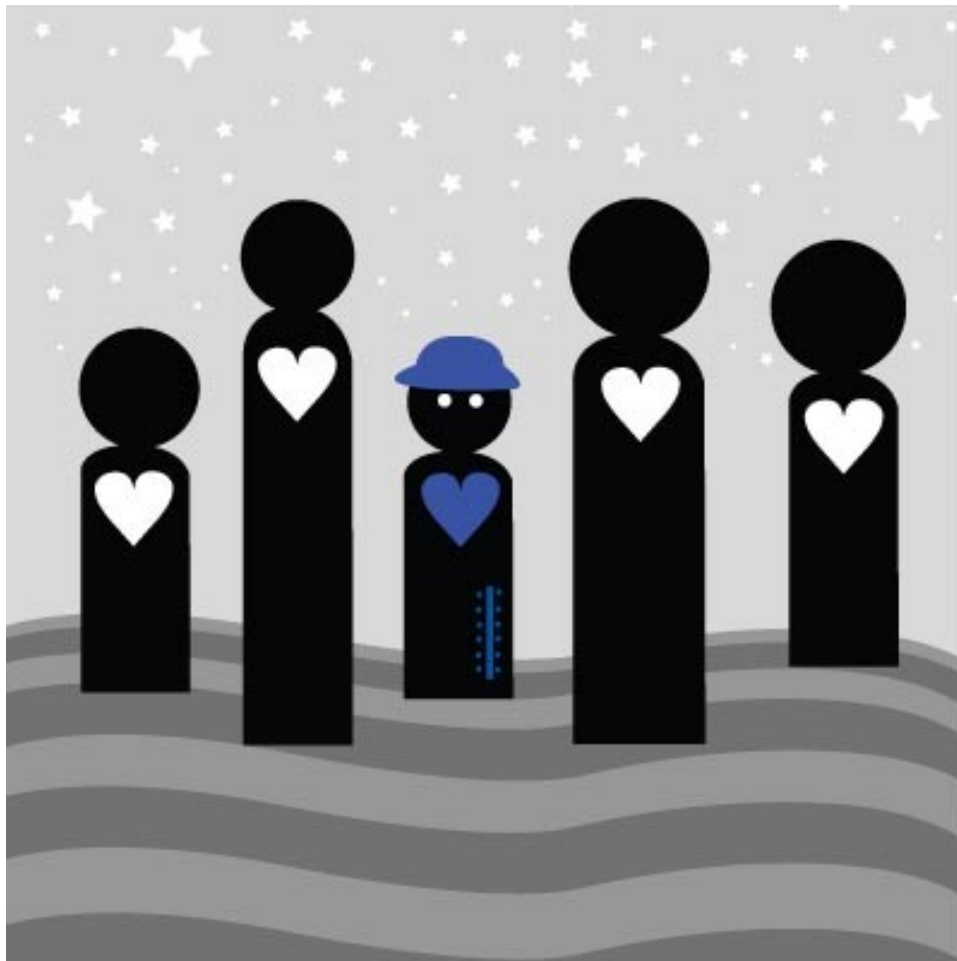


THE MHE AND ME HANDBOOK

**A Guide for Family, Friends,
Teachers and Classmates**



**THE MHE COALITION
MHE and Me**

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THE MHE COALITION

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Founded in 2000, The MHE Coalition is a 501(c)(3) non-profit organization dedicated to providing support and information to those living with this rare bone disorder. Our organization utilizes a multi-faceted approach to achieve our goal of helping to improve quality of life for MHE patients. Support includes development and distribution of information about this condition to patients, families and health care providers; telephone and email support to patients and families; assistance in finding qualified doctors and surgeons, and a website which provides information for patients, researchers and physicians. **We Care** Packages are sent upon request to children undergoing MHE surgery and their siblings, and annual gatherings are held each summer to provide MHE families with the opportunity to meet others and share experiences and information firsthand. **The Bumpy Bone Club** provides upon request free membership kits to all children and teens affected by the disorder. Membership includes a subscription to the Bumpy Bone Club Magazine, written for and by kids.

Research is an important focus, and we have participated in and/or provided funding for studies with many institutions, including the University of Texas Houston Medical Center study entitled ***Hereditary Multiple Exostoses and Pain: To what extent is pain associated with HME?*** Results of this study, which have been published in the Journal of Pediatric Orthopaedics, indicated that pain has been underappreciated and must be addressed in the medical care of MHE patients. We provided a grant to Dr. Christine Alvarez of British Columbia's Children's Hospital for her study on Quality of Life in HME patients, and many of our members participated in the first phase of this project, which we hope will lead to a better understanding of MHE's impact on daily life. ***Health-related Quality of Life in People with Hereditary Multiple Exostoses*** was published in the Journal of Pediatric Orthopaedics in March of 2012. Information on all research projects is available on our website.

