Index case reference number: ………………………..

To:   Relatives of (name of patient)

Dear relative,

Re:   (name of index patient)

          Problem:  (Name of condition)

Genetic change causing this: ………………..

I have asked your relative, XXXX, to pass this letter on to you.  He/she has agreed that the information in this letter can be shared with you and with doctors or other healthcare staff involved in your healthcare.

A member of your family has been diagnosed with XXXXX. Someone with this condition typically develops clinical symptoms with ………..…….. The condition is caused by a gene alteration which can be passed on through families.

This type of condition is called an autosomal recessive condition. When a person has one normal copy of this gene, and one altered copy, they are called carriers. Being a carrier does not usually have any effect on one’s health. We are all carriers of some altered genes and most people who are carriers are not aware of this. However, if both parents are carriers, then there is a risk of 1 in 4 that their child may suffer from the condition. This happens when a child has two altered copies of the gene, one from each parent.

As you are a blood relative of XXX, you may be a carrier and your children or grandchildren could be carriers or even inherit the condition.

We would therefore recommend that you ask for an appointment with your doctor to discuss this, and take this letter with you to that appointment. Your doctor can then refer you to a genetic clinic to discuss this in more detail, if you wish. If so, we would recommend that your doctor makes a copy of this letter to accompany the referral, so that the exact genetic details are also made available.

If you would like further general information on genetics and inheritance, or on the specific condition in your family, you may like to search educational sites on the Internet using the search terms: *Autosomal recessive inheritance* or …………..(condition name). Suggested sites could include: Genetic Alliance UK [http://www.geneticalliance.org.uk/docs/eurogentest\_RecessiveInheritanceA4.pdf].

If you or your doctor have other immediate questions, I would be happy to answer these for you. Please contact:……………………………………, quoting also the reference number at the top of this letter.

Yours sincerely        ……………………………………………