

Winter 2017

Welcome to NOAH Ed U!

The National Organization for Albinism & Hypopigmentation (NOAH) presents this complimentary supplement, geared toward educators, based on our quarterly magazine, *Albinism InSight*. We encourage you to share this publication with other educators who work with children with albinism. To enter your school or email address to this distribution list, please contact info@albinism.org.

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Does the family of your student with albinism know about NOAH? Share this supplement with them so they can learn what NOAH has to offer!

Dixon Teaches Class

By Meredith West

First grader Dixon proudly shows his classmates his braille typewriter. He and his Teacher of Students with Visual Impairments (TVI) demonstrated the typewriter and answered questions including one child's question about why the letter A in braille didn't look like the A that they wrote. About 2 weeks after this, the parent of one of his classmates relayed this story:

Her daughter told her that she wanted to learn braille like Dixon



because "one day Dixon could be all the way blind, but we



will still be friends. I want to be able to make him a card he would be able to read then." While it's very unlikely that Dixon will ever become "all the way blind", the normalization of the technology from the beginning is helping Dixon embrace and use tools like these.

Literacy Media and Children with Albinism

By Anne L. Corn, Ed.D.

This is the third article in a 3-part series. The first, published in the Summer 2017 issue of *Albinism InSight* provided an historical background to the controversies regarding literacy media - braille, print, or dual media (braille and print), as well as controversies in orientation and nobility and other areas of education for students with visual impairments. The second article focused on orientation and mobility skills for children with albinism (Fall 2017). This article speaks to the assessment and instruction of literacy media for children with albinism.

Come wintertime, parents may be thinking of how well the school year is going and how pleased they are with their child's learning, especially about how their child's reading and writing skills are coming along. Is your child progressing with his reading and writing skills? Was the

learning media assessment (LMA) useful? Has your child received access to the printed information available to classmates?

I am a former teacher of students with visual impairments (TVI) and now a retired professor of special education who prepared teachers of students with low vision and blindness. I also held a joint academic appointment in ophthalmology and vision sciences at Vanderbilt University. The emphasis in my research has been on the use of low vision. I have also taught braille reading and writing to future teachers, conducted research into young braille readers, and co-authored with Kelly Lusk, Ph.D. (2006) an early survey of teachers' reports regarding dual media instruction (braille and print). This article is based on my experiences and preferences with both print and braille. I am also a woman with congenital low vision who uses optical and electronic devices for my literacy.

Upfront, I should say that over the years, I have known individuals with various causes of low vision who have become efficient print readers. I have also known people who read braille as a literacy medium; they, too, have

become successful in educational and professional endeavors. And, I have also known dual media readers who choose which medium to use with various tasks.

My experience, however, tells me that most children with albinism who receive quality low vision evaluations, prescribed visual devices (for acuity and light sensitivity), instruction in the visual skills associated with reading and writing, and support for learning to use their vision, are very likely to become efficient print readers and writers.

Still, I also believe braille should never be considered a "last resort" for any child with low vision. I don't wish to see the

consideration of braille be postponed until a child falls so far behind his age and ability group that he feels like a failure.

Learning Media Assessments (LMA)

A "promising practice", sometimes referred to as a "best practice" is a method or procedure that has garnered a high level of consensus among professionals. Providing a learning media assessment (LMA) for a child with low vision is one of these practices. An LMA is a method of observing behaviors and existent reading and writing skills. A primary focus for the LMA is to recommend whether a child would derive a greater benefit from receiving literacy instruction using print, dual-media, or braille. However, the LMA is a thorough assessment of how a child uses his vision in literacy skills.

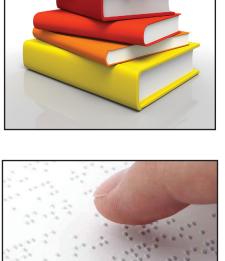
Learning Media Assessments may be informal assessments or structured observations. With an informal assessment the TVI describes observations covering many different

> reading and writing components (described below). A structured LMA may use checklists and forms to create a profile of how a child uses her visual and tactual senses. With a structured LMA, the TVI will have forms to complete and they should be included within an LMA report. If a "standardized" instrument is used, parents may want to ask to review the test manual.

