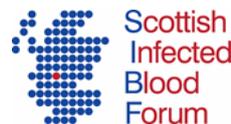




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6 May 2019

Dear Mr FitzPatrick

Thank you again for our last meeting on the 27th September 2018. We thought it was a very positive and constructive meeting overall. We are grateful to you for the commitment you have given to working with infected and affected people to improve the Scottish Infected Blood Support Scheme (SIBSS) which is already the superior package of support in the UK thus far. At that meeting we also agreed to come together again in six months, so we are writing today to request that meeting.

The issues we would hope to cover include,

- a) The successes and learning points from the implementation of the Clinical Review Group recommendations. We have some concerns that a few people may have lived with the impacts of infection for so long they may have normalised the detriments and understated the impacts. We will also be able to help with a reflective assessment of the process, such as, improving the use of descriptor-examples, naming the more common related physical conditions, and suggesting improvements in the use of language. We are also keen to discuss the process of auditing by selecting individual applicants for scrutiny.
- b) Approaches to protecting payments made by the Scottish Infected Blood Support Scheme from being devalued by inflation. The Welsh Government made an announcement on the 6th of March that the "...suite of ex-gratia payments currently available to those belonging to WIBSS will see their payments rise in line with the Cost of Living Price Index including Housing (CPIH)..."
<https://gov.wales/written-statement-welsh-infected-blood-support-scheme-wibss-enhanced-support>

We think that reference to the link to the Scottish Mean Fulltime Wage, as established by the Contaminated Blood Financial Support Review Group, is an important aspect of this decision.

- c) The way ahead for dealing with the final outstanding recommendations from the Contaminated Blood Financial Support Review Group Report, specifically,
 - a. "Recipients of the ongoing annual payments should have the option of converting these into a one-off lump sum payment by way of final settlement."
 - b. "Access to insurance products, and additional loading of premiums due to infections, should be given further consideration."
- d) Jackie Doyle-Price MP, Parliamentary Under Secretary of State for Mental Health, Inequalities and Suicide Prevention, announced on 30 April 2019 that she intends "...to approach the devolved administrations to look at how we might provide greater parity of support across the United Kingdom." This in relation to the increase in the budget of the England Infected Blood Support Scheme (EIBSS) from £46.3m to £75m. We would be grateful for the opportunity to discuss what position the Scottish Government will take in relation to these discussions.

We would also like to take this opportunity to reiterate our concerns about certain other outstanding issues.

- 1) The availability of financial and practical support to family members who experience financial losses when taking on caring responsibilities.
- 2) We continue to view the removal of the widow(er)'s pension payment from those that remarry as reflecting an anachronistic view of marriage and as a threat to the right to a family life of those it affects.
- 3) Similarly, we view the suspension of payments from those that are imprisoned as a threat to the financial security to the individual and family of those persons so affected, for example in the case of mortgage repayments.
- 4) The need to establish a clear rationale for setting the levels of support in the chronic moderate and chronic severe categories of support akin to the link to the Scottish Mean Fulltime Wage for the advanced category of support.
- 5) The lower than expected use of the one-off discretionary grants provided by the SIBSS.
- 6) We also continue to be concerned that important data was lost when people transferred from the old, UK, Alliance House schemes. We are anxious to find a way to make it as easy as possible to replace the missing data on route of infection.
- 7) Finally, we still strongly advocate for primary legislation to specifically recognise the Scottish Infected Blood Support Scheme. This would provide additional security to those relying on its payments; including by reassuring mortgage lenders that the payments represent a secure form of income. We believe that primary legislation would also provide an opportunity to revisit the double lock on entry to the SIBSS which requires that someone be both infected in Scotland and first applied for financial support from Scotland.



We think it is likely that some of the issues discussed above will be looked at by the ongoing Infected Blood Inquiry and that they may well make relevant recommendations. We are grateful for the commitment you gave at the last meeting that all these arrangements would be reviewed in the light of any relevant findings from the Infected Blood Inquiry.

Thank you again for your ongoing commitment to those of the contaminated blood and blood products community in Scotland.

With best wishes,

Yours sincerely,

A handwritten signature in blue ink that reads "Bill Wright".

Bill Wright
Chair, Haemophilia Scotland

A handwritten signature in blue ink that reads "John Rice".

John Rice
Convener, Scottish Infected Blood Forum