

REV. PREBANDRY ALAN TANNER
INTERVIEW

Interview with **The Rev. Preb. Alan Tanner** on 31 January 2008 at Charterhouse

You were Chairman of the Macfarlane Trust from its inception in 1988 until your retirement in 2000. You were also Chairman of the World Federation of Hemophilia from 1971 to 1996 and Chairman of the Haemophilia Society from 1975 to 1997.

Having lost a son with haemophilia to HIV as a consequence of contaminated blood products, you have had more than your share of personal tragedy but you are almost uniquely positioned, with your experience as Chairman of the Macfarlane Trust over a 12 year period, to provide an understanding of the changes that took place in the MFT community over the years when you were chairman.

When the Macfarlane Trust was first established in 1988 with the initial £10m and two subsequent amounts were provided of a capital nature to be distributed by the Trust (the last in 1991), the life expectancy of the registrant community was no more than a few years.

Did you regard the payments made back then by the Government as adequate/generous?

The answer to that is a very emphatic 'No'. We took the £10m because of the urgency of the situation and I always recall that, at the time the Secretary of State made the announcement in the House of Commons that this £10m was to be made available, Frank Field MP who has always been one of our great supporters, stood up in the House to say, 'I must congratulate the Secretary of State on being able to persuade the Haemophilia Society to accept such a limited sum' and that really put it in a nutshell. We accepted it because the urgency of the situation was that even as we were negotiating with the Government, people were dying and foremost in our minds was the fact that if we didn't get on with things, more would have died before there was any chance of their having any benefit of any sum of money made available by the Government. So that was the situation; we knew it was far from adequate, but we accepted it under pressure. But with the intention that we would go on and make further representations, as we did which is how Special Payments 1 and Special Payments 2 came about, because this again, was only as a result of hard pressure and negotiating. I remember when Kenneth Clark was the Secretary of State, we were before him when we were making another effort in the campaign. He very graciously said the monies would be available for another tranche and I said, 'Are you expecting to call me back every year to make additions to the monies available' and he said 'By no means'. That was supposed to be the end and that was the kind of environment in which we were negotiating, very, very distressing.

Given that for roughly a third of all registrants, who have survived to this day, their last 'substantial' capital payment was more than 15 years ago (and acknowledging that, as a condition of receipt, waivers to pursue compensation through litigation had to be signed) how would you describe the Government's response to this tragedy?

All sorts of comments come to mind – pitiful is one, parsimonious, niggardly, insensitive. To us, it demonstrated the Government had no real grasp of the distressing nature of the situation in which the people with haemophilia found

themselves. Regarding the waiver, that was more or less slipped into the small print. Again because of the urgency of the situation and our wanting to get on with it, people hardly noticed that that waiver had come in and it made us rather suspicious, later on, when we discovered the full import of that. That the Government had been rather crafty, knowing more than we knew, because, at that time, there was no thought of any kind of further measures being required and their putting in the waiver indicated to us that they knew more than we realised, what might be forthcoming with Hepatitis and other things later on.

It's quite interesting, in the Porton Down compensation package that's been in the papers recently, that the Government is requiring 100% acceptance. It's a similar sort of principle, isn't it?

It is. They put you all under pressure because there were some people who wanted to hold back and go through the legal process. Those that weren't expected to die immediately because it was not a satisfactory – it couldn't be called a settlement because the Government would never talk in terms of compensation – we can only speak about recompense. So it was by no means a settlement. Some wanted to hold back but, in holding back, we were in the same kind of situation, that the Government was [tallying] and we weren't going to get the £10m until you're all together. At the same time, there was pressure from some, who thought they were going to die tomorrow, to have a share out of the £10m and I think I mentioned in the written statement I made to the Archer Inquiry that for the 1200 roughly, £10m divided by that number would be £8000 each and you could only say that is niggardly in terms of their distress.

What do you see as the most striking change(s) over the past 20 years?

Is it the health/survival of the registrant community?

Is it the individual registrant's ability to meet their respective needs?

Is it the attitude of registrants, their partners and dependents?

Is it medical advances in, for example, anti-retroviral drugs?

Is it the Government's attitude and/or response to MFT's community of care?

Is it something else?