In 2007 the MHE Coalition established an annual educational grant to provide orthopedic residents and fellows the opportunity to attend the **Annual Baltimore Limb Deformity Course** to learn advanced techniques that will help MHE patients and others suffering from limb deformities. Grant recipients are selected by the course chairs, and we have received letters telling us how helpful the course was in teaching the planning of deformity correction treatments as well as hands-on training in specific procedures. On December 24, 2012, Tom MacDonell, husband of our beloved treasurer, Donna, lost his brave battle against cancer. Tom was one of our first members and one of our biggest supporters, and in his memory we have renamed this program ***The Tom MacDonell MHE Scholarship Fund***. Donations made in Tom's memory will provide a grant to the 2013 course, for a total of 15 orthopaedic residents who have been awarded this scholarship since 2007.

MHE AND ME - A Support Group for Kids with Multiple Hereditary Exostoses and Their Families

www.mheandme.com, mheandme@yahoo.com

This group provides a supportive community for children and teens affected by MHE, giving them a place to express themselves through their stories, poetry and artwork, and to find friends from around the world. The site provides tools and resources for families, doctors and schools, and is the home of the **Bumpy Bone Club** and **We Care** programs.

THE MHE and Me Handbook

A Guide for Family, Friends, Teachers, and Classmates

DISCLAIMER: While many find the information and experiences that we share helpful, they are in no way a substitute for professional medical care. Our support network does not engage in the practice of medicine. In all cases, we recommend that you consult your own physician regarding any course of treatment or medicine.

WHAT IS MHE?

Multiple Hereditary Exostoses ("MHE") is an inherited disorder of bone growth. People who have MHE grow exostoses or bony bumps on their bones that can vary in size, location and number depending on the individual. Although any bone can be affected, the long bones (legs, arms, fingers, toes, ribs, pelvis and shoulder blades) are the most common. MHE can be referred to by various names such as Hereditary Multiple Exostoses, Hereditary Multiple Osteochondromata, Multiple Cartilaginous Exostoses, etc. Multiple Osteochondromas ("MO") is the name now preferred by the World Health Organization.

An exostosis is a benign bone growth that is abnormal or different than the underlying architecture of the bone. These bone growths generally grow out or at an angle from the normal bone. Sometimes doctors refer to exostoses as "tumors" which like "exostoses" is a general term meaning abnormal growth. It is important to remember that not all tumors are cancer. Most tumors, like the exostoses of MHE, are benign. Exostoses grow near the growth centers of the bones which are near the ends of the bones. That is why many bumps grow near joints. Exostoses can be rounded or sharp and will continue to grow while a child is growing.

This condition is not contagious. MHE is a condition that is passed by the genes of the affected parents to their children. It is called an "autosomal dominant" disorder which means that if one parent has the condition, chances are fifty percent that their child could also develop MHE. Occasionally, a person can develop multiple exostoses with no family history of MHE. This situation is described as a spontaneous mutation meaning a genetic problem arose in that person without being inherited from a parent.

HOW ARE CHILDREN AFFECTED BY MHE?

It is important to note that some children will have few if any symptoms while others are severely affected and will have a great deal of difficulty. Because the bone growths can cluster around joints, children with MHE can have a great deal of difficulty with normal movements such as walking, running, lifting, carrying, bending joints, kneeling, grasping and arm and leg rotation.

Tumors can grow and increase at any time, but particularly during growth spurts. A child who has no problem with a movement one day may find that movement restricted the next and then back to not being a problem the day after that. A tumor may also grow in such a way as to create an entirely new restriction on a child's mobility. For example, a child who was able to sit in a certain position during the last semester may not be able to sit in that same position this semester, or in the future. A child who could run may not be able to do so following tumor growth. Some mobility problems may be corrected by surgery, but some may become lifelong limitations. Parents as well as teachers working with children with MHE must be aware of the changing nature of this disorder.

While children with MHE may seem extremely fidgety, they may be simply trying to get comfortable. Many tumors cannot be seen and their affects can be subtle. One child with MHE may have multiple tumors at many different sites in the body, while another child may have only one or two tumors. No one yet understands why different people are affected differently at different parts of their body.

