

MY CHILD HAS JUST BEEN DIAGNOSED WITH A RARE CONDITION, WHAT DO I DO NOW?

Take time to adjust to this new diagnosis. It can be very overwhelming at first. Reach out to our [Facebook support group](#), where you can meet other parents going through the same journey. Surrounding yourself with other parents who are experiencing the same emotions, will allow you to share your experiences and offer support, which is beneficial to all.

WHAT DOES THIS RARE DIAGNOSIS MEAN FOR MY CHILD?

This depends on the specific diagnosis affecting your child/family. . Each condition will have certain characteristics, which may or may not affect your child. It is important to note that each child will be affected differently. Developmental delays are common among a lot of children diagnosed with genetic conditions. Having the right supports in place as early as possible is very helpful. Although many of our children may have different genetic conditions, they will have a lot of common characteristics, so joining our private parents only support group can be a great source of information and more importantly, support.

WHAT SUPPORTS ARE AVAILABLE TO ME NOW?

There are many supports available such as financial support, home help, respite services etc., which we have more information on, in a section in our members forum. Contact Us for more information by emailing info@rareireland.ie or by calling 089 4220228.

DID MY CHILD INHERIT THEIR CONDITION FROM ME?

Genetic testing should be offered to both parents after your child is diagnosed. This will either confirm or rule out either parent having the same genetic variants. Genetics counselling should be offered after a diagnosis, where everything can be explained in detail by a genetic specialist.

All hereditary diseases are genetic but not all genetic diseases are hereditary. Genetic conditions are often what's referred to as DeNovo, this means that any changes in the gene sequence were not inherited from either parent. They are new mutations that are affecting your child, and have been absent in your family in previous generations.

WHAT IS GENETIC TESTING?

Genetic testing is a type of medical test that identifies changes/variants in genes, chromosomes or proteins. The results of a genetic test can confirm or rule out a suspected genetic condition or help determine a person's chance of developing or passing on a genetic disorder.

ARE THERE OTHER FAMILIES WITH THE SAME CONDITION?

Upon registering as a member with Rare Ireland, if you wish we can facilitate contact with another family, that is living with the same condition.

Any contact with members facilitated by Rare Ireland is done in confidence.