

Witness Name: Lynne Kelly

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**EXHIBIT WITN3988085**

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Meeting with the Haemophilia Society and Haemophilia Wales

Thursday 4 January 2018

4pm

Ty Hywel, National Assembly for Wales

**Attendees:**

Lynne Kelly - Haemophilia Wales

Julie Morgan - AM for Cardiff North & Chair of the Cross Party Group Haemophilia and Contaminated Blood

Helen West - Julie Morgan AM office

Mike Imperato - Watkins & Gunn

Raymond Bradley - Malcolmson Law

Debra Morgan - Public Inquiry Lead, Haemophilia Society

Jeff Courtney – Public Affairs, Haemophilia Society

Nigel Miller

**GRO-A**

David Thomas

Della Hirsch

Bev Tumelty

**GRO-A**

Pat Summers

Julie Morgan began by welcoming everyone to the National Assembly and asked everyone to introduce themselves.

**Debra**

Thank you everyone for coming to the meeting. My role is a new one as Public Inquiry Lead for the Haemophilia Society and I am keen to speak to all groups and everyone in the community about their views and opinions in regards to the inquiry. I recognise that there are differing views within the community about the best way forward, but I endeavour to find common ground and make this process work and get justice for all.

**Raymond**

Thank you for inviting me to this meeting. You are at the very beginning of your journey and Ireland were here about 15 years ago. The Irish inquiry provided answers, and opened the way for compensation packages to be set up.

The first thing that struck him about the situation in the UK was the disharmony between all the different groups. In Ireland they were fairly united and the Haemophilia Society in Ireland spoke on behalf of all of its members. Any disagreements that occurred were aired in private. The UK situation is very similar to that of another inquiry in Ireland which, due to disagreements between interested groups, resulted in less than adequate answers and

compensation for those affected. He would be fearful that this will happen in the UK with the contaminated blood inquiry.

The main aim of the Haemophilia Society coming to the meeting today is so that all opinions and questions can be aired and a discussion can be started. Events that happened in the past must remain in the past in terms of the actions of the Haemophilia Society. The Haemophilia Society will be under investigation as part of the inquiry as a matter of course.

**Julie**

Could I just clarify if you are here representing the Haemophilia Society?

**Raymond**

I am not representing the Haemophilia Society. I have been asked to assist them with the inquiry process.

The first thing that needs to be done is to identify what issues you want to be included in the inquiry and what you want to achieve. It is your inquiry and your opportunity to get answers. What is particular about Wales that you want to include? Why people became infected at particular age groups. I am here to try and facilitate the conversation between you the people and the Haemophilia Society. You also need to recognise the differences between yourselves and the Haemophilia Society and the other groups.

In 3-6 years the inquiry will deliver the report.

**Nigel**

I think that everyone in Wales has more or less agreed on our terms of reference, which has been discussed at the Cross Party Group and Welsh Government.

**Lynne**

We have supplied our submission to the DoH in August 2017 and outlined our proposed terms of reference. In Wales we do have consensus and none of the problems that the different groups have in England. We have worked hard in Wales to get to this position. Haemophilia Wales is like a community with people of all ages. Consensus has partly been down to Julie's support as an MP and now as an AM. We have a single voice and a common message. The issue is that it is unclear what will happen in England – there is no guidance on what people should be doing and no information about who is legally representing the Haemophilia Society. This has been the situation for a number of years now. We've been working towards the public inquiry for a number of years, even before the announcement.

**Raymond**

It is good to see that there is consensus in Wales as it is not there in the rest of the UK. It is also good to know that you have terms of reference. It would be best if you aired these and shared this information so that you can all speak as one.

**Debra**

It would be good to know in which areas we all agree so we can have one voice so we are more likely to succeed.

**Julie**

It is very helpful to have this discussion. The situation in Wales has had to be worked hard at. There was unanimous support of AMs at the Assembly for the inquiry and also the support of the Welsh Government. We are united and don't have any of the problems in England. The fear is that because we are a relatively small group in terms of population that we don't get heard. The way that Lynne and others have worked on this for so long means that it is very important for us to get our voices heard.

**Debra**

I have seen the work that Lynne and Haemophilia Wales has done here and I wish that we were the same in England. We have a lot of work to do. I have been brought in to try and facilitate this to happen.

**Julie**

The worry is because England is not united that it will reflect the same on Wales. It would be helpful to know what the situation is in England.

