Welcome to MHE

Dear MHE Parent,

We know hearing your child has been diagnosed with Multiple Hereditary Exostoses (MHE) can feel overwhelming; we have been there. You likely have questions, concerns, and uncertainty about what lies ahead. Please know you are not alone. While this diagnosis brings challenges, there is also support and care to help your child and family navigate the road ahead. Studies show that with self-advocacy and personal management strategies, people with MHE overcome challenges and lead full lives.

What is MHE:

MHE is a rare genetic condition where benign bone growths (known as exostoses or osteochondromas) form near the growth plates of (most commonly) long bones. These can lead to pain, range of motion challenges, limb length discrepancies, and changes in bone shape and alignment (sometimes called deformities). MHE is autosomal dominant so in some families many people have MHE; it can also be caused by a random mutation and in this case your child may be the first person in your family to have MHE.

Key Facts About MHE:

- The prevalence of MHE is about 1 in 50,000 individuals.
- MHE is caused by mutations in the EXT1 or EXT2 genes, which disrupt heparan sulfate synthesis, affecting bone growth and cartilage formation.
- While osteochondromas usually stop forming when the growth plates close at the end of puberty, many adults report symptoms of MHE; this is a lifelong challenge.
- There is significant variation in the extent of MHE symptoms and it is impossible at a young age to predict the sequence, severity, and challenges the disease will present.
- Possible complications include pain, limited range of motion, and a rare risk of malignancy (less than 5% and most often in adulthood).

Some Things to Expect:

- Regular check-ups, imaging (x-ray, MRI), and sometimes surgery are part of MHE care.
- Moving through childhood and into puberty, some children navigate pain, difficulty with physical activities, and challenges socially and in school.
- Treatment options may include guided growth procedures, surgery to remove osteochondromas, school supports, emotional supports, occupational and/or physical therapy.

Advice Upon Receiving a MHE Diagnosis:

- Take care of yourself; take time to process the diagnosis and to learn the basics of MHE.
- Build a knowledgeable clinical team you trust (including primary care, geneticist, orthopedic surgeon, and therapists as required). Ask questions of the MHE community and your clinical team as needed.
- Love your child and your family. It is impossible to tell what the road ahead will hold, so we encourage you to find comfort and joy where possible. You will know when and if MHE presents a problem to be addressed. While aspirational in this moment, we encourage you to soak up the times when MHE does not present problems.

The answers to many of your questions will come with time and experience. We have found MHE to be challenging and unpredictable, but it has also brought us many bright spots, unexpected connections, and adventures. We wish you comfort and solace as you embark upon your own journey.

With hope and care, The MHELS Team

MHE Learning System

MHELS.org