Learning media assessments may be completed at various times during a child's schooling. Some of these times include: during the preschool years, during routine comprehensive assessments in K-12 programs, in preparation for an IEP meeting, or when a child experiences changes in vision or visual needs. I strongly believe

an LMA should be conducted following low vision services that includes three components: a clinical low vision evaluation (by an ophthalmologist or optometrist with a low vision specialty), the provision of optical devices (including lenses for light control) and/ or electronic devices, and instruction in their use.

Since 1997 the regulations for the federal special education law (IDEA) requires that braille be the "default" learning media for children with visual impairments and



considered annually for a child receiving an IEP; as such, data from an LMA and other reading and writing tests (if given) should be a part of the discussion.

Accommodations for taking an LMA apply as they do for any other testing within a school program. If listed on an IEP or 504 Education Plan, a child should be able to:

- Use glasses or contact lenses
- Use optical and/or electronic devices
- Use lenses for light control (if prescribed)
- Use visors or other items that will assist with light sensitivity
- Place reading material at a comfortable reading distance from his or her eyes

Only with these accommodations can a child demonstrate his or her current ability and/ or potential to be a print reader during an LMA. As visual fatigue and reading rates may vary throughout the day, the LMA should be given at times of day when measures will be meaningful.

Based on the age and needs of the child, an LMA may include, but not be limited to:

- a profile of how a child uses and prefers his or her vision, tactual, and auditory senses
- behaviors during reading print at near distances, e.g., posture, visual fatigue and reading stamina
- measures of literacy skills, e.g., reading rate, fluency, reading level;
- visual skills, e.g., eye and/or head movements
- use of optical and/or electronic devices
- use of added- or lower levels of illumination
- identification of pictures, maps, and diagrams



- use of low, medium, and high contrast materials
- copying or taking notes from information at a distance
- writing behaviors, e.g., use of lined paper, ability to copy from a text and at a distance, skill at handwriting
- reading of various types of text, documents, mathematics, music, workbooks, diagrams, maps
- reading materials for daily living skills, orientation and mobility
- reading from a distance, e.g., whiteboards, projections
- use of non optical visual devices, e.g., to mark one's place or a tachistoscope (to block parts of a page), book stand
- psychosocial aspects of reading, e.g., feelings toward reading and writing in print and/or braille
- comparisons of optical device mounting systems, e.g., stand or handheld magnifier

An LMA may also be used to assess whether a child will do better with standard or other sizes of print. While I prefer a child not begin with large print, many children have this as their only option in school. While print is larger in the early grades for all students learning to read, if a child is only provided with large print after approximately 3rd grade, I encourage parents to ask why this approach was chosen among

other methods for print magnification.

If a child is able to comfortably and efficiently read standard print without optical or electronic devices, an LMA may be used to describe how low vision may or may not be impacting the child's literacy skills, e.g., reading stamina, reading speed. In this situation an LMA goes beyond standard assessment of reading and writing given to the general education population and it is used to determine if instruction is needed to improve visual behaviors, e.g., if words are missed, or speed of moving from one line to the next. If the child's reading rate is slower than peers, the TVI should provide an analysis of the child's reading behaviors and skills. Saying a child has low vision and therefore will read slower is only partly true.

Regardless of whether a child with a visual impairment is reading print, braille, or is in a dual media program, a reading speed should be provided to parents. In discussing any change of reading media, parents should also be provided with typical reading speeds for an age group with the new media. To compare a child's reading speed with that expected in general education classes, the following chart is offered (Hasbrouck and Tindal, 2006). Unfortunately, I have not been able to find a reading rate chart or obtain measures for braille for children with low vision. While testing it is generally accepted that a student who uses print receives time and

a half and those who use braille receive double the allotted time for typically sighted students. This is because many professionals believe the average silent reading speed for adults who read braille is about 125 words

per minute. From the chart below, this is about the silent reading speed of a typically sighted child between second and third grade. The assumption is also that a child with low vision who reads print reads somewhere between the two speeds. These assumptions have been made without research to substantiate the reading speeds of children who have low vision.

classmates. He is using head movements rather than eye movements to read across lines and he is taking approximately 2 seconds to change his gaze from one line to the next."

