

**User Satisfaction Survey Report****Date of report: 13/08/10****Survey name: Marfan syndrome****Date of survey: June – July 2010**

Questionnaires were sent to 15 random referring clinicians to enable a broad “ picture” of the disease service to be assessed. 8 responses were received for this survey; three from SW Thames Genetics, one from St. Georges Hospital / University of London, 3 from Yorkhill Hospital (Glasgow) and one from NW Thames Genetics.

**Results****1) Reporting times**

Reporting times rating - average 4.1/5

Two respondents commented on reporting times – one stated that reporting times were “ improving all the time”. Another stated that they could always get urgent reporting when required.

**Action:** none to be taken

**2) Reporting practice**

All respondents stated that the report information was “ about right” . One respondent commented that the report wording was “ careful, informative and complies with regular nomenclature” .

**Action:** none to be taken

**3) Marfan syndrome developments**

Several other genes have been identified as being involved in the Marfan syndrome phenotype and other cardiac conditions in recent years, two of which are *TGFBR1* and *TGFBR2*. Due to cost and workload implications, the laboratory wished to assess the feasibility of offering an expansion of the service to include these genes. Users were asked whether they thought that they would refer patients screened negative for *FBN11* mutations for these genes, and if so, estimate the proportion.

2/6 respondents (both from SWT Genetics) stated they would refer very few as they are not running specialised cardiac clinics.

1/6 respondents stated they would refer about 10% of their patients for this analysis (SGUL/SGH). This user also requested that other genes (ACTA2, Myosin II) be added to the service and a discussion regarding expansion of the service requested with the Head of Laboratory (which will be arranged in the future).

1/6 respondents (SWT Genetics) stated they would refer about 50 per year and that the service was needed as the user sees patients from NE, SW and NW regions at the Royal Brompton cardiac clinic.

1/6 respondents (NW Thames Genetics) stated that they would refer “ almost all” cases.

3/6 respondents (Glasgow) also stated they would refer the majority of cases. One user stated that in some instances, *TGFBR1* and *TGFBR2* would be their first line test.

**Action:** The possibility of expanding the Marfan service in light of these comments needs to be formally reviewed at a later stage (date to be arranged) as this would involve significant extra work for staff at the current time.

**4) Information**

Most users were aware of the departmental website and none had any comments regarding it. The information regarding sample sending was rated at an average of 4.8/5 and the advice from staff rated as 4.7/5.

One user commented that the online referral form was very useful. Another commented that "someone is always there to help".

**Action:** none to be taken

**5) Overall quality of service**

Users rated the service an average of 4.6/5 overall. One user (SGH/SGUL) stated that "this is an expanding service to patients with aortic aneurysms who come to our tertiary referral screening clinic and aneurysms follow-up clinic."

**Conclusions**

The Marfan service is generally considered to be of high quality. Improvements in the service's reporting times are ongoing and additional gene screening will be taken into consideration in the future.

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