Hands

Hand and arm problems can present unique challenges. Children with MHE may have problems manipulating small objects. For the younger child this may mean difficulty buttoning, zipping, and tying, skills which children need to dress themselves. Older children and adults with MHE can also have trouble with these skills. A child with MHE in preschool or kindergarten may need help with these tasks, leading observers to feel that the child has not yet met developmental guidelines for self care. Caregivers need to understand what the child is physically capable of and help them compensate. For children who cannot get their fingers to work correctly to tie shoes, Velcro has been found to be a wonderful adjunct that helps kids with MHE with independence. Most kids with MHE learn to compensate and do things in their own unique way while still accomplishing the goals of independence.

For the older child entering primary school the challenges can be daunting. Holding a pen, pencil or crayon may cause discomfort and pain.

"Nicole (10) has many, many bumps on her fingers and they get stiff and hurt where the pencil or pen rubs against them. We recently found foam rubber pencil grips that cushion. We also found special pens and automatic pencils that are large and cushioned. These do help but when she has a lot of homework her hands hurt and she becomes quite fatigued."

Even when a child can hold a pencil and appears to be doing fine other problems can arise:

"Julianne (10) has trouble with pain in her wrist and the teachers just don't understand. They keep giving her more handwriting homework as if she just needs to practice more. She uses little cushions and thumb pillows; that is all we were able to change. She just will not be able to get an "A" in handwriting. But she tries hard and that is what counts!"

Note: When children suffer pain and fatigue from writing, there are many things teachers can do to help them. Whenever possible, find ways for them to write less - not more! Sometimes this can be having them highlight copies of text, rather than taking written notes, or providing them with teachers notes. There are some tests or quizzes that require copying sentences or paragraphs. With a teacher's permission, the student can write just the answer without copying all of text. The pain caused by writing utensils against bone tumors in the fingers can be intense. Tumors in wrists and forearms can prevent the child from being able to hold a writing utensil at the proper angle and cause further pain. Pain, and the extra effort the child must use to try to write, cause fatigue, which further impacts his or her ability to concentrate. Children will often rush through tests, giving incomplete or insufficient answers, since they simply cannot tolerate the pain and fatigue any longer, though this can be mistaken for poor academic performance.

But even with cushions and special pens and pencils these children have severe problems writing for long periods of time.

"Bobby (8) has trouble gripping a pencil. He is in third grade and there has been a huge increase in writing. After much discussion with school staff, the school district has provided him with an Alpha Smart Keyboard. It is quite small, displays several lines of text and has a memory. He*

takes it everywhere with him and can complete writing assignments on it that can be printed out either at home or in the classroom."

Note: *The Alpha Smart* keyboard is now known as Neo and is available at www.neo-direct.com. As of June 23, 2013, it is priced at US \$119, and can run on 3 AA batteries! It has been used with much success by many students with MHE.*

For other children the problem may be more subtle:

"Christopher (13) cannot grip a pen or pencil properly and his handwriting is atrocious. His teachers constantly complain that they cannot read his writing."

Note: *In cases such as this, it may become more realistic to have the student either type his/her assignments on a computer, or use a voice-recognition program to dictate school work.*

Needless to say, these kinds of problems can lead to difficulties handling and manipulating other common objects in the school environment: scissors, chalk, glue sticks, paper clips, rubber bands, and the myriad of other small manipulatives that young children use in the classroom.

Arms

There are two bones in the forearm, the ulna and the radius. The radius extends from the wrist on the thumb side of the arm while the ulna is on the little finger side of the arm. In many kids with MHE the growth of the ulna is affected and it is quite shorter than the radius. This can cause the radius to "bow", pushing the hand to "cock" at an angle. This can cause severe wrist problems. Some kids with MHE cannot supinate or pronate their hand because of lack of rotation in the wrist. They will compensate by turning their whole arm from the shoulder, bending their elbow into the body to achieve supination and moving the whole arm in the other direction to achieve pronation. In the classroom, the child may be asked to do things they simply can't. For instance, at circle time when all the children join hands, the child with MHE may not be able to comfortably turn his hand to hold the hand of the child next to him. The child and his parents may not even have been aware of this problem with mobility.

Exostoses around the shoulders can prevent the child with MHE from rotating their shoulders: throwing a ball, playing windmills, playing airplane. An exostoses can affect, limit, or even totally block movement. Also, straps from backpacks can rub against exostoses causing discomfort and pain. Trying to hold heavy books can also be a problem for the MHE child. It may be necessary for a child to be provided an extra set of books at home so that the daily burden won't be too great.

Kate (26) "I could never swim freestyle/overarm; only breaststroke. In Australia, you learn to swim at primary school. My shoulder wouldn't ever rotate enough to swim overarm even after surgery. I can't swim very well because my arms are very different lengths and have very different strengths and I swim in circles."

