ABORTION, ETHICS AND TORT LAW
A RED HERRING?

I wish to start this editorial by posing a question. Should a young female patient who enters in your clinic, and whose father is known to you as suffering from Huntington's, be informed of her father's condition? As you may recall, Huntington's disease is an autosomal dominant neurodegenerative disorder, meaning that having a mutation in only one of the two copies of the *HTT* gene - the *HTT* gene provides instructions for making a protein called Huntington - is enough to cause the condition. When a person with Huntington's has children, each child has a 50% chance of inheriting the mutated gene and developing the condition.

So, returning to that young patient of yours who is of child-bearing age, would you inform her of her father's condition or confidentiality would prevail?

Well, we are currently experiencing this scenario in what can be considered as one of the first cases in the UK where judgement is expected on a relative's claim over issues of genetic responsibility. Lawyers are bringing a case against the St George's Healthcare NHS Trust, involving a woman who is suing doctors because they failed to tell her about her father's fatal hereditary disease before she had her own child. The woman discovered – after giving birth – that her father carried the gene for Huntington's disease and that her own daughter has a 50% chance of having it. The lawyers argument that if the patient knew about her father's condition she would have tested herself for the condition and if positive, she would have terminated her pregnancy. In keeping with this, her lawyers floated the idea that the definition of a patient may not just be the person who provided a genetic sample, but may be also defined as those affected by that genetic sample.

Well, should doctors share genetic test results with relatives, even without consent? How much effort clinicians need to put into tracing relatives? Well, knowledge on genetic components of diseases, including cancer, evolves with time and research; this poses a challenge on what is currently known, what becomes known, estimating the chance of developing or passing on a genetic disorder and whether such chance justifies the communication of information to relatives. One must remember that you cannot retract that information once you have given it.

The case involving the St George's Healthcare NHS Trust is unnaturally complex. The patient's father shot and killed his wife in 2007 and was convicted of manslaughter. In 2009, doctors at the St George's Hospital diagnosed him with Huntington's disease and proposed to tell his daughter about his condition in view of the fact that she was pregnant. He refused to do so and the doctors accepted his decision. In 2010 the woman gave birth and four months later she accidentally learned by one of her father's doctors that her father had Huntington's. In 2013 she tested positive for the Huntington's disease gene; her own daughter, now eight, has a 50% chance of having it.

Interestingly, in 2015 the High Court of Justice ruled against the patient's claim since such move was interpreted to undermine the doctor-patient relationship; also the court recognised that doctors might also be overly burdened if they are required to assess whether or not to make disclosures to patients' relatives. However, this decision was overturned by the Court of Appeal in 2017. The latter acknowledged the arguments of the High Court of Justice but said that these should not preclude the patient from having the opportunity to have the particular circumstances of her case heard in the High Court for a full trial. The trial is set for November 2019.

That a duty of confidence exists in relation to medical information is axiomatic. However, common sense dictates that the rule of confidentiality is not absolute. In special circumstances it may be justified to break confidentiality where the aversion of harm by the disclosure substantially outweighs the patient's claim to confidentiality. Before disclosure is made in such circumstances, an attempt should be made to persuade the patient in question to consent to disclosure; the benefit to those at risk should be so considerable as to outweigh any distress which disclosure would cause the patient.

Ian Ellul

Editor-in-Chief: Dr Wilfred Galea
Managing Editor: Dr Ian C Ellul
Sales & circulation Director: Carmen Cachia

Email: mpl@thesynapse.net
Telephone: +356 21453973/4

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