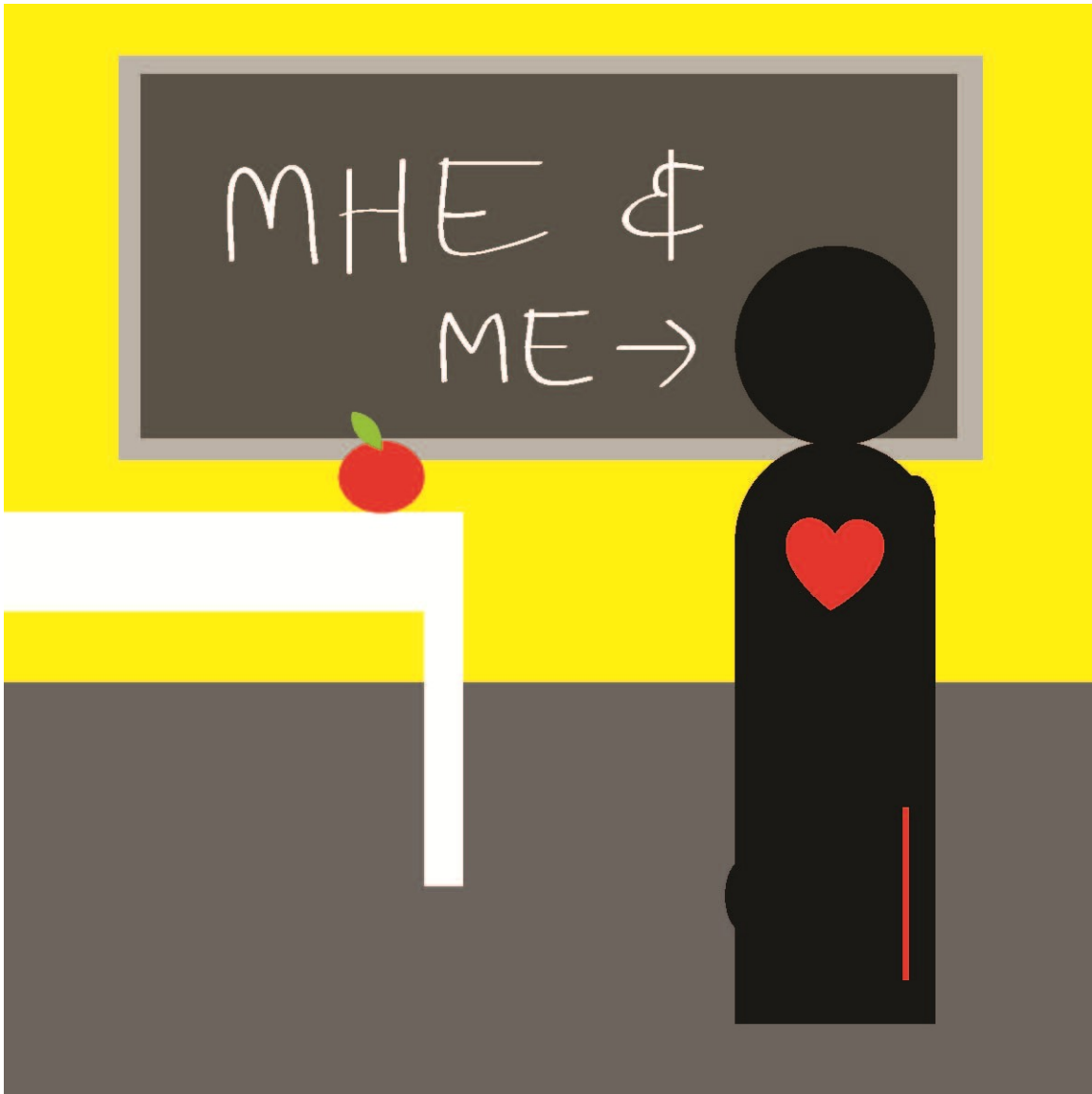


MHE: Impact on Education



The MHE Coalition and MHE and Me: A Support Group for Kids with Multiple Hereditary Exostoses and Their Families

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Cover Art: Nicole Wynn

School Needs Checklist for Kids with Multiple Hereditary Exostoses

You and your child can work together on this checklist or, depending on his or her age, your child may be able to answer questions alone. It can give you and teachers a good idea of your child's strengths and weaknesses, and areas where accommodations may be needed.