I think that has to be the advance in medical care because, in the beginning, when this first came into our experience, it was a very mysterious virus. In fact, they didn't really know that it was a virus; it was very, very mysterious and the doctors, the haematologists, weren't immunologists; they were feeling their own way and consulting all round to see what was the source of the virus and, then again, it was a matter of trial and error. Just as we were going along, some doctor would come up with a piece of good news, he felt, would hold it at bay. It was all in the sense of just slowing down the process, there being no cure, not even to this day; a matter of slowing down the progress and arresting the development and so the most important thing all round has been the advance in anti-retroviral treatments and so on.

In that context, the position now, and I am referring to the medical prognosis, is that those haemophiliacs who have been infected are not going to die from HIV but they are probably going to die from Hep C, cirrhosis and cancer of the liver. Now, to some extent, this means that people, who have benefited from the anti-retroviral drugs, have felt that they have been given a new lease of life and, now, the prognosis is bad because

Hepatitis C, which has a long, dare I use the word, 'gestation' period, sometimes 20/30 years, is going to seriously affect them, so they've got a second, serious, life-threatening disease. How do you think that is going to affect the community?

I think it will be a further cause for worry and I think for those, who have had a new lease of life, it will be another further blow and distressing situation. But these things occur from time to time; there was the surge of CJD, which is still hanging over people as well, and the fact that, with recombinant treatments and all that, you never know what kind of side effects there might be. But people with haemophilia, as you will have discovered by now, are survivors and they take each new situation as it comes and live for the day, as it were. They are not, even now, people who are making great plans for the future; they are living day by day. When it comes, it will be a further blow to them but the people with haemophilia have shown this particular quality by and large. Of course, there are always exceptions, of being able to rise above adversity but it will still be very distressing.

So thinking back to the £10m, and the further capital payments that were made back in 1991, you now have the Skipton Fund payment of £20,000 to those who suffered from Hep C, irrespective of Haemophilia, irrespective of HIV. Would you put that payment in the same niggardly terms that you expressed for the previous payments?

I think even more so. In the light of experience, when we hoped that the Government was becoming more sensitive to things, again here, they were very pushed into making a grant for which the Skipton Fund was established, because again our suspicion is, well more than a suspicion, that Scotland was on the move and they were going to do something about it. So we pre-empted that, but again it was done in a niggardly way; these figures are just plucked from the air - why £10m? It's just plucked from the air and that is it, as with the Skipton Fund too. But with the Skipton Fund, again it was done in this very, very insensitive way, of course; I expect you know there was a cut off point. Those who had died at a certain point, their bereaved families and dependents and so on, didn't qualify. When we tried to press that point they were quite emphatic 'No - that is it. That is the cut off point; there's no further negotiation'. And that again has been left in the air because of the Archer Inquiry. People had great hopes of that and thought perhaps Archer would be able to do something about it. Skipton is another example of just the kind of arbitrary way which Government deals with these things.

What do you see as the most important contribution made by the Board of Trustees of MFT during your time as chairman?

Well, I think the first point is that, when the Trust was established, it gave some measure of confidence to people with haemophilia and HIV infection and Hepatitis, that something was being done for them. The major contribution really was in our doing our best to be good stewards of the limited resources that were available to us, because it was quite a major task to decide what to do with the £10m. To begin with, we tried to determine what was the cost of living with HIV infection; what proper kind of medical needs had to be met and the kind of ordinary physical needs of nursing care. We tried to get a figure for that, consulting with social workers and the like and nurses and doctors, which was the basis of the regular payments, but then again that is still the lynchpin I imagine of the Macfarlane Trust. That was the

genesis of the regular payments policy. So we established that and our major task was to do our best within the limited parameters that we had, and to continue presenting ourselves as good stewards to the Governments, so that they felt that we were worthy recipients of any further monies they would make available. But again, it's all been very hit and miss. We started off with the £10m, plucked from the air, but as it turned out that became the base line. From then on, all [future] calculations went back to the £10m, so that there was never any kind of reassessment of how satisfactory that had been. It was all a matter of going to the Government and they said 'Well you've spent that' and we said, 'Yes, but we need some more. We need some more to maintain, as it were, the status quo'. No further developments in it all and so our major contribution has been, as it were, fighting for the people registered with the Trust.