The bottom line is that the LMA should be informative and recommendations included in the report should not only include a plan for use of learning media and technologies,

Grade	Oral Print	Silent Print
1	53	80
2	89	115
3	107	138
4	123	158
5	139	173
6	150	185
7	150	195
8	151	204
9		214
10		224
11		237
12		250
College		280

The narrative of an LMA report should not only include descriptions of what the child uses but also indicate the child's level of skill, efficiency and comfort. For example, saying "Becky uses a hand magnifier" is a fact but "With a 20 diopter hand magnifier, Becky is able to keep her eye in the optical center, use appropriate eye movements, maintain the focal distance and use smooth hand movements across lines and from one line to the next",

> provides for a better understanding of Becky's skills.

Another example may relate to how well a child is able to read across lines. Rather than say "Joe is a slow reader," it is more informative to say, "Joe is reading at approximately 2/3 the speed of his



but also guide the development of goals and objectives for the visual and/or tactual instruction within a literacy program.

At times the LMA will be considered as a part of a functional vision assessment (FVA). The FVA generally looks at a child's use of vision in various activities that are and are not a part of literacy instruction. One assessment should not obscure the other and they may both lend information that is useful in planning. In addition, reading assessments, either formal or informal will provide information that also needs to be considered, e.g., a child's reading level, reading vocabulary and fluency.

Media Considerations for Discussion

When discussing print, consideration should be given to four types of print for near vision tasks:

- standard print without optical or electronic devices
- standard print with optical and/ or electronic devices
- hard copy enlarged print (to a specified size, e.g., 30 pt.), and
- hard copy large print (16-18 pt. font)

Certain fonts may be more

easily read than others, e.g., a font which is sans serif, but which font to use is not always discussed. A child may benefit from a combination of these approaches. For example, a child may be able to read standard print without devices for reading but prefer the use of a magnifier for mathematics where fractions and superscripts present smaller font size numerals.

I want to note that optical and/or electronic devices can enlarge the print image to a size that is individualized for a child and be used with all print materials that typically sighted individuals read. A distance device enables children to read whiteboards, projections, see plays and so forth. These devices enable a child to become more visually independent.

There are times when large print is easier to use and when one might want information enlarged. However, there are serious drawbacks to large print as a sole or primary reading medium that may effect a child's literacy skill development, e.g., slower reading speeds. The scope of this article does not allow for a full discussion of this issue.

When discussing braille, consideration should be given to:

- literary code contracted United English Braille (UEB)
- literary code alphabetic alphabet only
- mathematics code Nemeth or UEB math (depends on which code a state is using)
 - foreign language codes

• scientific notation, music, and other codes needed by the child

In recent years, there has been a change in the braille code, from English Braille to the Unified English Braille (UEB). This was done to enable English speaking countries to have the same code and to be able to better exchange

books and electronic files. For a time, books will be available in both codes and braille instruction should include those configurations that students may find in books published only a few years ago.

If dual media is recommended, the discussion should include whether it is anticipated that both braille and print will be available to the child for all lessons, whether one medium will be primary and the other used for certain tasks or times during the day. As the child develops braille skills, there should also be an expectation of when a child will begin using braille in for specific tasks and/or when the child will be using braille for specific academic classes.



Whether a child is using print, braille, or dual media, an accepted practice is the use of live readers, recorded texts, or auditory downloads as a supplement for completing assignments. Auditory approaches should never replace a traditional literacy program in which reading and writing skills are paramount.

Colleges and employers are not known to provide either large print or braille texts or materials. As students become older the use of recorded texts and personally transcribed and enlarged materials take on a new meaning. Fortunately, technology allows for an individual to create transcriptions from computer to speech or braille and to enlarge images on a screen (as well as to change colors of letters and background).

IDEA and Assistive Technologies

One of the provisions of IDEA is for assistive technologies. These may include optical or electronic devices for use of

vision, equipment and software for braille reading and writing, and devices for recorded or computer-generated auditory books and materials.

IDEA includes provisions for: a medical evaluation is covered if the purpose is to improve a child's functioning in special education, assistive technology assessments, and purchase and maintenance of assistive technologies, and instruction in the use of prescribed devices - one of the roles and functions of teachers of students with visual impairments (TVIs) and certified orientation and mobility specialists (COMS). If low vision services are considered necessary so as not to discriminate against a child, e.g., to provide access to a curriculum given to classmates, they may also be provided within a 504 education plan.

The Association for the Education of the Blind and Visually Impaired, the American Academy

of Ophthalmology, and the American Academy of Optometry have each adopted a position paper or a professional guidance document calling for three components of evaluation, provision of devices, and instruction within low vision services.