A = always
S = sometimes
N = never

NA = does not apply to me

GETTING READY FOR SCHOOL:

- I can get out of bed without any help and without holding onto anything.
- It takes me less than 30 minutes to feel good after I get up in the morning.
- I must take a bath or shower to loosen up in the morning.
- I can go up and down the stairs when I first get out of bed.
- I can fully dress myself and put my shoes and socks on quickly in the morning.
- I can tie my shoes.
- I have a lot of pain in the morning before I go to school.
- I need to bring splints, crutches, a walker, cane, or wheelchair to school to help me get around during the day.
- I go to school later in the day than the other kids in school because of my MHE.
- I take pain medication before I go to school.

GETTING TO SCHOOL:

- I can walk to school or to the school bus stop without any difficulty or help.
- Waiting for the school bus is easy.
- I can get into the school bus without any difficulty.
- I need my parents to drive me to school or I take special transportation provided by the school.

ACTIVITIES AT SCHOOL

- I can go up and down stairs quickly at school without any difficulty.
- I can use the elevator at school by myself without any difficulty.
- I need to get up and walk around in the classroom because of stiffness or pain.
- I can carry my own lunch tray.
- I can open my own milk carton.
- I need to take pain medication at school.
- I get embarrassed when I have to go to the school nurse.
- I can use the bathroom by myself at school without any difficulty.
- I find it easy to carry my own books at school and to and from school.
- I can write at school without any pain or stiffness.
- I find it difficult to write quickly.
- I need more time than other kids to take exams or complete homework because of my MHE.

Common School Concerns for Students with MHE (Revised July 2009)

In most cases, having Multiple Hereditary Exostoses does not affect a child's ability to think and learn. However, pain, fatigue and mobility issues can affect both a child's ability to concentrate and a child's performance in school. The following are just a few of the many challenges that might be present for a child with MHE, as well as some possible solutions. It is important to develop a partnership with your child's school to find the best solutions for your child's particular needs. Some schools will supply needed accommodations on an informal basis; other times it will be necessary, and often desirable, to obtain a 504 Accommodation Plan or Individual Education Plan ("IEP") for you child.

It is important to remember that some of the most valuable ways to help your child are communicating with your child's teacher(s) on a regular basis, and informing school personnel when there is any change in your child's condition. There may be times when modifications are required due to fatigue and increased endurance levels, new problems with pain and/or mobility due to exostoses growth, scheduled surgery, recuperation, etc. Unless you let the school know what is happening, they will not understand what your child is going through. Accommodations are not just given. They must be requested and justified, and it is often up to the family to make appropriate suggestions as to what will best help their child. You may also want to request that your child be evaluated by an occupational therapist who can work with your child on finding the best solutions and adaptive equipment.

Remember that you are your child's best advocate, and that it will be necessary for you to teach your child's education team (teachers, school nurse, administrators) about MHE and how it affects your child's educational needs.

Difficulty:

Difficulty climbing stairs or walking long distances

Strategies:

- ⇒ Request elevator permit
- ⇒ Schedule classes to decrease walking and climbing stairs
- ⇒ Request extra time getting from class to class
- ⇒ Use a wheelchair if needed

Difficulty:

Inactivity, stiffness due to prolonged sitting

Strategies:

- ⇒ Change positions every 20 minutes
- ⇒ Sit at the side/back of room to allow walking around without disturbing the class
- ⇒ Ask to be assigned jobs that permit walking (collecting papers, etc.)
- ⇒ Have student use a cushion such as Move 'n Sit and Move 'n Sit Junior Cushions, Fit-Sit Cushions, or Disc-o Sit Cushions. These cushions provide movement without the student having to leave the seat! For students with hip/pelvic exostoses, these cushions also provide some pain relief.

Difficulty:

Difficulty carrying books/cafeteria tray

Strategies:

- ⇒ Keep two sets of books: one in each appropriate class, one at home
- ⇒ Have a buddy to help carry books/backpack
- ⇒ Determine cafeteria assistance plan (helper, reserved seat, wheeled cart)
- ⇒ Obtain a school aide to assist student in class changes, at lunchtime, and as otherwise needed.

