

# Genetic Laboratory Network (UKHCDO-GLN)

## Background

The UKHCDO GLN (formerly GTN) was formed in 2002, arising out of the UKHCDO Genetic Working Party, with the aim of improving collaboration between laboratories and of ensuring quality and equity of service across the U.K. The network currently comprises 13 laboratories, 12 across the UK plus Dublin, involved in the molecular genetic analysis of haemophilia and related inherited bleeding disorders (many of the laboratories are also involved in other areas as well).

Representatives of the Network attend meetings of the UK Genetic Testing Network (UKGTN) and the UKHCDO GWP, although this has been inactive during 2015.

The Haemophilia Alliance meeting has now been replaced by the Clinical Reference Group for Haemophilia. No role for a scientific or laboratory member has been created in the new group.

## Meetings

The UKHCDO GLN holds bi-annual meetings and met on 18<sup>th</sup> November 2014 in Cardiff and 13<sup>th</sup> May 2015 in Newcastle. The next meeting is scheduled for 23<sup>rd</sup> November in Cambridge.

## Chair & Secretary

Steve Keeney (Chair) and Vince Jenkins (Secretary) continued in these positions

## Current activities

### 1. UK Genetic Testing Network (UKGTN) revised remit – UKHCDO-GLN registration

As discussed in the 2014 report, the UKGTN have revised their remit to include "*Any genetic test provided by a UKGTN member laboratory for NHS service provision for rare disorders that usually affects fewer than 1 in 2000 as described in the UK Rare Disease Strategy*". Individual UKHCDO GLN labs that are not registered with the UKGTN have been advised that they may wish to consider applying for membership if they perceive it is in their interest. The UKGTN has since run a "grandfathering" exercise to allow laboratories to submit pared back additional provider forms for inclusion on the UKGTN providers list. The take up of this process by UKHCDO-GLN labs will be discussed at the November meeting. Note that the NHS England genetic laboratory re-designation exercise is currently underway.

### 2. Laboratory Audit – ISO 15189

Clinical Pathology Accreditation (CPA) or now working to the ISO 15189 quality standard applicable to laboratories. The GLN has had a great deal of discussion

related to this process and have been sharing practical advice and knowledge as the revised inspection process is applied to member laboratories.

### **3. National Haemophilia Database Genetics Portal**

The inclusion of a portal to the National Haemophilia Database for the upload of genetic mutation data is in use across the GLN. Some problems have been encountered in terms of matching input data with that on the NHD, leading to data entry failure in a significant number of cases. This has been discussed with NHD administrators and a plan developed to adjust data entry criteria – awaiting further feedback on this development from the NHD.

### **4. Bleeding Disorder Genetic Analysis Best Practice Guidelines**

The BPGs for Haemophilia A and Haemophilia B are still considered current, although nearing a review. The VWD genetic analysis guideline update is underway.

### **5. Haemophilia Genetics NEQAS scheme**

The Haemophilia Genetics EQA scheme, run by UK NEQAS in Sheffield, continues with bi-annual distributions. The results for each round of the scheme are reviewed and discussed at the following network meetings and any relevant comments fed back to the steering group. The scheme currently includes *F8*, *F9* and *VWF* gene analysis.

### **6. Participation in other groups**

A representative from the network attends the:

- Clinical and Scientific Advisory Group UK Genetics Testing Network (see item 1 above)
- Representatives of the Network attend meetings of the UKHCDO GWP, although this has been inactive during 2015.

Steve Keeney  
Chairman, UKHCDO Genetic Laboratory Network  
September 2015