

Marlene Winfield

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00:31:29

MW: Marlene Winfield

KS: Katy Sagoe

DB: David Body

CG: Caroline Glendinning

MW: Hi, I'm Marlene Winfield. I've probably, over the years, met most of you at these events but it's really good to be here today. I was just looking at ... I'm coming in a minute to ... I'm going to tell you a bit about the role of Trustees and then I'm coming to the hot topics and one of the hot topics was how best to work with the NAC to gather information from all of you to inform decisions without overloading you with constant questions? So obviously a very timely hot topic for the Trustees.

So I'm just going to talk a little bit about the role of Trustees, what it is we do. And what it is we do, basically, is do the strategy and the overseeing of the organisation. We don't do the doing, that's done by the staff and it's a delicate balance for Trustees to strike because if we get too bogged down in the detail then we get a lot of friction with the staff and we prevent them from doing their work. So we can't get too bogged down in the detail but if we don't oversee well enough, if we don't know enough of the detail, then we could get a situation like the one that's happening to Kids Club at the moment where things were going pear-shaped and the Board of Trustees didn't realise what was happening. So it's a very careful balance that Trustees have to strike to make sure that the organisation runs smoothly but to let it run smoothly.

So one of the things we do is to help keep the Trust within the law. We have to comply with charity law, other general laws; we also have to comply with the terms of the funding we receive. The Department of Health has imposed terms on us, we have a covenant with Diageo that we have to keep to so one of the things we have to do is to make sure, oversee, to make sure that we're not doing anything that goes outside of what we've agreed with our funders. So we have to keep the Trust honest.

We oversee the organisation's performance, including that the organisation is keeping to the budget, which I'm sure you would all want us to do. One of the most important things to all of us is that we have to maintain good investment performance. We've got a lot of money that's invested on your behalf, that you're dependent on and we have to make sure that it's invested in a way that maximises its value and its worth to you and Kevin Wesbroom, who some of you have seen here in previous years is in charge, he Chairs the Finance Committee, and he makes sure that we maximise the performance of the investments.

We receive the money from the Department of Health and from Diageo and we oversee how it's distributed to you, either in the form of your annual allowance and major grants and the most important thing we do in that respect is to make sure it's done fairly and that you're all treated equally. And that is very important to us, it's one of our highest priorities, to make sure you're all treated equally.

And we also ... you saw a lot today about the other things that are going on as well as providing you with money and we oversee all of that other provision that we make to you and the kinds of support we make to you which we change as we ... as your needs change. We try to keep changing those things to make sure that we are providing the non-financial support that you need as well as the financial support and that is down to me, to a certain extent, because I Chair the Health and Wellbeing Committee, working very closely with Simone and Roland and our Chair and Vice Chair of the NAC, a version of that committee.

We maintain a relationship with the Department of Health and with Diageo and we also support the efforts of the NAC to increase our funding from both those sources and, indeed, from other sources, which you heard about today in the campaign session.

We commission and oversee research like the Firefly research and our priority in that respect is ensuring that anything we commission, any kind of research that we do is something that's going to benefit you. And that is the ... the buck for that stops with Caroline who Chairs the Research Committee.

We deal also with new claims to join the Trust and the Claim's Committee is Chaired by Sir Robert Nelson, who also Chairs the Trust. We deal with other policy issues as they arise. And we deal with complaints.

So that's just a sort of list, a general list, of the things we do as Trustees. But, as Craig said this morning, and I just want to stress, we do very little without working in partnership with the NAC. And the only limits to that would be where there is a conflict of interest or where we're making a decision about an individual Beneficiary based on very personal information that you've shared with us, so that there would be a confidentiality issue because it's very important to use that we protect your confidentiality.

So that's what we do as Trustees. What are our hot topics at the moment? Well, as Deborah said this morning, one of our hot topics is how best we assess and meet the needs of individuals and you as a Beneficiary community. Ensuring that we're supporting everyone, not just those who have the ability to focus attention on them, that we're actually reaching all of you. And so that's why we've asked for a review of the Beneficiary review processes as you heard this morning, to make sure that when we assess your needs we do that in a way that's inclusive and appropriate to circumstances as we've heard and, as you well know, you're all experiencing increasing health problems as you age, so your functioning is all deteriorating to some extent. And so we need an assessment system that takes that into account for all of you and not just some of you. And also we need a system that gathers evidence that we can use in the important negotiations we're going to be having with funders.