Difficulty:

Difficulty getting up from desk; writing at desk

Strategies:

- ⇒ Request an easel top desk and/or special chair.
- ⇒ Slant top writing boards are available for better positioning.

Difficulty:

Handwriting difficulty (slow, messy, painful)

Strategies:

- ⇒ Educate teacher. Messy handwriting may be unavoidable at times, and extra writing assignments will only make the problem worse.
- ⇒ Use "fat" pens/pencils, crayons, and special pencil grips
- ⇒ Try a felt-tip pen
- ⇒ Stretch hands every 10 minutes
- ⇒ Use a tape-recorder for note taking
- ⇒ Obtain copies of teachers or classmates' notes
- ⇒ Use a computer for taking notes, writing reports, etc. Many students with MHE have had good results with the Alphasmart Keyboard
- ⇒ Request an alternative to timed tests (oral test, extra time, use of computer)
- ⇒ Have teacher minimize writing requirement (ex.: only write the vocabulary word, instead of rewriting the entire sentence; photocopy pages in text and highlight relevant portions instead of writing notes).
- ⇒ If a child has severe problems, or undergoes surgery and cannot write, there are good voice recognition software programs that allow your child to dictate to the computer.
- ⇒ A school aide may be provided to take notes for a student or record test answers.

Difficulty:

Difficulty with dressing

Strategies:

- ⇒ Wear loose-fitting clothing
- ⇒ Wear clothes/shoes with Velcro closures
- ⇒ Get adaptive equipment from occupational therapist. There is adaptive equipment that can help with everything from putting on shoes and socks, to long handled brushes and combs, zipper pulls and other aids.

Difficulty:

Difficulty raising hand

Strategies:

Devise alternative signaling method

Difficulty:

Difficulty reaching locker or manipulating lock

Strategies:

- ⇒ Modify locker, request more accessible locker location or request alternative storage place
- ⇒ Use locker with key lock instead of dial lock

Difficulty:

Your child fidgets in class or has trouble paying attention because of pain or fatigue,

Strategies:

- ⇒ The cushions mentioned earlier in this article also help with children suffering with pain and fatigue
- ⇒ There are many fidget toys available to help children relieve some of the stress that results from pain
- ⇒ Your child may need permission to keep gum or snacks available to help with his/her arousal level in class

School Needs Checklist for Children with Multiple Hereditary Exostoses and Common School Concerns for Children with MHE were adapted for children with MHE

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1330 W. Peachtree Street, Atlanta, GA 30309.**

For more information, please call the Arthritis Foundation's information hotline at 1.800.283-7800 or long on to www.arthritis.org

Resources

To learn more about your child's education rights, visit the web site of **The National Information Center for Children and Youth with Disabilities (NICHCY)** at www.nichcy.org You can also contact them at PO Box 1492, Washington, DC 20018, 800-695-0285, nichcy@aed.org.

Therapy Shoppe: The Extraordinary Little Specialty Shoppe for Schools and Pediatric Therapists, Teachers, and Parents, Too! This company carries the cushions mentioned, as well as many writing aids, fidget objects and hand strengthening products. They have solutions for many of the challenges faced by students with MHE.

PO Box 8875

Grand Rapids, MI 49518

Phone: 1-800-261-5590, Fax: 1-616-696-7471

Email: thershoppe@aol.com

www.therapyshoppe.com

Neo2 (formerly Alphasmart)

These affordable laptops are great for elementary and middle school children and the base unit is \$119! Visit the site and read their online brochure for more details. Many children with MHE have found this to be a great way to learn to keyboard and prepare for higher grades. Some schools will provide the units to children with disabilities.

<http://www.neo-direct.com>

The following websites provide aids to assist with dressing, mobility, writing, grooming and other basic activities:

North Coast Medical (formerly Functional Solutions)

<http://www.ncmedical.com/> (click on ADL section)

Dynamic-Living.com

<http://www.dynamic-living.com/index/>

Life with Ease.com

<http://lifewithease.com/>

Band-Aides & Blackboards: The introduction to this site says, "Welcome! This is a site about growing up with medical problems ... any ole type. Its goal is to help people understand what it's like, from the perspective of the children and teens who are doing just that. These kids have become experts at coping with problems that most of you have never heard of. They'd like you to know how they do it, and they hope you'll be glad you came to visit." In addition to the stories contributed by the children and teens (including three children with MHE who shared their stories 10 years ago), there are sections for parents, siblings, health care providers and teachers. This is a great site to visit with you children/students.

www.lehman.cuny.edu/faculty/jfleitas/bandaides

Visit the Site Map to find all the sections...

