

Haemophilia Scotland Response to the Penrose Report

Haemophilia Scotland Recommendations

Haemophilia Scotland believes the facts uncovered by the report constitutes an unanswerable case for the following actions.

Acknowledgement of the disaster and supporting its victims

- **An apology:** There should be a formal apology from the First Minister on behalf of the Scottish institutions for their part in the contaminated blood disaster. The apology must include an acceptance by the Scottish Government that there is a moral duty to those infected as a result of NHS treatment.
- **A Scottish Settlement for Financial Support:** Scotland should provide proper financial support for those affected by the disaster. This should be in the form of lump sum payments based on civil damages. It should recognise the pain and suffering caused by the disaster as well as the loss of earning of those infected and those who have cared for them. No payments should be contingent on the ability to provide evidence from medical records as many of them are missing or incomplete. It is unacceptable that the current support arrangements are not fully accountable to Scottish families and the Scottish Government and leave some people living in poverty.
- **Support for families:** The families, widows and dependents of those infected must be supported. Many of the survivors of the disaster are extremely anxious that their reduced earning potential and lack of access to financial products means they have not been able to make provision for their families. Therefore, all those affected by the disaster should be entitled to make a claim under the scheme, assessed against the standards of civic damages for their loss.
- **Psychosocial support:** There should be a commitment to rolling out psychosocial support to everyone with a bleeding disorder in Scotland and to ensure that a sustainable Scottish patient association.

Securing the safety of the blood supply

- **Blood should never again be collected in prisons and borstals:** Although not current practice we fear that arguments that fulfilling civic duties, such as blood donation, can play an important role in reducing recidivism mean that constant vigilance is required. We believe the epidemiological evidence is clear that prisoners are at increased risk of transmitting blood borne infections and would therefore represent a threat to blood safety when the next blood borne infection emerges.
- **Early adoption of new donor tests.** The threshold for using a new blood test, including surrogate tests, to exclude donors is too high with too much emphasis placed on false positives reducing the blood supply. Tests should be introduced

early to increase patient safety with any shortfall in blood supply addressed by recruiting more donors. It is clear that with better funding the Scottish National Blood Transfusion Service (SNBTS) could do even more to recruit and retain donors.

- **Look-back.** The Report recommends a full look-back to find the untold number of people infected through a blood transfusion and offer them a test. It is vital that this work includes efforts to identify those with a mild bleeding disorder that have been lost to follow-up from Scottish Haemophilia Centres. At the end of this process we must be as sure as possible that all those infected have access to the medical care they need.

The patient at the centre of decision making

- **Nothing about me, without me:** All decisions about the treatment a patient receives should be taken by that patient (or where appropriate their carer) based on the professional advice of healthcare professionals. For example,
 - When new risks are discovered in relation to a current treatment (such as was the case when the risk of HIV in clotting factor products was identified) patients must have the risks explained to them and be offered alternative treatments or treatment regimes where they exist.
- **Nothing about us, without us:** No decisions about the healthcare services in Scotland should be taken without patient representation. This includes decisions about;
 - **Service design**
 - **Service specification or standards, including auditing**
 - **Product safety or purchasing**
 - **Communicating risks**

The patient voice in all of these decisions should have statutory protection.

- **Duty of Candour:** Patient and the groups representing them, must be advised at an early stage when any potential risks or problems with past, current or future treatments, products are identified. The new Duty of Candour should be extended to ensure openness between all healthcare professionals and agencies. Both Healthcare professionals and patients should be encouraged to voice concerns without fear of prosecution, reduction in service provision, or impact damage to career prospects

Research

- **Full and informed consent for the use of samples in research:** No blood or tissue sample, including historic samples, should be used for any purpose which the patient has not given full and informed consent for, or their next of kin if the person is deceased.

- **More research:** Government funded research is required to address some key question where the Penrose Inquiry found there was simply not enough evidence. For example:
 - Are there any clinical implications of being repeatedly infected with multiple genotypes of Hepatitis C?
 - In particular, does this have an impact on the likelihood of ‘clearing’ naturally; immune response fatigue; the success rate of treatment; or prognosis?
 - Why are natural clearing rates lower for people affected by bleeding disorders?