Ankles and Feet

The foot has many, many bones and most of these are considered "long" bones and subject to the development of exostoses. When an exostosis forms and grows it can affect the length of the bone, shortening it considerably. Children with MHE can have pretty strange looking feet: bumpy, lumpy feet with minimal or even nonexistent toe nails. Like the fingers, toes can be longer or shorter than normal even on one foot. The big toe can be longer than usual while the toe right next to it can be shorter than

normal.

Ellen (16) "I have really strange feet - toes completely out of order, and they make footprints with three toes only. So that was thought of as strange but in an "aren't-you-lucky" kind of way."

Pain and discomfort walking, as well as an uneven gait may be caused by valgus deformity. This condition is caused by bone growths around the tibia or fibula, which cause the ankle to bend outward.

Melissa (15) "One of the things that bothers me a lot is my ankles. I cannot stand it if anything touches them, like shoes or heavy socks, or even when I go to sleep. It bothers me when I lay down and they touch the bed."

Kids with MHE may be unable to stand on tiptoe. Bone growths in the metatarsals can push the toes to the side causing the big toe and the other toes to form an angle pointing to the outside of the foot called hallux deformity. Hallux is the great toe.

Legs

Uneven growth caused by exostoses can cause the fibula or tibia to be shorter. This can cause the other bone to bow out. To even out the bones' growth an external fixator can be surgically attached, which over a period of months causes the bone to lengthen. Some children may be candidates for this surgery, while other children may qualify for a procedure wherein staples are surgically inserted into the growth plate at the end of the longer bone to slow its growth and give the shorter bone a chance to "catch up"

Lydia (17) "My legs give me the most trouble and sometimes it feels like there is constant pain, the sort of pain that I can live with or I just got so used to it. I think they hurt more when I sit all day. A little walking actually helps and it feels like I can "walk" away some of the pain."

Surgery that is meant to offer a solution to a problem can have its own complications:

"Nicole (10) had surgery over summer vacation: stapling of the proximal tibia (near the knee) and removal of a large exostosis just below that. Three months later she had to have surgery on the same leg to remove three exostoses from the fibula which were compressing a nerve and had caused a nerve palsy resulting in drop foot. Drop foot is the inability to move the foot. Nicole is being tutored at home while she recovers and undergoes extensive physical therapy to relearn how to walk."

Knees

Bone growths around the knees can cause limited flexibility or even inability to bend the knee and can cause the child to be unable to kneel because of pain. Bone growths frequently make the knees appear bulky and larger than normal. Many kids with MHE cannot sit on the floor cross-legged not only because of bone growths around the knees but also bone growths around the hips and pelvis.

Gil (53) "I can't get into a crouch, you know like catchers do. I have never been able to crouch. My knees only bend about 40 degrees. My knees used to give me a lot of pain

when I was a kid but once I got older they only hurt occasionally."

Hips and Pelvis

As mentioned above, growths around the hips and pelvis can make it impossible for a child to sit cross-legged on the floor but these can also cause other mobility problems.

"Susie (age 11) has trouble with stairs. She cannot get her leg into the proper position to climb to the next step. She must take each stair one step at a time. She steps up with her right leg and then brings the left one up. Her left leg is more severely affected due to tumors on her hip and pelvis. She also has a bone growth above her knee and in the back of her leg that prohibits her bending that leg very much. She climbs the stairs at an angle."

Hip and pelvic tumors can prevent a child from bending over, touching their toes or spreading their legs.

Ribs

Exostoses can form on the inside of ribs or the outside.

Roger (21) "They can catch on the muscles in your chest, which can make it really painful to even breathe. It is possible to uncatch them - to basically shove your chest muscles back to the other side of the offending lump and this takes away the pain."

Skull, Neck and Spine

Although bone growths of the skull, spine and neck are extremely rare they can occur.

THE MHE CHILD IN SCHOOL

Because the affects of MHE can be so varied from child to child it is important to keep the school apprised of any changes. Before the child is enrolled in school, write the school and let them know that your child has a disability and what mobility limitations or pain problems your child may be having. If you notice a new limitation, write the school and let staff and teachers know exactly what it is and what affect it may have on your child's participation. If the situation over the summer break changes, for instance a surgery or new limitation is noted, write the school and let them know. At the beginning of every new school year, a letter explaining MHE directed to staff and teachers would help refresh the school's memory that your child has special needs.