Chronic Kids: Awareness of Childhood Health Issues on Educational Outcome

This site was developed by a teacher who grew up with chronic illness, and is geared towards elementary teachers and school officials. The workshop format is helpful to both educators and parents in understanding challenges faced by children with chronic illness, and in suggesting ways to make a 504-plan effective.

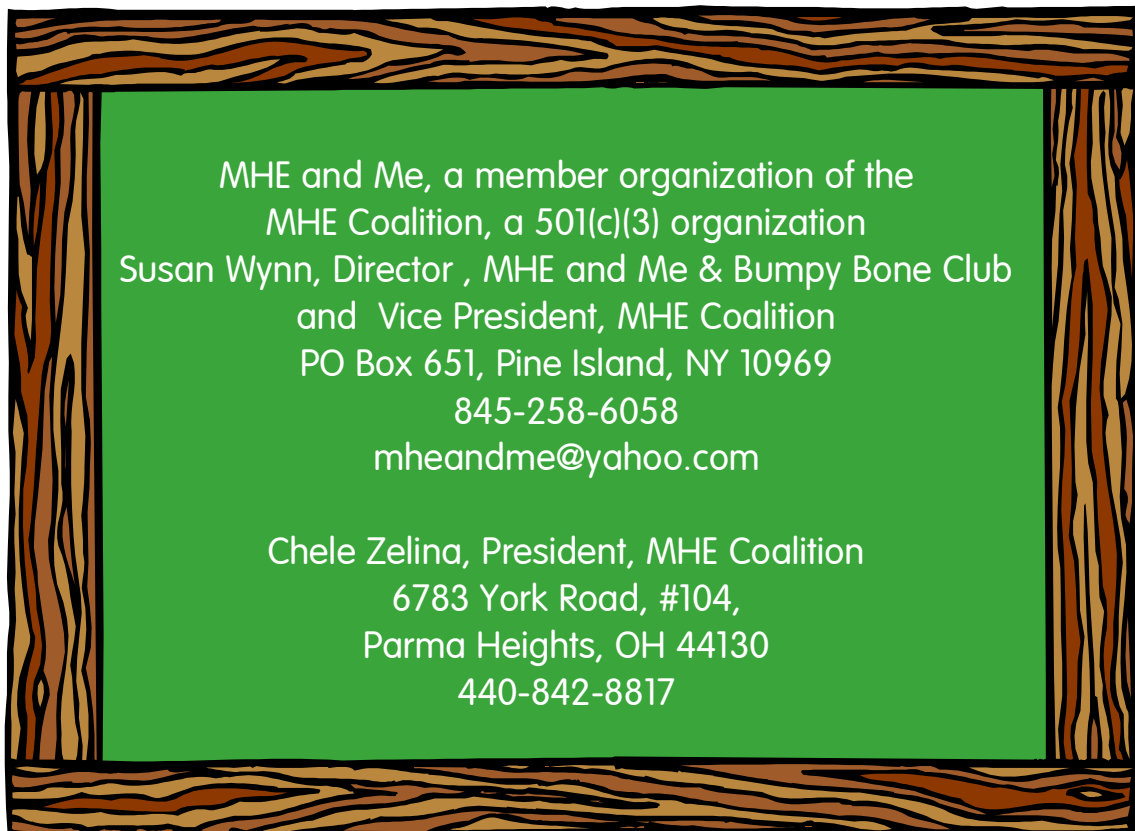
www.ibsgroup.org/chronickids/index.htm

The Arthritis Foundation

Many of the issues faced by children with MHE are similar to those faced by children with different forms of arthritis and related illnesses. This organization and its site provide valuable resources and information.

www.arthritis.org

Because of the nature of MHE/MO, it is often necessary to think outside the box in finding educational solutions to best help the student reach his or her potential. We are here to help the children, families and schools find some of those creative solutions, if needed, or to provide support and information.



