

## Genetics Working Party

The Genetics Working Party (GWP) has met three times in 2010-11.

### Membership

### Attendance

John Pasi	Chair	3/3
Keith Gomez	Secretary	2/3
Chris Ludlam		2/3
Tony Cumming		2/3
Ted Tuddenham		0/3
Dianne Marshall	UK RCN Haemophilia Nurses Association	3/3
Alan Fryer	Joint Committee for Medical Genetics	3/3
Heather Skirton	Association of Genetic Nurses and Counsellors	2/3
Mike Mitchell	Chairman Laboratory Network	3/3

### Remit

The purpose of the Genetics Working Party (GWP) is to advise and inform the UKHCDO on relevant issues in genetics.

The Genetics Laboratory Network (representing the laboratories providing services in genetic analysis to haemophilia centres) remains a sub-group of this working party and reports to the UKHCDO via the GWP.

The GWP will maintain a clinical governance role overseeing the provision of genetic services in haemophilia services.

### Meetings and work streams

Aside from the regular work of the GWP in providing a governance and feedback forum, identified work streams for this current iteration of the GWP are:

#### *Guideline review*

The existing guidelines are being updated to take into account advances in technology and changes in consent procedures. The next iteration is in the latter stages of compilation in accord with BCSH procedures. Mike Laffan has been co-opted as BCSH rep.

*Discussion and engagement with Haemophilia Society regarding genetic educational needs and support for patients*

This has taken place and joint skeleton documents are being developed

*Audit programme*

Oversee and compile the audit that has been carried out by the laboratory network in 2010. Proposals for potentially including the genetics audit within the triennial audit have been made.

*Capture of genetic information on HCIS and UKHCDO NHD*

Work has continued on delivery of a module for HCIS for use as a genetics register and ensure appropriate capture of genetic information on NHD for research purposes in liaison with the Inhibitor Working Party and Data Management Working Party. A prototype is now being tested.

Prof KJ Pasi  
Chairman, Genetics Working Party  
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