Apart from the one about not overloading you with questions, another hot topic for us is how to deal with the increasing demand that some of you are making on us, quite justifiably, for large grants and how to do that in a way that's in your best interests so that you're sure that your grant is unaffordable because that has implications, not only for you as an individual, but for the whole of the Beneficiary community. And that is a balance that we always have to maintain, a balance between what we do for an individual and what we do for the Beneficiary community.

We have to ensure that our investment strategy, as a Trust, is fit for the next stage of your lives with your increasing health needs, your changing work patterns and also

your changing plans for your later years of life and I hope that you have many more of those later years.

And also important for this year of negotiations to build up evidence in any way we can to inform the future negotiations with the Department of Health and with Diageo.

And finally, renewing how we deal with new people wanting to join the Trust, with new people making claims to join the Trust, to ensure that we're always making decisions based on the most up to date criteria. And with that we're working very closely with the World Health Organization in St George's Hospital to help us ensure that we are using the best criteria.

So that's what we do, that's what's occupying us at the moment, and with that I will pass on to Deborah.

Oh, you did yours this morning didn't you? Right, so we won't pass on to Deborah now.

Well, we lost two very long-serving Trustees this year who had served for, I think, twelve and thirteen years, Oleg Eremen and Mike Napier. Oleg was our representative from the hospital side of health and Mike was our expert on personal injury law and product liability law. And we also, for family reasons law, lost Joe Curtiss who was our investment expert. But we've been very fortunate in replacing them with some equally excellent people, one of whom you'll hear from in a moment and two others. Professor Tim Briggs from the Royal National Orthopaedic Hospital who is a consultant orthopaedic and traumatic surgery ... consultant in orthopaedic and traumatic surgery and is a past president of the British Orthopaedic Association and has very recently been appointed to a very important job in the Department of Health, he is one of the health tsars to do with safety so he will be in charge of the Safety Policy of the Department of Health. So we're very lucky to have him.

I will introduce Katy Sagoe, who you met very briefly this morning. But first I want to introduce you to our other new Trustee and let him say a few words to you; David Body, who is a very distinguished personal injury lawyer, who has recently retired from full time work but specialised in product liability which is very, very pertinent to us. He's an experienced Trustee, including he's a Trustee of the Patients' Association and he writes and edits journals on topics such as Risk and Safety in Medicine. So we're very pleased to welcome him. He's going to do a great job on your behalf and I'd like to invite him to say a few words.

DB: Ladies and gentlemen, first of all it's great to be here. I very much wanted to spend the day and hear what was said.

F1: I can't hear you.

DB: Can you not? I always mumble, I apologise. It's great to spend a day with you and to hear what's going on and to hear the presentations that have been made which, I think, reveal a huge amount of the concerns and achievements that a relatively small group of people have made and continue to make.

I've been invited to say a few things about myself which is always rather disconcerting. When you're described as a distinguished lawyer, you have to bear in

mind the advice I was given about 20 years ago that distinguished, when it's applied to lawyers, generally means that they're over 50 years old and not currently under indictment. I am certainly over 50 years old and I'd like to reserve my position on the other side of that definition. Because you never know.

I should say I live in Sheffield although I am originally a Welshman, which means that Phil Williams, who was on the interview committee when I was interviewed to be a Trustee, immediately wanted to know my views about the Welsh rugby team to see if they were appropriate and fully formed and I have since been joined onto an email list of his which has been pretty intense recently, as you might imagine.

I'm a sort of trainee Yorkshireman because I've only lived in Sheffield for 23 years but I have two children born in the city who are eligible as, they point out to me, my daughter at least points out to me that she is eligible to play cricket for Yorkshire. We'll see. Time will tell.

To say a word or two about what I have done ... [phone rings] that's really good because I haven't got the most embarrassing ring tone in the room. It could be so much worse, let me tell you. I was at a meeting last year when my ringtone went off and it was with a really rather distinguished judge chairing it. I got a glare from the judge who immediately said, when he heard my ringtone, "That was by Creedence Clearwater Revival, 1972." Passed straight on. And I went up to apologise, because you always need to apologise to judges when you've been stupid, and I said, "that's your ringtone then if you're being so ..." and he said, "Well, actually it's The Boy are Back in Town but I always switch my ringtone off." Good trick if you can do it.