In some schools TVIs and COMS distribute optical devices to children. There are three reasons why I consider this to be a disservice to the child. First, these professionals do not have the academic background to understand the optical characteristics of certain devices, e.g., light gathering properties of specific lenses. Second, there are many lenses that may be helpful to children that these professionals

are unable to provide, e.g., low light transmission lenses and contact lenses. Third, TVIs and COMS may have access to the kit of devices provided through the American Printing House **AUDIOBOOKS** for the Blind (APH) (which are available to schools on federal quota funds), but there are a

> very limited array of devices within the kit and within the materials there is a statement that the devices should only be used following a clinical low vision evaluation. While a TVI or COMS may choose a device that is the right device for a child, there are too many limitations to this practice.

Recommendations for Print

Access. When print is recommended as a child's reading medium, a TVI will work to ensure that the child has access to print materials that typically sighted children receive. This includes print that is in texts, tests, on computers, on whiteboards, on projections. In addition, children should be able to access print found in daily living activities, e.g., reading food packages, measuring devices. Of importance is also that children have access to books that are read for class assignments. For example, if children are reading a hard copy of a play script, it too



should be available for a child who needs a different size print.

Accommodations. Regardless of how print is accessed, accommodations may or may not be needed for near and distance viewing, e.g., the general education teacher may write with a black marker on a whiteboard rather than lighter colors, a child's seat may be chosen so as not to experience reflections from the whiteboard, use of a bookstand. When a bubble sheet is used for a multiple choice standardized test, a variation of the answer sheet may be an accommodation.

Extended time for assignments and testing (described above) is also an accommodation for a child who has low vision. Bold line paper,

use of markers, use of a slant board, or use of markers instead of pens, may be accommodations. Also, a child may be given the opportunity to use a computer to write rather than used ruled paper with a pen or pencil.

Accommodations should always be placed on an IEP or 504 Education Plan. This inclusion insures that a child will be able to have accommodations in both daily classroom and in testing situations.

Instruction. While the general education teacher will often provide reading and writing instruction, a TVI will work to provide instruction that is relevant to a child's having low vision. Instruction may include reading and writing skills, learning to use prescribed optical and/or electronic devices, and skills to independently adapt print to meet one's needs. The TVI may use checklists of skills with a device as a child's skills are developing.

Instruction in reading print is also available within orientation and mobility services. Learning where to look for printed signs, how to read a building directory, or how to scan for signs within a store, are examples of reading print at a distance. Further, a youngster who travels independently may need to read signs from a moving bus or how to look for addresses. Those who have the potential for becoming a low vision driver will need to read road signs while traveling at various speeds.

Goals and objectives for instruction with print should be written into IEPs and other service plans.

Recommendations for Braille Only or Dual Media Instruction

When braille is recommended for children with low vision it is generally introduced as part of a dual media literacy program. Parents will want to learn about the advantages and disadvantages of braille instruction. Braille

> can be fun to learn and parents' conveying their enthusiasm to learn braille is very important. When I taught braille reading and writing to typically sighted future teachers I knew that their reactions to learning braille skills would impact their own students' feelings and acquisition of literacy skills.

When children are learning and using braille, I strongly encourage parents to learn literary and mathematics braille (and other codes as needed) along with their children. This will enable parents to assist with homework and to have a shared communication media with their child. Although it is important for a typically sighted parent to understand and experience the mechanics of reading braille by touch, parents with typical vision are often relieved to know they can learn to read and write braille using their vision. By looking at the patterns of raised dots, parents can read the letters and other configurations that are part of the braille codes.

The messages a child receives about his or her "sightedness" or "blindness" may help or hinder a child's learning process. A child



who tries to hide his visual impairment may be more reluctant to learn what he considers a "blind skill" whereas a child who is eager to use whatever approach is needed to complete a task may view braille as a welcome opportunity to more easily read and write. The Braille Challenge is a nation-wide program that encourages skill building and competition among students in first through twelfth grades who are learning and using braille as a literacy medium. Schools should have information about local, state, and national competitions.

There are two points I want to make. First, braille will not solve a reading problem that originates with the process of reading. Years

ago, educators tried to teach braille to students with reading difficulties who had typical vision. It became evident that those with reading problems in print also experience reading problems with braille. This is because reading occurs in the brain where the reading process occurs once sensory information is taken in. And second, while braille is more accessible through computer transcriptions, downloaded books and use of other equipment than

in the past, large print texts and braille print in various environments are not available in braille. Being able to access print through direct, optical or electronic enlargement will provide far more access to information than braille. In a day, consider how much a typically sighted person reads in print - from food packages to price tags, from road signs to building directories. Braille is an excellent medium for many tasks but the ability to read print is far more functional.