THE MHE CHILD AND PE CLASS

This is an extremely difficult area because MHE children can be affected in so many various ways and in so many different body parts. On top of this, children with MHE may be able to do a certain motion one day and find that same motion constricted or painful the next. Most MHE children can participate in physical education but the instructor is going to have to be not only aware that the child has special needs but also sensitive to the changing status of the MHE child. A child who says they cannot do a particular motion or function should be respected. If there is any doubt about the veracity of such statements, parents or guardians can be con-

tacted for verification. Children with MHE should not be encouraged to "just try" something they have said they cannot do. Some Kids with MHE appear "normal", while other children will have obvious deformities.

Some children with MHE may reach the point where they are unable to participate in physical education classes for extended periods of time; some may not be able to participate at all. This may be due to the need for surgery to relieve an obstruction or simply because the movements necessary for physical education class are impossible or cause too much pain. Even after surgery to relieve an obstruction caused by a bone growth, the child may never be capable of full mobility. All children want to "fit in" and be treated the same as the other kids. Children unable to participate in sports should not be looked down upon or made fun of. They should also be encouraged to use that class time for a productive activity, such as library time, etc. Many children with MHE have physical therapy exercises they can do during this time.

Note: It is possible for children forced to do certain activities, even after stating that they could not, to sustain injuries, or flare-ups of severe pain and fatigue that can keep them from normal activities for several days or more. Always assume that the child knows his/her body and what they need to do, or not do, to take care of it!

FATIGUE

Kids with MHE can tire easily. Exostoses can put significant pressure on vital structures, making it necessary for the child to stop all physical activity for periods of time. A child may be dealing with a lot of mobility issues and be in pain. Pain in and of itself can be exhausting. Some kids and adults with MHE note a significant increase in pain during wet and cold seasons. In addition, many children suffer from night pain and discomfort severe enough to interfere with their sleep. The performance of these children in school the next day will obviously be affected by their lack of sleep and their physical discomfort. When fatigue becomes a major problem, a child with MHE may have to go to half days or have a tutor come to the home to continue schooling.

"Andrea (8) suffers from over-all fatigue. By the end of her school day I have to meet her at the bus and carry her backpack, and she holds on to my arm to help "pull" her up the road to our house. She takes breaks when she needs them but sometimes other kids, including her sister, just can't understand that she can't keep up with them and has to rest."

DISABILITY & YOUR EDUCATIONAL RIGHTS

Section 504 of the Americans with Disabilities Act is not an education law but a civil rights law that prohibits discrimination on the basis of a disability. The intent is to meet the needs of disabled students in the least restrictive environment possible. Section 504 finds a person as having a disability if the person:

1. Has a physical or mental impairment which substantially limits a major life activity;
2. Has had a physical or mental impairment which substantially limits a major life activity, or has had a physical or mental impairment which substantially limits a major life activity, is

regarded as having a disability by others.

Section 504 requires the provision of a free and appropriate public education (FAPE). School districts that receive federal funds are required to establish procedures for the evaluation and placement of students with disabilities who require either special education or related services.

Major life activities include walking, seeing, hearing, speaking, breathing, learning, working, caring for oneself and performing manual tasks. The disability need only substantially limit one major activity in order for the student to be eligible.

Note: Please see our booklet on educational challenges facing students with MHE, and some suggested solutions for those issues.

MHE AND PAIN MANAGEMENT

Simple Analgesics

In MHE there are many different kinds of pain. Sometimes its the sharp pain of having a bone growth bumped, hit, or knocked, or an achy pain and discomfort that can be mild or severe and that can last for minutes, hours, days or weeks. There can also be nerve pain, which has different symptoms and may require different treatments. There is also the pain that follows surgery. ***Any pain that is not relieved with pain medications, impinges movement, or recurs should be checked by a doctor. Dosages of various pain medications can be tailored to the needs of the patient, but your doctor should determine this. .***

Normal recommended dosages of pain medications like Acetaminophen (Tylenol) and Ibuprofen (Motrin, Advil, etc.) can be very helpful in pain management but can lose their effectiveness over long periods. Your physician can prescribe stronger dosages to help recalcitrant pain. ***Never increase the dose of a pain medication unless under the advice of your doctor. Acetaminophen can be dangerous and toxic in too large a dose. Aspirin is never recommended in children.*** MHE can cause long term, recurring pain. Some have found a dose of pain medication used as a prophylactic at night can help with sleep problems due to pain. ***This is a very individual decision as the use of long term pain medications have complicated implications and any use of long term pain medication should be under the supervision of your doctor.***

Note: For some children, pain management may become necessary and include prescription pain medications, physical therapy, counseling, and other treatments prescribed by the physician.

