

SPEECH BY BILL WRIGHT, CHAIR OF HAEMOPHILIA SCOTLAND

DELIVERED AT THE RICHARD LYLE MSP HOSTED JOINT PARLIAMENTARY RECEPTION WITH THE HEPATITIS C TRUST ON 10 DECEMBER 2014

Reasons for event

1. Penrose –the report was expected after two and a half years on from the closing submissions in March 2012. The first hearing took place on March 2009. It has been longer still since the Inquiry was announced.
2. We want to mark a 15 year milestone. It is 15 years since petition P45 calling for the Scottish Parliament to hold an independent inquiry into hepatitis C and other infections of people with haemophilia. It is also 30 years since disaster was at its most intense.
3. New treatments are on line.

So to the very murky matter of the contaminated blood disaster, the Penrose Inquiry and what happens next.

Recent commentary

During the recent Vale of Leven Inquiry Report publication – it has been worrying that media and some political attention focussed on inquiries and costs rather than infections and people. The story of that particular disaster, why it happened and its impact was somehow lost in the reporting, as media organisations favoured making the story the cost of the inquiry and the inquiry process itself.

One of the worries about this is that if the subject of the inquiry process, and the process itself are both under the spotlight at the same time then we are in seriously deep water indeed.

Indeed the media coverage of this disaster in recent years during the Inquiry has at best been patchy and that is why Dogstar's brilliant dramatic portrayal means such a great deal to us.

Think not of the news media commentators but take a look round the room at the faces of those who this disaster was visited upon. We never asked for it. We never wanted to have to spend so much time trying to get to the truth. We never wanted this story to become the defining factor in our lives.

The Penrose Inquiry

After 15 years spent firstly campaigning for an inquiry then spending thousands of voluntary hours during the inquiry, a number of us affected in Scotland can speak with considerable knowledge, experience and authority on the judicial inquiry process as it stands.

We have a very great deal to say about this. That will be for another time.

The Disaster and Those Affected

But as Dogstar have so dramatically illustrated in the excerpt from their production Factor 9, it is those infected and their stories that matter. In the Vale of Leven debate in the Parliament Chamber two weeks ago, host Richard Lyle made the probably the most welcome intervention, in seeking that families are involved at every stage of the follow up.

The disaster, not only in Scotland, has been on a quite unprecedented scale. For those still living, the impacts very much remain to this day. Time is not on our side. Since the Inquiry hearings finished we know of two of its core participants passing away.

Personal testimony

I personally can testify to the frustration and angst that having been infected with hepatitis C via blood products can cause. It could have been you if you had a seemingly straightforward blood transfusion prior to 1991.

The difference about this particular disaster is that it did not take place at a single place at a single moment in time but was felt across Scotland over many years and it continues, decades on, to blight lives and livelihoods.

So while there have been calls down south for a UK-wide inquiry, we instead want to see the Penrose Report published and move on with action rather than talking about actions.

Ireland

A couple of months my colleagues Dan Farthing, Susan Warren and I went on a day long fact finding mission to the Irish Haemophilia Society in Dublin. What was utterly startling was their relating to us that in Ireland, the bitterness from their infections disaster had dissipated. So how?

Patients and families had benefitted from an early public inquiry and its swift reporting. Compensation was readily arranged and it was a single payment, rather than staged monthly, to each depending on needs and losses. The 'victims' were also afforded their 'day in court', a step emphasised as vital by the Irish CEO, in 'victims' coming to terms with what had happened to them.

Here in the UK, Scotland has indeed led the way. Despite the length of the timeline, it is clear that Government and Parliament here have been ahead of the rest of the UK in addressing the disaster. Tribute must be paid not only to Nicola Sturgeon in ordering the present judicial Inquiry but also to Malcolm Chisholm for establishing the

Ross Panel that led to establishment of the Skipton Fund. However that progress has even now left a lot of work to be done. 10 years on from Ross we commissioned an independent assessment and virtually none of the recommendations were wholly fulfilled.

So what happens next?

So for us the key question to be answered now in response to this tragedy is when – we need the Parliament to agree to rapid targets for decisive action.

We need to see some swift but lasting and meaningful outcomes. We think, subject to the publication of the Penrose Report, world haemophilia day 2016 is an ambitious but achievable target to have the bricks in place to bring some resolution to this story and to help those affected to come to terms with the remaining years before them.

We need:-

1. Realistic fair financial support. We welcome Nicola Sturgeon's statement from March 2011. "a further review of Stage 1 payments from the Skipton Fund and the implementation of the new measures announced today will be reviewed when the final report (and any recommendations) of the Penrose Inquiry, are considered. It must be administered by a Scottish based Trust to achieve democratic accountability.
2. Greatly improved support for bereaved families.
3. Access to optimum treatment for all.
4. Haemophilia Centres and emerging generations of families need to be able to move on and NHS Boards need to deliver the means of firmly restoring trust from patients.
5. Strategic funding for the charities supporting those infected.
6. Follow up on the Inquiry. Regular monitoring by the Health Committee until April 17th 2016. There might be slippage but urgency is the watchword.

So what remains is very much a test for this Parliament and you its Members. MSPs will often have heard before of the success countries and their Parliaments being not about GDP and economic success. But on this issue if ever there was a test for a Parliament it is this story and of the Parliament's sensitivity, kindness and humanity.

ENDS

CHECK AGAINST DELIVERY