Genetic Alliance UK
Supporting. Campaigning. Uniting.

Additional Information to Oral Evidence

Inquiry into access to medical technologies in Wales

Genetic Alliance UK, 13th March 2014

Introduction

1. Genetic Alliance UK is the national charity supporting all those affected by genetic conditions. We aim to improve the lives of people affected by genetic conditions by ensuring that high quality services and information is available to all who need them. Our membership represents more than 160 voluntary organisations working for a wide range of conditions, many of which pose complex health and social care needs and require a diagnosis for effective management and treatment where possible.

2. Genetic Alliance UK delivers its work through support networks and strategic advocacy. One of our support networks is SWAN UK (Syndromes without a name) which supports families of children with undiagnosed genetic conditions. It is estimated that around half of all children who attend genetics clinics in Wales do not get a diagnosis for their condition – they may be affected by novel genetic mutations or chromosome rearrangements. Due to lack of a diagnosis, many families experience difficulties in accessing help and support from various services including health, education and social services.

3. In 2008 Genetic Alliance UK launched Rare Disease UK (RDUK), the national multi-stakeholder alliance for people with rare diseases and all who support them. RDUK is campaigning for a National Strategy for Rare Diseases in the UK, to ensure that patients and families living with rare conditions have equitable access to effective services.

4. In addition to the oral evidence that Genetic Alliance UK presented to the Health and Social Care Committee on 6th March 2013, we are submitting additional information in response to a number of the questions that were asked by members of the Committee.

5. In response to the Chair, David Rees AM's question regarding clarification of the relationship between UK Genetic Testing Network (UKGTN) and National Institute for Heath and Care Excellence (NICE):

   UKGTN is a clinical network of NHS laboratory scientists, clinical geneticists that collaborate with genetics commissioners and patient representatives. The Steering Group is chaired by Professor Peter Farndon. UKGTN aims to promote the provision of high quality equitable genetic testing services for NHS patients across the UK. This involves evaluating new tests that would not meet the NICE diagnostic selection criteria and recommending to specialised services commissioners those appropriate for service. There are 52 member laboratories from regional genetics and other specialist laboratories. A small project team and four working groups carry out the work on behalf of the Steering Group. The working group members are nominated representatives from

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healthcare professional groups, member laboratories and patient representatives from across the UK.[1]

6. UKGTN has established links with NICE Diagnostic Programme Board to ensure there is no duplication in the evaluation of genetic tests. UKGTN advises the Diagnostic Programme Board of new developments that have wider implications for NHS which may benefit from an evaluation by NICE. The UKGTN seeks to link the UKGTN Testing Criteria with NICE quality standards where appropriate.

7. Another useful link sets out how UKGTN helps commissioning in the NHS. The document focusses on England but the premise is the same for all UK countries - http://ukgtn.nhs.uk/resources/commissioning/

8. In response to Lynne Neagle's question relating to whether Individual Patient Funding Requests (IPFRs) would be an appropriate mechanism to access genetic tests:

   Commissioning genetic tests (approved by the UKGTN) should not go through IPFR in Wales because the patient needing the test isn't 'exceptional'; they just need the approved test to be commissioned by the Welsh Health Specialised Services Committee (WHSSC).

9. In addition to the evidence that was given about commissioning of UKGTN approved tests in Scotland:

   National Services Division in Scotland funds the Scottish Genetic Laboratory Consortium in Scotland which provides genetic tests to Scottish patients. The Consortium decides on the tests available, using the commissioning advice made available by the UKGTN. The National Services Division will fund the tests available in Scotland and where necessary, will also fund UKGTN approved tests sourced from England or abroad.

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Genetic Alliance UK

[1] http://ukgtn.nhs.uk/fileadmin/_migrated/tt_news/news_files/UKGTN_RESPONSE_Commissioning_for_patients_Oct_10.doc