietly with a pot holder on my head (perhaps nature's way of helping me to know which part of me was up.) There were really only two outward signs of my physical limitations - the fast-moving eyes and the extremely poor sense of balance, which frequently left me on the floor or falling up or down stairs. My intelligence manifested itself in my being able to read before I entered school, much to my parents' dismay, since prevailing child development theory in our community was that this was dangerous because there was a "very thin line between genius and insanity." So I learned very

young that it was definitely not good to be different and found a child's way of covering up my differences.

I couldn't do much about the fast-moving eyes, except to be very careful not to look directly at others, especially children, who might turn to their mothers and say, "Look at that funny girl with the crazy eyes." Besides, quite soon a completely separate problem, considerable near sightedness and astigmatism, forced me into eyeglasses, which didn't help my racing eyes, but hid them behind thick lenses. My lack of balance soon relegated me to the last chosen for the team and eventually into a spectator or scorer. My sister, a born teaser, found delight in her odd little sister and, out of my mother's hearing, would ask me, upon bringing new friends home, to "Turn around quick, Patsy, and show them how

you fall." I was always very obliging and very grateful that we had soft carpets.

By the time I was in 2nd Grade, probably even before, I had learned that nobody liked people who were "different" and that telling my mother or doctors about the "weird" things that happened to me, like sudden shudders from the top of my head to my toes, sudden extremely sharp pain in the back of my neck, shooting up into my head and momentarily paralyzing my face, constant fatigue, the need to concentrate on walking, turning, or doing anything involving balance, not seeing many of the things everybody else seemed to see, only elicited a questioning look and to my mind a negative doubt about my truthfulness.

I was social and had many friends, who often helped me up and down stairs without

sided smile. However, he warned us that the surgery might not be permanent, that Benjamin's eyes might readjust and the head tilt return. In that case, Benjamin would need the surgery a second or even third time. We scheduled a follow-up visit, and then rushed home to do more research.

The first place I went was to the Nystagmus List. I emailed out a desperate plea for any information about this surgery. And I received a very mixed bag of responses. Several people wrote me saying that their Drs. didn't recommend this surgery until a child was much older, around 7 or 8 years old. Apparently, around this age a child's vision quits changing, making the surgery more likely to be permanent. Other List members responded that

there was no need to put a child through surgery for "cosmetic reasons". I only heard from one mother whose son had actually been through the surgery and had good success with it, although he was much older than Benjamin. But her email gave me an idea of what to expect. The thing that decided the issue for me, though, were a couple of emails I received from people who had chronic neck/shoulder pain and headaches that they attributed as a direct result of their head tilts/null points. Mike and I knew we didn't want Benjamin to go through that kind of pain in his adult life. This seemed to validate what Dr. Brodsky was saying: that Benjamin's muscles and nerves would not grow right without the surgery.

So in March of 1998, almost exactly a year after

10 p.m., and then visited two different emergency rooms after I tripped and dropped Benjamin on the parking lot! (That's a whole different story!) We returned to the hotel around 1:30 a.m; Benjamin had a large swollen area on the back of his head, but the Drs. had determined he was otherwise fine. His



Benjamin at 7 months

parents, on the other hand, were nervous wrecks. And his appointment with Dr. Brodsky was for nine o'clock the next morning.

Refreshed and rejuvenated (NOT!), we met with Dr. Brodsky the next morning. Dr. Brodsky performed many tests, and had other Drs. look at Benjamin. The hardest part was when they needed to lay him flat; his poor head was so sore that he couldn't lie still! Finally, Dr. Brodsky told us what we had heard before: that there was no cure for his Nystagmus. But then he laid a bombshell: that Benjamin would definitely need surgery for the head tilt, and the sooner the better. Dr. Brodsky was very concerned that Benjamin's head tilt would cause his face and neck muscles to grow wrong. Benjamin was already developing a lop-

railings, over railroad tracks (a terrifying ordeal to walk across every day); but I always felt extremely alone, afraid that what was "wrong with me" was really "all in my head" meaning all in my imagination or that I was crazy.