Heat Providing Devices

For simple episodic pain many have found heat to be an immense relief. Electric heating pads, hot water bottles, gel packs and fabric bags with organic husks can all be useful. Heating pads can be dangerous for those who get pain in the night and fall asleep. There is the danger that

the heating pad can overheat and burn if it is left on unattended, kinked or rolled over on. Hot water bottles are old fashioned but much safer. They do not get hotter but gradually cool down. Gel Packs and husk bags can be quickly heated in the microwave and also gradually cool down. Organic husk bags come in many shapes and sizes and many can be wrapped around the painful area providing great ease and comfort. Uncooked rice can be sewn into a fabric bag of any desired shape or size and warmed in the oven or microwave. It can then be placed on or wrapped around the painful area. For a child with pain in the night these are much safer alternatives than a heating pad and can help to speed everyone back to sleep. Night pain is common in children with MHE because the distraction of daytime and daytime activities can mask pain until the child calms and tries to sleep; then they feel the pain.

Pads and cushions on chairs can help relieve discomfort sitting and a feather bed can cushion bumpy bones that are difficult to sleep on.

During the day at home, warm baths, hot tubs, warm showers can ease mild pains.

Note: For some, cold is more effective in treating pain. There are cold packs available in stores, including some with cartoon characters on them for small children. However, the old standby is a bag of frozen peas (mark it as a cold pack so you don't try to serve it at dinner), taken from the freezer and placed over a cloth on the affected area, then put back in the freezer for the next time. Cold packs can be used approximately 15 minutes on, then 15 minutes off. Ask your doctor or physical therapist the best way to use.

Pain at School

The use of pain medication at school can become complicated and controversial. Again, some parents opt for the use of a pain medication as a prophylactic to try to prevent pain while the child is in school. Many parents feel this much use of pain medication is not warranted and can be dangerous. Children with MHE can have a private place at school where they can rest, take pain medication if warranted, use a source of warmth to ease pain and then return to class when they feel better. Many school districts insist that pain medication be kept in the office under the supervision of a nurse or secretary. This is not always feasible. A parent reports:

"I asked that my third grade son have his pain medication available in the classroom to be administered on an as needed basis for pain by his teacher. I was told no, that medications had to be in the office. Well, one day when my son asked to go to the office to get pain medication the teacher told him to wait until the spelling test was over. By the time he was allowed to go to the office, the pain had escalated. The classroom was in a bungalow and he had to cross the playground to get to the office. He didn't make it. Something called me to his school that day and I found him lying in the rain against a wall in too much pain to walk. He was soaking wet and crying; not only in severe pain but extremely frightened. I really don't know what would have happened if I had not listened to my instincts and gone to check on him that day. Since then I have absolutely

insisted that his pain medication be available to him in his classroom. Sometimes it has been quite a fight but when I tell them this story they understand and make an exception."

Sometimes, simply asking the school to make accommodations works. Schools seem much better prepared for scheduled doses of medication like antibiotics. The "as needed" basis of pain medication can make school staff very nervous; and rightly so. If the child has pain in the morning and the parent medicates and three hours later the child has more pain it is not appropriate for more medication. A simple form can be designed that travels with the child and contains dosing information. That way neither school staff nor parents have to worry that the child is being "double dosed."

Younger children present some unique problems.

"When my son was in kindergarten, his teacher noticed a pattern of behavior and expressed her concern to me. My son would get very quiet and withdrawn and then would act out by being mean and sometimes actually hitting other children. This was quite contrary to his normal behavior. We were able to identify this as pain onset. He would not tell the teacher he was in pain because he did not want to stand out and be different so he would ignore the pain until it was quite bad. The teacher learned to recognize this behavior and would take him aside, ask if he was in pain and quietly and privately give him pain medication and a quiet place to rest until the medication took effect. Eventually, he was at ease and was able to simply go and ask her for his pain medicine."

Young children in pain can be angry and aggressive or can regress and mimic younger children's comfort behaviors: thumb sucking, rocking and other self-comforting strategies. A perceptive, sympathetic teacher can intervene, minimizing disruption and stress in the classroom.

Note: It is important to remember that severe, chronic pain and fatigue can affect students of all ages, and at times affect their behavior or ability to learn or participate effectively in class. Behavior is often a key to knowing that the student is having an episode of pain, or is suffering from fatigue that can be incapacitating.

Non-traditional Pain Alleviation

Primarily in this category would be acupuncture, acupressure and chiropractic. Many traditional doctors have become knowledgeable about these alternative modalities. Results have been very mixed with some reporting a great benefit and others reporting little or no benefit. Stress can aggravate pain. A child in a classroom where everyone knows and understands his medical condition may experience less stress and therefore a reduction in pain.

