

# EDUCATOR'S GUIDE TO COBALAMIN DISORDERS HCU + MMA



## What are Cobalamin Disorders?

HCU + MMA are group of rare genetic conditions that cause both Methylmalonic Acidemia(MMA) with Homocystinuria (HCU). They are usually referred to as Cobalamin disorders or cobalamin processing disorders. All these conditions lead to the body not being able to use vitamin B12 (cobalamin) properly and so the body cannot process certain fats and proteins appropriately. This results in the build-up of harmful levels of homocysteine (HCY) and methylmalonic acid (MMA) and a decrease in the amino acid, methionine. The more common disorders are Cobalamin (Cbl) C and CblD deficiency. More rare disorders include CblF, CblJ, CblX, and transcobalamin II deficiency.

## How can HCU affect the body?

The buildup of homocysteine levels can have **dangerous** and **life-threatening** impacts.

### High homocysteine levels may cause:

- Feeding Difficulties, Vision Problems
- Seizures
- Poor Muscle Tone and Coordination
- Developmental Delay, Microcephaly
- Cerebral Atrophy, Neurological disorders
- Blood clots or strokes

## How can I help?

**Teach** your student as you would anyone else. Your student with HCU + MMA may need additional time or attention to keep pace with the classroom. However, your student is not 'sick'. If they follow their treatment plan, they can be just as successful as their peers.

**Help** to ensure that your student takes their medication(s). Peer pressure may cause children to secretly empty or hide formula. It is important your student has a place they feel safe storing and consuming their formula.

**Communicate** with parents and ask questions. Since you spend a fair amount of time with your student, you may be the first to notice issues related to HCU. Successful HCU management will rely on both parents and school staff communicating with each other.



Individuals with HCU + MMA can have strokes. If you are concerned that your student is actively having a stroke (symptoms include but this is not an extensive list: sudden confusion, loss of skills, difficulty communicating, one-sided weakness or facial droop), please seek immediate medical attention. If you feel that your student has had a stroke (in the recent or not so recent past), promptly discuss this with their parent.



Treat them the same as your other students. Your student is not sick and shouldn't be treated as such. If they follow their medication regimen they can be just as successful as their classmates



Patients **can't** feel when their HCY levels are high (unlike a diabetic who can feel when their insulin is low/high). Regular blood draws are required to manage medication and mitigate negative effects. Symptoms usually occur after a prolonged period of high homocysteine levels. Levels increase gradually, they do not spike suddenly.



### Possible Medication Side Effects

- Bruising
- Circular redness for injection site
- Stomach upset
- Unpleasant body odor/breath (often described as fishy)
- Nausea



# EDUCATIONAL ACCOMMODATIONS



Children with HCU + MMA *may* experience challenges at school. It is important to meet with the student and their family prior to the beginning of the school year to discuss what, if any, accommodations may be needed to ensure the student's educational success. These accommodations may be in the form of a 504 plan, IHP or IEP, depending on the student and their needs.

**HCU + MMA impacts the whole body. Some students may need additional services.**

- Vision Itinerant
- Reading Help
- Speech, OT or PT
- Counseling
- Occupational Therapy
- Protection from bullying



Ensure that ALL teachers and staff members are aware of the students' condition and accommodations. (related arts, school nurse, administrators, cafeteria staff, etc)



If the student rides a bus, you may need to make the accommodations available to their bus driver.

# CLASSROOM ACCOMMODATIONS

- Preferential seating
- Modified textbooks or audio-visual materials
- Oral test and visual aids
- Low vision Accommodations
- Easy access to bathroom and/or nurse
- Accommodations for fine and gross motor activities
- Assisting with self-help skills
- Access to assistive technology

# OTHER ACCOMMODATIONS TO CONSIDER



- ✱ Your student may need to establish a time during the school day to go to the school nurse for medication.
- ✱ If necessary, please allow your student to consume an approved snack before taking medication as it helps alleviate nausea and stomach pain.

**Even though HCU + MMA is a metabolic disorder, your student should not need a special diet. Check with your students guardian to make sure snacks given out during parties are okay.**

**Communication is key!** 

Don't hesitate to ask questions and reach out to your student's parents should you notice anything that seems 'off' with your student.

