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**B I L L**

TO

Make provision about screening for conditions leading to sudden cardiac death in the young; and for connected purposes.

**B**E IT ENACTED by the Queen's most Excellent Majesty, by and with the advice and consent of the Lords Spiritual and Temporal, and Commons, in this present Parliament assembled, and by the authority of the same, as follows:—

**1 Action to be taken following a sudden death**

- (1) If a post mortem undertaken following the sudden death of a young person, is—
- (a) unable to identify the cause of death, or
  - (b) identifies the cause of death as a cardiac disease that has a genetic basis, the pathologist who carried out the post mortem shall append to the post mortem report a pro forma and a statement recommending that first degree relatives of the deceased young person be screened to see if they have a cardiac disease. 5
- (2) Once the GP of the deceased young person has received the post mortem report and appendices he shall attempt to contact first degree relatives of the deceased and invite or recommend that they be screened to see if they have a cardiac disease. 10
- (3) The minimum requirements of the pro forma and statement under subsection (1) are prescribed in the Schedule. 15

**2 The role of the GP**

- (1) Where a young person who—
- (a) has the relevant symptoms, or
  - (b) has a first degree family member who, at under 40 years of age, has or had a cardiac disease that has or had a genetic basis, 20
- presents himself to his GP, the GP shall advise him of the desirability of consulting a relevant specialist.

- (2) For the purposes of subsection (1) the relevant symptoms are breathlessness disproportionate to activity, palpitations, chest tightness on exertion, and frequent faintness or giddiness.

### **3 The role of the specialist**

- (1) Where a relevant specialist finds that a young person has a cardiac disease that has a genetic basis, the specialist shall – 5
- (a) advise the young person that it would be desirable for his first-degree relatives to consult their GPs, and
  - (b) issue to the young person a letter for his first degree relatives to give to their GPs if they so wish. 10
- (2) The letter issued under subsection (1) shall state that a first degree relative of the GP’s patient has a cardiac disease that has a genetic basis and it would be desirable for the patient to be referred to a relevant specialist.

### **4 Interpretation**

- (1) In this Act – 15
- “cardiac disease that has a genetic basis” means a cardiac disease that close relatives are likely to suffer from, which includes but is not limited to hypertrophic cardiomyopathy, coronary artery anomalies, arrhythmogenic right ventricular cardiomyopathy, Long QT/Brugada’s syndrome, Marfan’s, mitral valve prolapse, Wolfe-Parkinson-White syndrome, dilated cardiomyopathy and premature coronary artery disease; 20
  - “relevant specialist” means a person with clinical or academic knowledge of conditions predisposing to arrhythmia and sudden cardiac death in the young; and 25
  - “young person” means a person under 35 years of age.

## SCHEDULE

Section 1

### STATEMENT AND PRO FORMA UNDER SECTION 1

- 1 (1) The statement under section 1 shall indicate that—
- (a) a young person had recently died a sudden death and that the post mortem had either—5
    - (i) been unable to identify the cause of death, or
    - (ii) identified the cause of death as a cardiac disease that has a genetic basis, and
  - (b) it would be desirable for first degree relatives to consult their GPs.
- (2) The following pro forma shall accompany the statement—10

#### **Pro forma for next of kin of suspected cardiac deaths**

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To: [NAME OF NEXT OF KIN]

This form is sent whenever a young person dies suddenly. A proportion of sudden deaths are caused by underlying heart problems with a genetic basis and therefore run in families. It is possible that [NAME OF DECEASED] suffered from an underlying heart problem that may be genetic, so it is desirable that their parents, children and full siblings be screened for this condition. It is recommended that they present a copy of this form to their GP.15  
20

This form has been sent by a pathologist, [NAME OF PATHOLOGIST], who carried out an autopsy of [NAME OF DECEASED]. You can contact the pathologist at [ADDRESS AND PHONE NUMBER OF PATHOLOGIST].

The autopsy found that [RESULTS OF AUTOPSY, INCLUDING THE NAME OF SUSPECTED CONDITION].25

# Cardiac Risk in the Young (Screening) Bill

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