**Bev**

There are too many factions in England. There are 3 groups that I have dealings with through mutual friends and there is a lot of infighting. They are not singing from the same hymn sheet.

Wales is a bit protective of our position – we don't want the situation in England to rub off on us.

My brothers would be appalled at the amount of infighting going on in England at the moment. They worked long and hard to get to this stage before they died.

**Raymond**

It is very sad that this has happened and it will create huge difficulties going forward in getting what people are entitled to.

There needs to be an exchange of information and trust on all sides for this to work. The Haemophilia Society and Haemophilia Wales need to work together so that they can be stronger together rather than separately.

**Jeff**

I have met with a lot of campaigners, leaders of different campaign groups, Lynne, Haemophilia Scotland. What I have found is that all objectives are the same – truth, justice and the correct treatment for those with bleeding disorders. The need for compensation

for those who have been affected. As soon as there are more people in the room, people find differences between the groups and it's frustrating to see that we all have a common goal but the differences are coming through stronger.

**Della**

Worked with Lynne for a number of years. Met on Department of Health Haemophilia Alliance meetings which were set up after the Archer Inquiry and got in touch with Lynne privately to work together. I had twin sons, no history of haemophilia in the family and when we were tested it was a spontaneous occurrence of haemophilia. My son died 6 years ago and I have been involved in this issue for a long time. Met husband in San Francisco and was well aware of the problems regarding contaminated blood. Used to support the Haemophilia Society but was told when son died that their only interest was with the newly diagnosed and children. They did not want to know about her son's case, so her trust and commitment to the Haemophilia Society was gone.

Her son was not treated with US blood, treated in Elstree.

My sister is Baroness Featherstone who has been working with Lynne.

The head of the Haemophilia Society is so bad that I don't want to be represented by them. I don't know where to go for help. I feel like the Haemophilia Society have abandoned me. I tried to make them listen but there was no hope. I would like to join Haemophilia Wales if I could

**Raymond**

Della, what issues can you put forward so that you can join together?

**Della**

If Haemophilia Society had someone who was independent and came into post now, I could consider joining with them. The reason there are so many different faction groups is because of the Haemophilia Society.

**Raymond**

The actions of the Haemophilia Society will be investigated as part of the inquiry.

**GRO-A**

The chair of the inquiry needs to look at the support given to those affected. Including the support that was not given. They need to speak to the Haemophilia Society and those who were not helped by them.

**Raymond**

The Haemophilia Society's actions were examined in the inquiry in Ireland.

Bridge building needs to occur between those affected, the Haemophilia Society and the fraction groups. Most of the fraction groups will get representation and they all have their own agendas and will say different things. If there is no cohesion between groups the inquiry could all go wrong.

We have a duty to victims to get this inquiry right. We have to put the divisions with the marginal groups to one side and unite under one group in England.

**Debra**

Part of my role is to speak to all of the different faction groups and make connections.

**Bev**

It is great to have your new role and that you are trying to make things better, but where has your role been for the last 40 years? It should have happened a long time ago.

**Raymond**

You should have had an inquiry 15 years ago too. But we are where we are and we need to make sure we move forward, not stay in the past.

Della, how would you resolve this?

**Della**

It is very difficult. Listening to so many different groups who have different opinions will be very difficult. Now that some groups have legal representation it will be even more difficult.

**Debra**

Is there any way that we can move forward as one?

**David**

We are all fighting for one thing. There was a focus from the start with the Irish Haemophilia Society. The problem here is that the Haemophilia Society is not working together.

**Nigel**

Haemophilia Wales wrote and met all victims to ask for views and created consensus through communication. It helps that we are so small. It is only recently that the Haemophilia Society is involved.

**David**

The Haemophilia Society have a mammoth task to unite everyone.

**Raymond**

We shouldn't let the past effect the future and how we move forward. The new people coming into the Haemophilia Society are not the same as those that worked there in the past. Della, you have got to know Jeff and you trust him, don't you?

**Della**

Yes I do. But I don't trust the Haemophilia Society Chief Executive, I have no trust or confidence in her.

**Debra**

Will you give me a chance to make things better and build on it? I completely appreciate that there have been problems but I want to make it better. There are roadshows being planned all around the country.

**Lynne**

It seems that the Haemophilia Society have no direction and not communicating to victims. We need to get all group leaders together to talk and get consensus.

**Raymond**

It is imperative that you should all have one voice on issues. All groups should speak as one.