And so my life went on, with natural adaptations as part of my unconscious way of being - always holding a handrail on stairs, deciding to "watch" games, always sitting down while dressing, stretching my hands in front of my face to avoid walking into clotheslines in the backyard, or even find them while trying to hang out the laundry. My small suburban town's only high school prided itself on its sports and phys ed program, even for girls. Mandatory gym three times a week became a source of great frustration. My ninth grade teachers became concerned after

observing my brightly flushed face and very unsteady gait after gym, but my parents wanted everything in my life to be absolutely normal so they did not accept the school's offer for an exemption from gym. Therefore for four years I changed into gym clothes, participated in any activity which did not involve turning around, balance or good sight (i.e., very little), learned the rules and methods of sports, and sat on the bleachers watching my classmates.

We didn't have eye tests for driver's licenses when I was 16, but my father was extremely demanding when he taught me to drive. I am sure he was quite aware of my slower visual reaction time and so emphasized defensive driving, even back in 1949. Wisconsin only introduced the fancy eye test machines about 20

years ago and does allow the alternative for my eye doctor's approval for renewal, so I have driven regularly with only one accident, for which I was not judged responsible, during the past 52 years; but I am a very defensive driver.

Somehow my high school record had some indication of my poor eyesight, although I had never asked for or received any accommodation in school. (It wasn't done in those days.) So when I applied to Bryn Mawr College, I had to get my eye doctor's statement that I could do college work. He tried hard to convince me "to find a nice young man who could support me well and provide me with household help, and raise wonderful, bright children." However, I prevailed; he signed, and I graduated *Magna cum laude* with honors four years later

and then completed my Ph. D. and postdoctoral studies. I admit that I couldn't copy from blackboards frequently, often didn't have time to finish reading assignments, never had time to re-study my classnotes and could never cram. I did train myself young to pay very close attention in class, to review mentally over and over what I had just learned, to use a unique shorthand mix of abbreviations, Greek, Latin and Spanish words with some math symbols thrown in to take good notes in class. (Fellow students never asked to copy my notes after one look at them!) Around age 30, plastic lenses and improved techniques allowed my good eye's vision to be corrected to 20/40.

I always thought my lack of balance was due to my

nice, very thorough, and very matter-of-fact. He told us that Benjamin had Congenital Nystagmus (CN), that there was no cure, that he might have to have surgery when he got older, and to come back in a month. We were stunned. We couldn't even remember how he had pronounced that funny word he had written down for us, "Nystagmus". And surgery? He had said there was no cure, so what was the surgery for? Mike and I felt like we had been hit in the stomach. I cried most of the way home.

After the initial shock, we turned to the internet to educate ourselves. The first place I found was the ANN Website. I quickly signed up for their email list, then read everything I could find on that site and others about CN. I learned that the "cute" head tilt was really called a "null point", and was

Benjamin's best position for seeing things. The surgery our Ophthalmologist had mentioned was designed to straighten the null point. By the time we went back to the next appointment with the Ophthalmologist, we were armed with a list of questions and understood enough of what the Dr. said to ask more intelligent questions. He finally told us that he could refer us to Arkansas Children's Hospital if we wanted a second opinion, but that there was really nothing that could help Benjamin. We wanted that second opinion.

When Benjamin turned 9 months, we found ourselves on the way to Little Rock, Arkansas, to meet with Dr. Michael Brodsky at Arkansas Children's Hospital. We had a harrowing 4 hour drive through fog and rain, arrived at our hotel around

Benjamin's Story

by Kerri Johnson

Benjamin Thomas

Johnson was born in March of 1997. He was a full term, happy, healthy baby with no complications. Benjamin's development was normal; however, around four months of age, an uncle pointed out to us that Benjamin's eyes moved back and forth. My husband, Mike, and I were certain that it was just part of the normal development for a baby. Benjamin was our first child, so everything was new to us. Besides that, we took Benjamin to a wellness checkup every month, and even though we saw a different Pediatrician every time, not one of them had mentioned anything about his eyes. A short time later, we began to notice that Benjamin had a cute way of looking at people. He would tilt his head to the left and

look up at them, almost as if he were studying them. People thought he looked adorable. We thought his head tilt was a little unusual, but quickly convinced ourselves that it was just his charming little personality coming through (Remember, we were brand new parents.)