Is there anything you would have liked to have seen achieved that was not and, if so, what would that be?

I would like to have seen more monies available because one of the really distressing parts of our work, I think, was that there were certain categories that we weren't really able to help, particularly widows because when a person died, all sorts of things stopped. Some of the benefits ceased immediately, like if they had a car through Mobility, the car went away. In Macfarlane, we were only able to maintain the payments for a limited period and that, to me, was always one of the most unsatisfactory parts of the work. We weren't able to look after widows and other dependents, bearing in mind what a severe matter it was for a family, say to lose the breadwinner. This meant for the many months, sometimes the few years, that the person had been deteriorating, there was no regular money coming in, in a lot of cases, and so the family itself had to support them. So the family had suffered financially, quite apart from emotionally and spiritually, over that period and that was a very severe moment at death, when all the benefits stopped and we weren't able to do much about it. We kept it going as far as we could but, with the limited resources, that was it.

If you had your time as Chairman of MFT over again, would you have done anything differently?

It sounds rather strange if I say no, because our position again was changing almost day by day in the beginning. We were just doing our best to meet what was a most unknown situation, first how to deal with the £10m, then to try to assess what were the needs of people. You've done it much more systematically and professionally now, but we were just trying to glean people's opinions and, of course, it was a very painful experience. People coming along, especially if they had lost a breadwinner, or they themselves weren't able to support their children, their wives and so on. To deal with that in a kind and supportive, sympathetic way, that was difficult, but we steered through it as best we could, taking proper advice and getting good financial advice and we were very fortunate in having good administrative support in the beginning. I say nothing about after that because that's not really my concern and responsibility. In the beginning we had superb administrative support and so we did our best.

Is there a strategy that you can think of now, or one that was either used or in contemplation when you were chairman of MFT, that might be appropriate for the current Board to use to secure adequate financial resources to meet the present and future needs of its community of care?

I read that question and I'm in some doubt about the response to make to that, having been so caught up with the Archer Inquiry and what might follow. My own view is that if the Archer Inquiry were to report as I think it should report, and if it doesn't and then if there is a further inquiry, which would produce adequate compensation, I suppose we then have to consider a new situation where Macfarlane might almost be redundant. If the compensation were adequate, then the need for Macfarlane, in meeting the needs as they are presently identified, would be markedly reduced, almost in a few years to the point of extinction. So, my own view about it is very much influenced by the outcome of the Archer Inquiry and what might follow. In the immediate situation, I think, especially seeing here this latest news from Lord Morris, with Scotland again coming into play and probably pressing on ahead of the United Kingdom, means that there may be, in due course, better prospects of appropriate compensation following Canada, Ireland and other places. But I think the Archer Inquiry has certainly taken note of the fact that the United Kingdom is very far behind other countries.

Lord Morris is particularly concerned, it seems, about Hep C and the Scottish inquiry may be limited to the Hep C infection, excluding HIV, which would be a bit of a shame.

Yes, but I think they would be interactive if Scotland makes some progress there, even if it is limited to Hep C, then I think the Macfarlane Trust and the Haemophilia Society should be alert, ready for the pressure to be brought to bear for the next stage of our campaign.

Given our Government's past record and its 'niggardly' response, to use your word, even if Archer was to write a pretty damning report about the 'generosity' of the UK Government, given Treasury constraints, given all the news about the possibility of economic turndown, what realistically do you think the Government's response is going to be?

I expect it to be the same as it has always been, that the Government has only ever moved, with regard to Haemophilia and these particular situations, after intense campaigning and I think it would call for another intense campaign by the Haemophilia Society, coupled with the Macfarlane Trust. I can't see the papers falling on the Prime Minister's desk and him saying to his chums in the cabinet, 'we really must do something about this immediately'. I think something will only happen as a result of further intense campaigning, all the way, along the line of Special Payments 1, 2, and Skipton; it's only happened after that.

Reverend Tanner thank you very much. Is there anything that you would like to add that hasn't been part of my questions?

No, no, except I'm delighted to hear that you're putting your mind to this in such a careful way, because I am sure that your work is going to give us further armoury for our representations.