Access. Access to manual and electronic braillers, a slate and stylus for "hand writing", and an electronic embosser need to be accessible during the times when the student is using braille. Braille paper, labelers, diagraming devices, and devices for specific subjects, e.g., geometry, should also be available. If the student is to write print or script, raised line paper should also be available.

In order for a TVI to have braille books and day-to-day in-class materials available in braille a system is devised to allow for transcription time. For example, a general education teacher may email printed materials to the TVI one week ahead of the time they will be presented in class. This will also allow for the TVI to provide any instruction needed prior to use; for example, a child may need to learn new braille mathematical symbols

for a first lesson in geometry or a raised-line map may need to be prepared.

Accommodations

Accommodations for students who use braille include but are not limited to:

• additional work space to accommodate equipment on desks and the size of braille books

• additional storage space for books and materials within the classroom

- extended time for testing as described above
- alternative answer sheets for testing as needed
- permission to use equipment that add sounds to a classroom environment, e.g., a Perkins braillewriter

Accommodations for braille readers should be included on IEPs and 504 Education Plans.

Instruction. Once the goals and objectives have been determined for literacy instruction, how, when, where, and who provides instruction needs to be articulated.

When Lusk and Corn (2006) asked TVIs



who were teaching braille to children with low vision about the environmental methods they use, there was no consistency in their responses. Some TVIs allowed children to look at their braille, others showed the print on a screen, others blindfolded children and still others used a frosted plexiglass between the child's hands and the braille. TVIs may choose a method they believe to be the best method for an individual child but as yet there are no "best practices" for teaching.

In a Delphi study by Holbrook and Koenig (2000) the authors looked at 11 areas of literacy and asked an expert panel about the intensity and consistency of instruction needed

for a child in a traditional literacy program. After a few rounds of questions, the panel came to a consensus on their response. While it is understood that each student needs an individualized program, the panel recommended students should receive direct instruction daily from kindergarten through Grade 3 for one to two hours per day. This level of consistency and intensity of instruction was recommended to ensure students' steady progress. When Corn and

Koenig (2002) conducted a mirrored study on low vision literacy, they also repeated the question about beginning dual media readers. The expert panel of low vision professionals were of the same opinion regarding this type of instruction.

A TVI should be the professional to provide direct instruction in braille. In some school districts, a person who reads braille, but without certification to teach in public schools, or to teach reading, or to teach braille, is hired as a paraprofessional. I don't recommend this approach. An analogy would be hiring anyone who can read to teach a group of typically sighted children in an elementary school classroom to read. While some children would learn to read, it is not a legal practice in public schools.

Sufficient time for braille instruction should be included on an IEP or 504 Education Plan. In addition, a TVI should have sufficient time to order and prepare materials in braille including diagrams for class lessons, for direct instruction in braille reading and writing, and to transcribe what a child has written in braille into print for a general education teacher to read in a timely manner. While it is unrealistic for everything available to sighted students to be put into braille, there are items that children will need, e.g., to play games which have printed cards, to be able to independently read a grade

on a test along with a teacher's comments. There should be a clear understanding of what will and will not be available in braille and whether equipment will be readily available when children need it.

One of the issues that has arisen with children who have low vision and are learning braille relates to the curricula that are used. There are instructional programs for teaching reading with braille to young children,

e.g., Patterns, Braille Fundamentals, or older youngsters, e.g., Read Again. Because a child with low vision may be in a general education class, the curricula offered to the class may be very different than that used for braille instruction. For example, vocabulary and spelling words may not be the same. Another problem may occur when contractions in braille don't align with phonetics taught in print. Further, if a child is receiving instruction in the use of optical or electronic devices, the choice of printed materials should consider what is taught in the general education class. For these reasons, it is important that TVIs and general education teachers coordinate their efforts for literacy instruction.