At 7 months, Benjamin came down with a little cough, so we quickly bundled him off to the Pediatrician. We saw yet another different Pediatrician this time, because the clinic was large enough to have several Pediatricians on staff. I remember thinking it odd that this Pediatrician wasn't very concerned with Benjamin's cough, but instead, strongly urged me to take Benjamin to an Ophthalmologist.

So away we went to the Ophthalmologist, with no idea what to expect. The Ophthalmologist was very

congenital nystagmus. I still do not know. When I was 59 I needed to see an ear doctor for very minor care, not knowing that this doctor, referred to me by a colleague, was a specialist in otoneurology, particularly balance problems. He offered to do a new computerized balance test on me. I truly thought that I performed very well. However, on my return visit for the results, the doctor told me that I had flunked the brain test. I was apparently born without that part of the brain that puts all your balance sensory messages together and tells you how to stay upright. This struck my funny bone and led me to think for the first time that "it really was not all in my head." I had to live for over half a century before science caught up to explain to the mind of the

little girl with the dancing eyes, tipsy body and severe headaches what wasn't in her head. Since the government had recently passed the Disabilities Act, I decided it was finally time to stop hiding and proclaim myself somewhat disabled unabashedly.

Throughout my life I have maintained that I was born with a headache (possibly the result of the "corrugated" skull,) but learned very early that any mention of the way too frequent headaches was most apt to elicit an "I don't know why" and look of "it's all in your head" from doctors and my mother. When I had the first MRI of my brain in 1996, the neurologist reported that she found no cause for my increasing difficulty with balance, but she also showed me over 100 slices of my brain on the x-ray

film, each clearly showing the radiologist's circle around one or more "holes" (officially called cysts of unknown origin) in my brain. She assured me that all three specialists who reviewed the films concluded that they had been there from birth and apparently were insignificant. Much to the neurologist's bewilderment, I found this wondrously humorous and started to chuckle, reflecting to myself, "It's not that it's all in my head; it's that it's all not in my head." I also don't know if this is related to CN.

So much for the congenital problems! There is no future in going into detail about the other parts of my body that have gone awry – a cervical laminectomy 24 years ago that left me with chronic neck, arm and hand pain,

multiple allergies, a crummy digestive system, extensive arthritis, other neurological problems, etc. Suffice to say that I am a master at adaptation. As a result of the many falls, concussions and a skull fracture, I have a hard head, a totally deaf ear, no sense of smell, with the concomitant lack of 98% of my taste, and a variety of stitches on my skin.

Because of my arthritic spine and lack of balance, for the past four years the college community has come to know me as the mad driver in the three-wheeled Safari cart that dashes through the tunnels, corridors and in and out of elevators. My cane, which I started using at age 60 for balance safety, serves for everything - opening and closing windows and doors, retrieving dropped papers, pens or bottle tops, pushing

Although this change may go unnoticed in those with 20/20 vision, for someone with optic nerve hypoplasia, this change could theoretically reduce vision further. More research certainly needs to be done in this area before any conclusions are reached, but it is something to consider.

LASIK is a very good procedure for the right candidates, but not all

people are good candidates for this surgery. It is also important to go into this surgery with realistic expectations. Individuals interested in LASIK should seriously weigh the risks and consult with their primary eye doctors regarding whether or not it is appropriate for them.

- Jen Hensil is a practicing optometrist specializing in low vision -

A decorative border consisting of a repeating pattern of stylized eyes with blue irises and black pupils, set against a yellow background. The border frames the central text.

