



# American Nystagmus Network

## Parent/Teacher Communication

Student Name \_\_\_\_\_

Date \_\_\_\_\_

### Overview of Nystagmus

Nystagmus is a condition characterized by an *involuntary* shaking or jerking of the eyes, which usually results in some degree of visual loss. The degree and direction of eye movement, amount of visual loss, and resulting impairment varies greatly from person to person. It is a complex ocular condition that is well recognized, but not yet understood. Patients with nystagmus often hold their heads in a seemingly abnormal position, in an effort to maintain a null point - a position whereby eye movement is minimized. Nystagmus results in a decreased visual acuity or low vision that *cannot be corrected* to 20/20. Corrective lenses (i.e., glasses or contact lenses) and low vision aids (i.e., magnifiers or telescopes) can provide some clarification. Most people with nystagmus rely on their eyes for reading, and do not use Braille.

Website with more information: <http://www.nystagmus.org>

### Fluctuation in Vision

Some research suggests that an increase in the speed or magnitude of the eye movements results in decreased visual acuity. Other research suggests the causal link is reversed and the eye moves in response to decreased visual acuity. Regardless of the causation, this decrease in visual acuity can be caused by stress, emotional state, fatigue, or the direction of view. **[Insert Name of Student]**'s vision fluctuates between 20/\_\_\_ and 20/\_\_\_\_. **She/He** is somewhat aware of his periods of decreased vision, but is commonly unaware of the variations in his vision. Eye fatigue also causes decrease in visual acuity. **His/Her** best vision is early in the day.

### Null point

The null point is the head position at which the student has the most eye control. **[Insert Name of Student]** most typically achieves this by turning **his/her** head to **his/her left/right**, while looking to **his right/left**. **[Insert Name of Student]** will naturally do this when **his/her** visual acuity has decreased.

## Glasses

**[Insert Name of Student]** wears glasses to correct **his/her astigmatism/myopia/hyperopia**. When **his/her** nystagmus is calm and **he/she** is wearing **his/her** glasses **he/she** has **20/\_\_\_** vision. Unfortunately, when the eye movements increase and **he/she** needs to use his null point, the glasses actually can decrease **his/her** vision. **[Insert Name of Student]** will take off **his/her** glasses sometimes when they are not helping to provide better vision.

## What **[Insert Name of Student]** Sees and the Challenges.

Students with nystagmus commonly:

- Do not know what the "sighted" world sees. They only know their own reality.
- Process less information from their visual frame. As a result, "lower resolution vision" is a better description than "blurry vision," especially because the latter description implies correctability with glasses. (Show classroom picture on next page.) It helps if teachers say what they are writing as they write it.
- Encounter difficulty looking from one surface to another (board to paper) or one block of text to another (paragraph to questions).
- Do not readily see facial features, facial expressions, or other sources/forms of non-verbal communication. For example, they struggle to detect a teacher's stern glare implying, "Silence!" These students need to hear it.
- Struggle to recognize friends and classmates at any meaningful distance. If a teacher or student waves to them from across the playground, they may not respond to the gesture simply because they cannot see it. People with nystagmus may inadvertently be viewed as "stuck up" because they do not acknowledge people, when in reality, they simply do not see or recognize people. Please encourage students to call out and use words when interacting with a student with nystagmus.
- Encounter difficulty locating/finding lost papers/class work.
- Experience eye fatigue. It is important to allow these students to take a break and rest their eyes.

## Remember **[Insert Name of Student]** is a child

- **He/she** does not want to be different.
- If you ask what **he/she** wants, he usually wants to be treated like all the other students. Sometimes **he/she** has been teased by other students over **his/her** "special" treatment.
- **He/she** loves to play on the computer and check **his/her** social media. (Unfortunately, these activities cause eye fatigue. So it is difficult to be a normal child and still get all the homework done.)

## College (Middle School and High School prepares students for college.)

Teachers often say that their class is preparing students for college. Students with nystagmus will have special services provided to them in college.

The Americans with Disabilities Act requires that colleges offer accommodations, such as:

- Paid note taker for each class
- Technology available in each classroom
- Testing accommodations e.g., extra time on tests, testing in another environment, or oral tests.
- Exam and accommodations coordinator to work with all professors.

### Classroom Accommodations for this year

- Should sit in the front row so he/she can see the board, overhead projector, or videos.
- May need to change seats to avoid glare from overhead lights or windows.
- May need to wear hats and sunglasses in the classroom as well as outside to address light sensitivity.
- Will likely encounter difficulties sharing materials; he/she should have his/her own worksheets and books.
- Should be permitted to copy another student's notes.
- Should be permitted to digitally record class lectures.
- Should be provided enlarged tests and handouts, as well as have materials presented in high contrast. Reading handouts in 8 and 9 point font is difficult. As a point of reference, standard business correspondence is written in 11 point font. Some people with nystagmus need enlarged and large print materials. (Best font size varies by person.)
- Visual acuity changes: what he/she can see one day, he/she may not be able to see the next day. Stress including timed test decreases his/her visual acuity. Allow student to use stress reducing techniques in class.
- It is difficult for a person with nystagmus to copy from a board or an overhead. Please copy overheads if prepared ahead of time. Otherwise allow him/her to copy straight from the transparency or the teacher notes.
- Other useful nystagmus education tools include: raised line paper, slant boards, highlighted reading guides or colored paper.
- Use of visual aids like telescopes, magnifiers, video cameras may also be needed.
- PE may require using bigger and brighter balls.
- Allow the student to take eye rest breaks.
- Student may need extra time to complete assignments and tests.
- Allow the student to visit the classroom the day before school starts so they can spend time viewing all the walls and the layout of the classroom before other students arrive.
- No bubble answer sheets. Student should be allowed to write answer directly on the test.