Evaluation of Literacy Skills

Once instruction has begun, progress in the acquisition of literacy skills should be monitored and reviewed. Objectives include observable and measurable criteria for achievement. As such, parents may anticipate receiving data sheets or reports about their child's new skills and pace of learning. These reviews should be coordinated with assessments of reading and writing given to all students who are engaged in a literacy program. As children become older, and peers

have acquitted literacy skills, the emphasis on basic literacy will be reduced in the general education classroom. For the TVI and the COMS, however, there should be a continuing consideration of approaches and use of literacy skills.

Conclusion

Learning media assessments (LMAs) are useful tools in determining whether children will benefit from a

print, braille, or dual media literacy program. However, LMAs can also be used to identify and plan for the development of visual skills that are needed by a child who has albinism. All recommendations should be based on observations that substantiate that recommendation. Regardless of the media that is recommended, parents should receive sufficient information for an informed choice. There should also be assurances that children will have access, accommodations and instruction in using learning media for literacy instruction.

Program Note

Reading and writing are considered to be core subjects such as math and social studies and science. In schools that have adopted the Expanded Core Curriculum for Students with Visual Impairments (ECC), instruction in print and/or braille may also be listed under such areas as: Sensory Development and Efficiency, Technology Skills, Compensatory Skills, Daily Living Skills, and Orientation and Mobility skills.

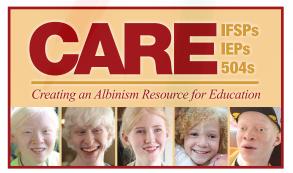
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New School, New Worries

By Bryan Rodden



This year I started a new school- middle school. I was really nervous about making new friends, changing classrooms, and getting lost. We just moved to North Carolina a year ago, so I didn't have lot of friends going into middle school.

In fifth grade, I did many things to get ready for 6th grade. I tried making friends. I tried to do well on my homework and tests. I tried (and failed) at opening

combination locks. I visited the school 3 times with my Orientation & Mobility teacher.

When 6th grade started, kids asked about my hair a lot, but they stopped asking after the 1st week. I didn't have any problems changing classrooms or getting lost. I did have problems packing up from band and getting sunscreen



for PE in enough time. The problem was solved by the PE teacher giving me more time.

My iPad is the best tool for my vision. I use my iPad to take photos and zoom in on them. I

also use my iPad as a digital notebook.

My school does BYOD: bring your own device. If your school does that you should take a device. I like to bring both a monocular and a magnifier; it really

helps me see the board or read small print.

Overall, I am having a good time in middle school. I'm getting good grades, and joining some clubs. It is much harder than elementary school, but you still do fun activities and other things.

Teamwork

By Fiona Kelly

The whistle blew for the final play she shot the puck that sailed over her right shoulder to win the game. Just one hour ago I stood still butterflies in my stomach beat their wings faster and faster. I stared into the wild eyes of my coach, and realized, he wanted this as bad as we did. The pressure heightened and it felt as though my heart would leap out of my chest. My mind was set on the game. Nothing would go by me, Nothing.

At least that is what I told myself. The puck slapped the ice as it fell and the game began. "Ping!" The puck landed in their net the excitement didn't last though soon after the puck landed behind me. I laid stretched out on the ice it's all my fault I thought to myself it's all my fault. Soon another goal was scored by both teams three periods were over and the game was tied two goals each team. To overtime. My stomach tightened I began to shake my legs were stiff and my breaths were short. The referee came to our bench to tell us the rules I waited anxiously for him to finish. Leaning on the bench I glanced at the stands looking for my family I saw our team colors a sea of blue and vellow balloons pom poms, cow bells and horns. The referee finished and I staggered to my net my legs wobbly. But nothing changed. Determined players shouting coaches

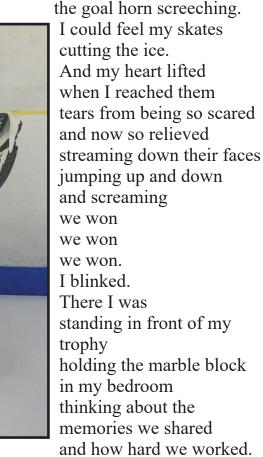
sticks clashing but no goals.

Second overtime.

by my coaches.

A timeout was called

The team gathered coaches were going over plans. I couldn't listen. I was so shaky, and distracted. The whistle blew for the final play she shot the puck that sailed over her right shoulder to win the game. The bench flooded and I skated as fast as I could to my teammates I could only hear



The image of my memory forever in my mind. What we went through as a team a team together to make such a beautiful moment, an incredible dream, come alive.