**Lynne**

The problem is is that the faction groups will not want to work together if they know that the Haemophilia Society is leading the way. The other groups feel that they have got this far without the Haemophilia Society so why should they work with them now. The groups would be willing to work together but without the involvement of the Haemophilia Society.

**Raymond**

I have spoken to the faction groups about the inquiry and 80% all agree on the same issues.

**Lynne**

There is underlying mistrust of the Haemophilia Society. Who is representing the Haemophilia Society legally?

**Debra**

No one has been appointed yet.

**Bev**

I am a member of the Haemophilia Society and I have received no correspondence from them about anything. There is a total lack of direction from them.

**Debra**

There will be communication coming out very soon, but we want to make sure we get it right before we send it out.

**Bev**

I have lots of information that could be used for the inquiry that my brothers gathered before they died, and more that I have got since. I have not been asked to produce anything yet.

**Raymond**

Comparing medical records was a key point in Ireland to see which professionals followed protocols etc. Medical documents went through by legal teams to get the most information.

**Della**

Mike, what do you want to say about all of this from a Welsh perspective?

**Mike**

I am very pleased to hear from Raymond about the perspective in Ireland. I agree with Lynne about being able to get all of the group's representatives in a room and getting them to agree 80% of the agenda and then agree to disagree on other things. The mechanics of getting people into the room is the problem here. If the meeting was called by the Haemophilia Society, the groups would not be willing to take part because of the underlying mistrust they have with them. There needs to be an honest broker who calls the meeting so that all groups will be willing to participate.

**Julie**

This is a very important point. There should be someone independent to get representatives together in the same room so that they can agree on the 80% or so. This could be a way forward. The Haemophilia Society would need to be one of the participating groups, not holding any special status, so that the other groups would be willing to work with them. Who would be the person to take this forward?

**Jeff**

I don't think that we (the Haemophilia Society) are wanting to tell everyone what to do or have everyone follow us. We want to participate and for people to be ok that we are participating.

**Della**

It is so terrible that people were excluded by the Haemophilia Society in the past and were told that they were only interested in the newly diagnosed and the young. I can't get over that.

**Lynne**

When I was a trustee of the Haemophilia Society, they were always the last ones to do anything despite the amount of evidence.

The problems with the Haemophilia Society go back further than Liz (current chair of Haemophilia Society).



There needs to be an independent facilitator that brings people together face to face. Brian O'Mahony who has been affected could be a good person as he is someone who people would trust.

Liz needs to be more hands on and give more direction. Need a strong leader.

**Raymond**

You have an opportunity now to go forward. You need to decide what issues you need to have investigated. You are better having consensus around these issues so that you will get a stronger answer.

You have to put the past behind you. It would be awful to have a situation in the UK wide inquiry like they did in Scotland where questions were not answered. You can shape it now so this does not happen. It is the people that have lost lives, it is the families that are affected – they should be able to shape the inquiry to be whatever they need it to be.

**Della**

But we don't get to choose who leads us. Who decides the leader of the Haemophilia Society?

**Jeff**

The Board of Trustees decides.

I joined the Haemophilia Society to fill a gap in the Haemophilia Society in terms of contaminated blood. I attend Board meetings. The Haemophilia Society published an apology last year about the contaminated blood scandal and their actions/contributions towards it. This became the basis of actions of the Haemophilia Society over the past year.

This has been made a priority because of the voice of its members. Previously this would have been dismissed.

**Lynne**

Does anyone want to add anything before we bring the meeting to a close?

**Della**

I have campaigned on this issue for a long time. I have worked with Lynne and she is a complete inspiration. I wish England had the same leadership as you do in Wales.

We shouldn't be fighting with our own society.

**Raymond**

I hope that the 20 year delay is set at zero now. I hope that the families get the answers they deserve and patients get the treatment they need. Don't blow this opportunity.

The entitlements that the people in Ireland had are similar to Wales – they should get the same.

**Debra**

I would like to share my contact details with you all so that you can get in touch. I am working on my own at the moment so I am very busy but I will do my best to get back to you as soon as possible.

**Lynne**

Will the Haemophilia Society be writing to its members to ask about what they want from the inquiry?

**Debra**

Yes we will be writing very soon. It is just me and Jeff working on this at the moment so we have a lot to do!

**Julie**

I think this has been a very useful meeting. Haemophilia Wales needs to go away now and think about the next step and the best way forward, and who the honest broker should be to bring everyone together.

Thank you very much everyone for coming today.

The meeting was brought to a close.