Going to School with MHE/MO

Robin Schwartz

Reprinted with permission from The MHE Coalition, Newsletter No. 20, June 2006

As an individual with Multiple Hereditary Exostoses/Multiple Osteochondromas (MHE/MO), one may feel alone and like they are the only one dealing with a condition that sets them apart from their peers. However, this is not the complete truth. In fact, 20 percent of children have a chronic condition and 6.5 percent of students claim their conditions affect their academic performance and participation in school (Kaffenberger, 2006). I am not going to take the time with this article to define MHE/MO; we know what it is and how difficult school can be for children and teens. I am also not going to take much space explaining what it is like to be a child or teen with “bumpy bones” as our younger members do so eloquently online: <http://www.mheandme.com>. Suffice to say that our members are a diverse group who are trying to succeed in the face of physical pain, long absences from school, and teasing from ignorant peers. By utilizing school resources and communication skills, students may better be able to succeed in an academic environment.

MHE/MO students often miss school for surgeries and doctor’s appointments. The longer students are away from school, the harder the return will be. As a result, students can experience anxiety, social withdrawal, and depression. In other words students can feel sad, helpless and alone. This can not only prevent academic success but can delay recovery (Kaffenberger, 2006). It is important to know that students with MHE/MO should not feel alone, but should understand there are individuals in your school who can help the school experience to be successful.

Your primary resource within your school should be your school (guidance) counselor. It is the role of a school counselor to facilitate transitions to and from school, work with peers and teachers towards MHE/MO education, and even work with the school nurse to coordinate accommodations. Most elementary, middle and high schools do employ school counselors. If your school does not have a counselor, a social worker may be filling a similar role.

Barriers to success for a MHE/MO student

School counselors help students deal with barriers to success in not just their transitions to and from school but in their daily routine. In order to do so school counselors need the assistance of parents and students. Students often experience barriers due to the following:

- Lack of communication
- Lack of information and training
- Unsupportive policies (Kaffenberger, 2006).

Let’s face it, MHE/MO is a unique diagnosis and most do not know what it is. In addition, when families receive a difficult diagnosis or find out another surgery is coming up, the school may not be the first call you make. Without information, the school can not adequately address the student’s needs. When a student starts a new school, it is a good idea

to make an appointment with the school counselor. If the student is younger, their primary teacher should also be involved. Explain to them what MHE/MO is and how the child is affected. The school, parents, and child as a team can determine the best way to ensure a positive school experience. An excellent resource to share is the MHE and Me Handbook (available online at www.mheandme.com).

MHE/MO affects everyone in a unique way. Giving a few pages of information to the school is not enough. Parents need to be advocates for the children and teens must learn to be their own advocates. The best way to accomplish this is to be knowledgeable about MHE/MO and proactive with accommodations. Complaining after one fails physical education or lamenting that you had no notes because it hurts when you write, the day after the exam is not going to be helpful. Be sure to share the following with the counselor:

How does MHE/MO affect day to day life? For example, do you walk slower, have difficulty sitting down for long periods of time, or writing?

Are there any apparent visible bones which you can show them?

Will you miss school often for doctor's appointments?

Are you having an upcoming surgery?

Who else in the family is affected?

What can the school do to make you feel more comfortable?

1. Can your classes be arranged in such a way which would lessen the amount of walking expected?
2. If you are expecting to be out of school for a surgery, is there an option for an online class for a particular quarter which will help facilitate continuity. (Many school districts offer online classes and outside of a particular school district, there are accredited online classes available which would likely meet requirements.)
3. Would it help if you had a copy of notes, so you would not waste limited writing energy taking notes?
4. Which physical education option is the most appropriate?
5. Would you like to rest in the nurses office during school?

Armed with knowledge, the counselor can advocate for your needs within the school. Your counselor should adhere to a professional ethics code, in which they do not necessarily need to share the details of MHE/MO with others (ASCA, 2004.) Rather they can simply tell others what accommodations are needed. The school counselor may suggest an Individualized Education Plan (IEP) in order to meet the school system's regulations and policies.

Even more primary to a school counselor's role of coordinating services is counseling students. A school counselor can help the student deal with the frustrations of having a chronic condition, help students process their feelings, or the difficulty of having a sibling who is ill. They can also work with other issues requiring emotional, academic, or vocational counseling. In addition, a school counselor can help one learn to strategize and problem solve. (With MHE/MO, sometimes creative problem solving can certainly be an asset.) Remember, the school counselor is your advocate.

