

Treatment aimed at regulating some of the GRIN Clinical Symptoms

IMPORTANT: None of these treatments described below has been proven to work specifically on GRIN.

For Gastrointestinal disorders:

Nutrition and diets: For those children affected by gastrointestinal problems, chose easy digestible diets, including diets free of gluten / lactose and / or free of milk / dairy might be beneficial. High caloric foods and specific high caloric food supplements are recommended for children who struggle with gaining weight / suffer from failure to thrive.

For Epilepsy

Ketogenic diet: The ketogenic diet is mostly used in cases where children are affected by drug-resistant epilepsy. A ketogenic diet is in principle low in carbohydrates and proteins, and high in fat. The use of a ketogenic diet in the treatment of certain forms of epilepsy is fairly well known. However, in the case of GRIN disorders, further studies need to be conducted, but it might be an acceptable alternative in cases of drug-resistant epilepsy. However, a close weight control needs to be maintained if putting a GRIN child on a ketogenic diet.

Dr. Amy Ramsey of the University of Toronto, found that her GRIN1 mouse models are less effective at processing glucose in the brain. As a result, the brain lacks fuel /energy, and cannot function optimally. Although the brain accounts for only for 1 to 1.5 kilograms of the total body weight, it is responsible for no less than 20% of the total glucose requirement of the body. By offering a ketogenic diet, glucose as fuel for the brain is replaced by ketones, which can have a positive effect on the functioning of the brain.

Please note that in the case of a complex medical condition such as GRIN, and especially in the case of children, a ketogenic diet should always be offered in consultation with and under the supervision of a doctor.

https://en.m.wikipedia.org/wiki/Vagus_nerve_stimulation

Small indwelling device, similar to a pacemaker, that is surgically placed close to the left side of the neck and shoulder area of a patient affected by uncontrollable epilepsy. This device automatically “corrects” the abnormal electrical impulses that happen during an epileptic crisis.

For Sleep disruption

Many drugs and supplements have been recommended for GRIN, with some variable effects.

Melatonin (drops, capsule and slow release)- Helps with the initiation of sleep. It also has an added antioxidant effect.

5-OH tryptophan: Precursor of Serotonin and Melatonin.

Vitamin B12 and Iron supplementation: these important metabolites are associated with good sleep patterns. Deficiencies in B12 or Iron have been related to poor sleep and can easily be assessed by blood tests.

Risperdal: antipsychotic drug known to improve sleep patterns in people affected with schizophrenia. It is a serotonin-dopamine antagonist!

Clonidine: an attention deficit and hyperactivity disorder treatment. It can be used to help initiate and maintain sleep, possibly through its effect on the autonomic system, by lowering blood pressure and heart rate.

Neurostorms:

What we believed to be Paroxysmal Sympathetic Hyperactivity Storms (PSH- <https://www.uptodate.com/contents/paroxysmal-sympathetic-hyperactivity>).

These neurostorms have been treated with some success with different medications aimed at controlling the autonomic nervous system dysregulation, such as Clonidine. Treatments aimed at controlling non epileptic crisis, such as Gabapentin and Carbamazepine, have also worked in some cases.

More to come

Until now, none of the above-mentioned treatments have been shown to be curative, but in some cases treatments could improve these symptoms.