

Meeting of the PCA Familial Breast Cancer Group

Monday 5th March 2018

The Arundell Arms Hotel, Lifton, Devon

Chair: Dr Carole Brewer

Consultant Clinical Geneticist-Royal Devon and Exeter NHS Foundation Trust

1.0 Welcome and Introductions

- 1.1 Please refer to separate record of [attendance](#).
- 1.2 The minutes of the previous meeting were considered and accepted as accurate.
- 1.3 No matters arising declared.

2.0 Updates from across the Peninsula

2.1 Plymouth Hospitals NHS Trust

- 2.1.1 PHT hope to set up a family history clinic, with the assistance of Matilda Bradford (Genetic Counsellor).

2.2 Royal Devon and Exeter NHD Foundation Trust

- 2.2.1 Family history clinics are currently undertaken by Di Cameron at the Heavitree site and are going well.

2.3 North Devon Healthcare NHS Trust

- 2.3.1 A moderate family history group is running in Barnstaple; virtual follow up clinics are also in place.
- 2.3.2 A gap in the service currently provided has been identified for patients whose family history has changed.

2.4 Torbay and South Devon NHS Foundation Trust

- 2.4.1 The service is currently led by Gill Bishop who is due to retire this year. Plans thereafter are yet to be clarified.

2.5 Cornwall Hospitals NHS Trust

- 2.5.1 No changes to current service.

3.0 Group Discussion

- 3.1 There have been a few instances of patients requesting prophylactic chemotherapy-practice variation for this is not clear, however NICE have produced a useful information booklet.
- 3.2 Prophylactic treatment is currently off licence; it is not really known when it should be taken, or how long for.

3.3 The general feeling was that patients do not appear keen to take up prophylaxis, despite encouraging evidence emerging as to the risk reduction for patients actively treated. It is likely that for the majority of patients, the treatment will not cause harm and on balance, will probably do more good than harm.

3.4 It may be that healthcare professionals need to consider providing literature for patients to enable them to make an informed decision as to the risks vs. benefits of prophylactic chemotherapy.

4.0 POSH Study

4.1 The study (led by Diane Eccles) looked at the outcomes of women diagnosed with breast cancer under the age of 40 years.

4.2 The mainstream media reported the results of the study as being that risk reducing surgery was not a good idea.

4.3 The outcome of the study actually found that there was no overall difference in survival rates between BRCA +ve and BRCA –ve patients at 2, 5 and 10 years.

4.4 For further information, refer to Dr Brewer's presentation slides. (attached)

5.0 Urgent Referral Criteria

5.1 Some referrals have been received via the new referral proforma.

5.2 NK will circulate the proforma again to the wider group.

6.0 MDT Discussion of High Risk Patients

6.1 The criterion for risk reducing surgery across the Peninsula has been collected and will be discussed at the next Breast SSG meeting (September 2018).

6.2 It was thought that the most pragmatic approach to ensure equity of access to surgery across the region would be to produce a one page genetic assessment.

6.3 Current practice suggests that patients are currently being offered surgery if they have a lifetime risk greater than 25-30%.

7.0 AOB

7.1 The admin support difficulties that were encountered at Exeter have now been resolved.

7.2 It was suggested that the familial breast cancer group has fulfilled the original need for which it was set up, but now it would seem reasonable to include a brief standing item in the Breast cancer specialist nurses' group (to be agreed with chair), and the Breast SSG- agreed with chair, Miss Charlotte Ives.

7.3 The next meeting will be held with the Breast SSG meeting on Monday 24th September (details TBC nearer the time).