

MULTIPLE HEREDITARY EXOSTOSES

EDUCATIONAL IMPLICATIONS

The child will most often be able to participate in a regular school program. It is important that school staff be knowledgeable about the student's illness. Students who have MHE present differently. In many students, symptoms may be largely nonproblematic, resulting in minor mobility issues. In other students, the condition may prove to be quite painful, and fatigue from chronic pain may be a factor, and there may be significant mobility issues. Depending on the locations of the exostoses, multiple surgeries may be needed throughout the child's growth span, and the possibility exists that the student may miss significant amounts of school as a result. Adaptive Phy Ed may be a needed related service to address mobility concerns.

Comorbidity.

- The lack of *Heparan sulfate*, the defining trait of students with MHE, has also been associated with social and cognitive problems, such as autism. For this reason, children with MHE are much more likely than their non-MHE affected counterparts to have autism or other brain-based difficulties.

It is important that the teacher meet with the student to address concerns such as:

- Will others stare at me because I look funny?
- Will I still be included, or dropped out of my group?
- Are teachers upset with me because I missed so much school?
- Will I not know as much as other kids?

Respect a student's choice of not speaking with teachers or peers about how they are doing or feeling.

Although over-protectiveness is a frequent emotional response of school staff, children need to know limits, and be expected to follow rules. Many studies have shown the importance of having the student be involved in normal daily routines as much as possible.

RESOURCES

MHE Coalition

6783 York Road, Apt. #104
Parma Heights, OH 44130-4596
Tel: 1-440-842-8817, Cell: 1-440-821-5038
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Hereditary Multiple Exostoses

<http://ghr.nlm.nih.gov/condition/hereditary-multiple-exostoses>

MHE Research Foundation

<http://www.mheresearchfoundation.org/>

MHE And Me

(A support community for children affected by MHE).

<http://www.mheandme.com>

INSTRUCTIONAL STRATEGIES AND CLASSROOM ACCOMMODATIONS

- Curriculum modifications (extra time for assignments, every other problem, no time limits, alternative ways to test and get information).
- Keyboarding may be a viable option for one whose hands have been affected.
- Buddy system for notes, teacher outlines.
- Absences may require repeated instruction, modified requirements as noted above.
- Tutorial services/homebound instruction when necessary.

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