New Research in Pain Management

In the past few years, pain management has become its own subspecialty in medicine and there is more of an emphasis on research and the development of new pain medications. In

the past, intractable pain was unfortunate but not much could be done to alleviate it without the use of narcotics. New philosophies regarding pain management and new medications for pain are being developed all the time.

There are many options available and working closely with your doctor is critical in alleviating serious or chronic pain. At different ages, at various times, and even during different seasons of the year, different strategies can be used, combined or discontinued. When one thing stops working move on to try another; you can even go back to try something that worked in the past. Pain can be managed and alleviated. There is no reason for children to suffer unnecessarily.

ORTHOTICS

Most children with MHE will need some form of medical treatment at some time. Some children with MHE will need orthotics: braces, splints, supports, casts, walkers, crutches. Not only can this type of equipment limit mobility but also it can be embarrassing to a child who wants nothing more than to not appear different.

"My son had to wear a cast on his left foot and ankle and had to wear a brace on his left wrist. He was constantly questioned as to why he had to wear these but he was also teased by classmates that he had been in a car accident and only been hit on his left side. After a couple of days of teasing he did not want to wear the brace (although he needed it) and insisted that the cast be removed early (it couldn't be)."

The teacher could simply explain to the class, with the child and parent's permission, that the child has a bone condition and that this type of equipment helps the child function. Once children understand the function of an orthotic they tend to move beyond fascination and confusion to simple acceptance.

SURGERY

Often the treatment will also be surgical and the child will be hospitalized. Some children with MHE will have numerous surgeries. Surgery is usually an extremely traumatic event for a child or even for an adult. Children may experience anxiety once they know that surgery will be scheduled. They may require pre-surgical tests that are frightening and/or painful, and they naturally fear the operation, pain, discomfort and scarring they will experience afterwards. They may miss a significant amount of school and will need helping catching up. Returning to school while still in some degree of pain, weakness and awkwardness can be quite challenging. Many children with MHE have to wait to have surgery until growth plates fuse (at fifteen or sixteen). If surgery is performed too soon, the exostoses can simply grow back.

Consideration needs to be given to children in these situations. Understanding their needs, abilities and limitations must be looked at realistically to make it a smooth transition for all concerned. By law, schools are required to take responsibility for some of these needs. It is important for all concerned to discuss and plan a child's return to school after surgery and to realistically schedule make up work. Again, a simple explanation to teachers and classmates of

what the child has been through and why will help alleviate anxiety for everyone. Before and after surgery, the child can be provided with a tutor to help stay as current as possible with schoolwork and to help the transition back to the classroom when it is deemed appropriate. The provision of a tutor is something your school district should provide.

"In my school district they have a program called Home/Hospital for kids who have a serious illness, injury or surgery. The tutor comes to our home once a day for an hour and she has truly been a godsend. She talks to his teachers at school and picks up assignments and supervises his completing them. Every time he has had to miss school for long periods because of pain or surgeries we have had the same tutor. It has really helped my son keep up in school."

EMOTIONAL ISSUES

Self Esteem

Children with MHE may grow up thinking they are the only children in the world who have this disorder. They may become very self-conscious about the appearance of their bumpy bones, bowed or shorter-than-average limbs, their inability to walk or run or perform other sports related activities in the same manner as their peers. As children grow older, they become more and more aware that they are somehow different. Some children may stop wearing shorts or short sleeved shirts, in an attempt to hide the physical signs of MHE.

Most of us are more comfortable with what we understand. Many parents have reported that a short teaching component on MHE piggybacked with another study area, for example, the skeleton helps everyone understand MHE and feel more comfortable, including the child who has MHE.

"My daughter would never allow anyone to know she had MHE. She was too afraid of being different and of being made fun of. By the time she reached the fourth grade her symptoms became too severe to ignore and the school personnel had to be notified. She required individual counseling by the school psychologist to deal with her feelings of insecurity and low self-esteem, and to deal with anxieties over her first surgery, which would take place during summer vacation. As she needed more and more "special" treatment (she had to sit on a chair instead of the floor, and be excused from many activities in gym) her classmates needed to be told about MHE. She was amazed that no one made fun of her. In fact some of her friends were jealous that she got to sit on a chair during assemblies, while they had to sit on the floor! A weight was lifted from her shoulders when she stopped feeling that she had to keep her disorder a secret."

"I once asked my son what bothered him most about his bumpy bones and he said, 'Nobody else has them.'"

Some children can become angry or depressed:

"I am just 10 years old and I have lots of trouble with my bones in school. I hurt a lot when I write new teacher is real tough and I don't think she is going to understand my not being able to write very much. Being 10 isn't easy, but it really isn't easy being 10 and have crummy bones and being small."