Providing emotional support

In addition, to individual counseling you may want to see if the school counselor runs support groups for students with chronic illness. If not, they may be open to beginning one. Such a group gives students a place to connect with peers who are experiencing similar issues and provide skills to deal with the emotional stress which comes from a painful and chronic condition. If the counselor does not have an appropriate group, they should be able to refer you to an outside resource.

In addition, for younger students the counselor should be able to give a classroom guidance lesson on chronic illness, providing a safe place for other students to ask questions and learn to be sensitive to those who are living with a chronic condition such as MHE/MO. It may also be appropriate for a counselor, perhaps in conjunction with a parent, to address a faculty meeting in order to educate the community regarding MHE/MO.

Having MHE/MO is difficult enough. When barriers arise to academic success, the emotional effects of MHE/MO can be heightened. With proactive communication and the support of a school counselor, it is possible to do well in school while living with a chronic condition.

ASCA, (2004, June 26.) Ethical Standards for School Counselors. Retrieved April 22, 2006, from American School Counseling Association Web site:
<http://www.schoolcounselor.org/content.asp?contentid=173>.
Kaffenberger, C (2006). School reentry for students with a chronic illness: A role for professional school counselors. *Professional School Counseling*. 9(3), 223-230.

Robin Schwartz has lived with MHE/MO since birth and has had numerous surgeries and family members who also have MHE/MO. She is a certified school counselor and has a MS in Human Services. Robin also consults as a college and vocational counselor for teens. She specializes in student success strategies and communication.

Tell Your Story

Caroline Eaton

Reprinted with permission from The Bumpy Bone Club Magazine, Issue No. 2, Winter 2009. This article was written for children with MHE by a 4th Grade Teacher who also has the disorder and underwent multiple surgeries in adulthood.

My name is Caroline Eaton, and I am a 28-year-old with MHE. As a child, the effects of this disease on my life were pervasive. From not being able to participate in gym class, to avoiding the monkey bars and jungle gym at all costs, to feeling sick to my stomach when a teacher insisted that everyone sit “criss-cross, apple sauce,” also known as “Indian style,” and of course the dreaded doctor appointments. These challenges made me feel different and alone. My mother, a clinical social worker, pleaded with me to be more forthcoming with my feelings, to advocate for myself and to let it be known when I was in pain. A naturally shy and introverted child, I did just the opposite. Instead of telling my friends why I couldn’t play with them on the monkey bars, I avoided them. Instead of telling my teacher that I was unable to sit “Indian style,” I did the best I could, even when that caused me to be in pain. Instead of telling my friends why I was leaving before the official end of the school year (to get a jump start on a summer surgery), I simply disappeared.

Years later, I am a fourth grade teacher, no longer required to swing on the monkey bars or participate in a formal gym class, yet I am **still** forced to share the impact that MHE has on my life. Over the past three summers I have had limb lengthening and two hip procedures, all requiring me to begin the school year on crutches, limiting my mobility in the classroom. As a teacher, I know how easy it is for children to sense when adults are not being honest with them, and therefore I knew I could not offer my students some simplistic explanation such as, “I hurt it” - the very explanation that I would have given my peers when I was in fourth grade.

Little did I know that my students and colleagues were dying to know about MHE, and what it is like to recover from surgery year after year, and of course what they could do to help. Never did they judge me or overcompensate for me in some way. In fact, at the end of the year, one student wrote to me and said, “It’s your leg that makes you special and our class unique.” If only I could have heard those words when I was the fourth grade student!

There are many lessons to be learned from any obstacle that you face. Whether I was eight or twenty-eight, everyone around me sincerely wanted to learn from my experience - to feel like they were truly walking beside me in the healing process. The only way for them to do so was to **hear** my voice, to **listen** to my story. I know that all of my teachers along the way could have done much more to make my experience in grade school easier, had I been able to better advocate for myself. As a teacher, I have an infinite desire to help my students in any way that I can. Similarly, children have this same desire to be compassionate. Having to tell your story of MHE does not end when you become an adult! So begin now, and you will be amazed by how those around will listen and learn from you.