Research Update

Wonderful news. The NFED have awarded John McGrath, a member of our Medical Advisory Board 24,000 (US Dollars) for his research work on "Abnormalities of the p63 gene in ectodermal dysplasia and related syndromes". John is working with two other members of our Medical Advisory Board and they are looking at the gene responsible for AEC (Haywells), Rapp-Hodgkin, EEC and similar types of ED. They have recently carried out a DNA based antenatal test for EEC syndrome, the first in this disorder and, as the test indicated, the child has been born unaffected. Most of the research uses genomic DNA from blood samples and all the work has been approved by local Ethics Committees.

The team are always looking for willing participants in their research programmes, so if you have AEC, EEC, RH or split hand/foot and are willing to help, then they will be very happy to examine the p63 gene for you. Please get in touch with the EDS office.

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