Teasing and Ostrasizing

Children with MHE can appear "different". Part of the curriculum of every school should be the appreciation for and respect of others and our diversity. The terrifying increase in violence in our schools should teach us one basic lesson: we all need to learn to respect each other and treat each other with courtesy.

Mike (13) "A kid walked up to me on the playground and looked at my arms which are visibly deformed. He stared and then started chanting, "What are you some kind of mutant?" He said this several times and then asked, "What are you stupid, too?" when I didn't know how to answer him."

A simple teaching component on MHE would probably have alleviated this child's confusion and lessened the chance of his saying something so obviously inappropriate. We tend to fear what we don't understand.

Achievement

The most important step in making life easier for a child with MHE is also the hardest, and that is recognizing the child's difficulties. Children need to feel loved and valued just as they are, whether short or tall, thin or heavy, lumpy-boned or perfectly formed. Once parents, teachers, and others come to terms with the child's limitations, they can talk about them with the child in an open and realistic way. Children may have a hard time putting their feelings into words, but that does not mean they don't have feelings about being different. Children with MHE usually know they are different by the time they reach school age, if not before. These children may be relieved to have parents, teachers, and friends who can help them identify and express feelings about being different.

In a society that values achievement and being the best, be it in sports, school, or business, it can be difficult for some to understand that not all limitations can be "overcome". For many children with MHE the simple act of finally being able to tie a shoe can be a major milestone. That accomplishment, however, does not mean that child is now capable of running a race. Too often we set unreasonable expectations for our children, whether able-bodied or disabled. The media shows us examples of amputees skiing and paraplegics playing basketball. While these are laudable achievements, they are not realistic goals for every disabled child, just as not every able-bodied child will become a professional ball player or figure skater or Olympic Gold Medal winner.

"My daughter has shown amazing courage and strength in relearning to walk after several tumors in her leg stretched and entrapped a major nerve there. However, sometimes people think that recovery from an MHE surgery is just like recovering from a broken leg. They think you heal and are done with it. They don't realize that there can be other tumors in other places that are still blocking and restricting other movements, causing other problems. Sometimes someone will make a comment on how my daughter will be able to do this or that soon, and she'll reply that she won't be able to do that. People think they're helping by saying things like, "My family motto is never say never!" My daughter knows her body and she knows her limitations, but she also knows her

talents and her strengths, and that should be enough! Sometimes you have to acknowledge that "never" is the reality, accept it, and move on to what is possible!"

MHE AND TEENS:

As children with MHE enter their teen years the challenges of living with this disorder may intensify. Many surgeries for MHE take place after the growth plates close when children are fifteen or sixteen years old. Add that to the normal challenges of being a teenager!

"As a 17-year-old girl, I find it very hard to be different from other people. I'm strong enough to be my own person mentally, but it's tough to be physically different. My fingers are short and the way my fingers grew on my left hand it looks as though what should be the third and fourth fingers were switched! , I'm shorter than I should be. What has been the worst is what this disease has done to my ego and self-confidence. In the beginning of high school you learn that being different is not all right, and therefore not attractive. "

But even when the teenager feels they are dealing well with the implications of their disease the people around them can still have a profound effect:



"Today in my psychology class we were all asked to introduce ourselves and discuss a hardship that we had to face in our lives. Stories ranged from the death of a parent or friend, parent's divorces, to being grounded or getting a speeding ticket. Obviously, my toughest hardship to date has been MHE. So, when it was my turn I stood up and told the class that I have a bone condition where spurs form on my bones, usually at the growth plates, and because of that I'm short, have abnormally short fingers, and have eight scars on my knees and right wrist. That I was unable to do anything very athletic or lift heavy objects, walk up the stairs from the first floor to the fourth. The teacher was nice, she asked questions about malignancy, if I knew other people with the condition, and how it might affect me later in life. The stares; I hate the stares the most. High school students know nothing about compas-

sion. I either was getting looks of extreme pity, or scared looks, almost as though half of the class was afraid they would get it just from being in the same room with me. It isn't the common cold, you know! Seems to me the looks of pity should go towards the poor people who have lost a parent or good friend, not to the girl with the bone condition and the scars. It's so frustrating a lot of the time. I deal with my bones well and without much self-pity. Why can't other people?"

This Handbook has been designed to help educate those around children with MHE: parents, family members, teachers, classmates and friends.

***We would like to offer a special thank you to the
many families affected by MHE
who graciously shared their experiences and insights with us.
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Illustrations: Nicole Wynn

***(Updated: June 23, 2012. Notes have been added, and some minor changes
have been made to the text)***

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pages:**



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- Bumpy Bone Club
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