Visit the website of the
American Nystagmus
Network

www.nystagmus.org

LASIK and Nystagmus

by Jen Hensil, O. D.

The advertisements for LASIK surgery often promise to rid a person of glasses, to improve uncorrected vision to 20/20 or better, and provide a new independence of vision previously impossible. To a person with low vision, this may sound like a miraculous procedure that could provide them with perfect or improved vision, but this is not the case.

Vision loss, whether it be associated with nystagmus or any other eye condition, is not related to a person's refractive error (their glasses prescription). Glasses or contacts only change the way light bends in order to focus it on the retina. LASIK works exactly the same way, changing the

way light bends within the eye to address refractive error, not the cause of the vision loss.

There are also complicating factors to consider with LASIK. Virtually all post-LASIK patients experience increased glare and decreased contrast sensitivity, particularly at night. For those with low vision, who already have poor contrast skills and sensitivity to glare, LASIK can compound these factors and decrease potential vision.

Recent research indicates that LASIK may reduce the nerve fiber layer in the retina, which limits the amount of visual input reaching the optic nerve.

elevator buttons. It seems that each month my body dreams up a new challenge and each month I use all my problem-solving skills to discover another way to adapt. The President of our College told me that I reminded her of the Energizer Bunny, I just keep going. A stuffed Energizer Bunny, from a faculty colleague, sits on my desk!

A love of others, a good sense of humor, strong determination to keep going, the knowledge that "I'll lose it if I don't use it" and "the best way to handle pain and disability is to distract yourself from it" gets me out of bed each day and on my way. However, there are times when everything seems to give out at the same time (even the battery on my electric cart went kaput at a particularly low point recently) when I repeat the

words of St. Teresa of Avila when she was once sorely tried, "If this is the way you treat your friends, Lord, no wonder you have so few." (Only my version, with a chuckle, goes, "If this is the way you treat your friends, Lord, maybe I could be a bit 'less of a friend' for a while?")

In many ways I am grateful for the challenges that life has brought my way. I believe it has made me more sensitive to others' hidden or obvious pains, differences, sufferings. I don't go looking for others to help, but somehow we seem to sense each other instinctively. I can seldom be more than one who listens, understands and supports them as they face their challenges, but I trust my being there is of help. It certainly is for me. My adult world has

encompassed many college students, faculty and administrative colleagues, hundreds of children, youth and adults in the inner city of Milwaukee through various alternative schools and programs I have founded or co-founded, foreign students, teachers, and most especially my Religious Community, the

School Sisters of Notre Dame, and my ever-supportive and understanding personal family. Each one has enriched me and helped to energize me, somewhat like the tangible spirit of God's love being there to support me and keep the old Bunny going along its always a-little-tilted, twisted path.

Sister Patricia Ann Preston graduated from Bryn Mawr College magna cum laude with honors in Spanish. She was granted her masters' degree in 1961 and her Ph.D. in 1964 from Catholic University in Washington. She has done post-doctoral study at the University of Valencia (Spain), the University of New Mexico, and Washington University in St. Louis.

She has been a professor of Spanish at Mount Mary College in Milwaukee, Wisconsin, since 1971, and has filled a number of positions including serving as Academic Dean from 1971-76 and 1984-92.

Sister Patricia Ann has a special interest in bilingual education. In 1965 she founded the first bilingual Head Start in the United States and served as its director until 1971. The program is still flourishing.

She has a long list of professional awards and publications to her credit.

Nystagmus E-Mail Discussion List

An Internet mailing list is available to people with nystagmus, parents of children with nystagmus, vision researchers interested in nystagmus, and others to communicate informally via e-mail.

The list name is **ann-list**.

It is intended to be an open forum for anyone with any connection to or interest in nystagmus. It is completely free. The list can be used to ask questions, answer others' questions, or to share information about nystagmus. All messages sent to the list become public domain, unless they contain a copyright statement. Information on the list is for discussion purposes only.

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