Just to say a word or two about my background as a lawyer. I have acted for claimants for 34 years. I've worked in clinical negligence for individuals predominantly. And I've had experience during that time of doing high value damages work for individual claimants with birth injuries, chiefly. And I've done a huge number of those.

As far as group actions are concerned, I've done a lot of product liability work, most recently I've been involved in doing things about hips and knees that have gone wrong. But through the 1990s I did a series of cases about Creutzfeldt-Jakob Disease. The first set of claims arose from the treatment of young children who had growth hormone deficiency and were given a contaminated version of that and that then led to me being involved in leading the lobbying for and then subsequently representing about 150 families at what became the BSE Inquiry. And, after that, I was involved in negotiating and implementing a compensation scheme for them.

In the last twelve years, I've been involved in bringing claims on behalf of children who've been affected because their mothers took a drug called Epilim whilst they were pregnant and Epilim, -Sodium Valproate -, is an unresolved problem even as we speak.

I've never had an involvement, from a legal viewpoint, with thalidomide but I think it's fair to say that my career at various points has had resonances of thalidomide in it. For instance, when I was at university and I was learning about the law, I was taught by someone who was one of the junior counsel for Distillers. As you might imagine, we had a few arguments when I had found out enough to understand what he was doing. I didn't get it very right then but then neither did he. If you look at the situation that prevailed in the 1980s when I was a young lawyer in practice and the way things have changed, a great number of the things have happened in the field of personal

injury law have happened because people have said 'we must never have another thalidomide'.

In fact, there is a piece of legislation which arose because of the experience you have had. It's called the European Product Liability Directive. Its domestic expression is the Consumer Protection Act 1987, it arises directly because of what happened and the inability of the law properly to respond to thalidomide as a problem and it's that legislation that we've been using in the last 20 years and, latterly, over Sodium Valproate.

So I feel as though I don't know very much yet about thalidomide and I am learning, I am learning a lot, and I'm hoping that what I'm going to be able to do is to help with the enormous amount of work that's going on. One thing particularly that I've had some limited involvement in recently and I hope to do more with, is the ... say again?

F1: [Unclear 17:43]

DB: I will do my best. I always do. I spent a whole career whispering in corridors, that's mostly why I am occasionally difficult to hear. As I said, there's a piece of work which Caroline Glendenning and Liz Buckle are running relating to earnings loss, earnings diminution and pension losses and I'm hoping sincerely that's something I can help with because I think that's going to be a major concern in the coming year and the discussions with Diageo.

I'm trying to think if there's something else I should say about myself. I'm very fond of the West Wing. I think that's probably about the only other thing I can comment. I'm on my fourth or fifth viewing which is a bit over-emphatic. Anyway, that's what I do.

MW: Thanks very much David. I don't know what it is about you but you've managed to attract some really terrific Trustees. I don't know what it is you've got but whatever it is, I'd like to have some of it too. Now I'd like to introduce Katy Sagoe who is our new Director for Health and Wellbeing. She spent fifteen years as a senior manager in social care and social housing and particularly on support services and health and wellbeing services for people with a variety of different types of needs. And she also chairs an organisation for people with disabilities. And she describes herself as a campaigner with a face for the radio, but when you see her, you'll know that's not true.

KS: I made some notes because when you're in this situation your mind goes blank, even when you're talking about yourself! So, I have been involved for the last fifteen years in working in social care services and for the last eleven of those fifteen years in social housing, supported housing, care and support needs, advice and advocacy services, housing adaptation services, setting up new approaches to user-led community wellbeing responses to respond to the new integrated health agenda. So all of these sort of buzz words but the core through it is trying to facilitate people who know what their needs are in working out solutions with people who have the money and often the power.

And I haven't only been working for fifteen years, the ten years before that I was living and working in West Africa on local community led projects to get people who

are on the margins of society or the margins of involvement heard and influenced. So that's my interest and my passion really.

I have quite a lot of experience of working with volunteers and working with the third sector. I am the Chair of a Community and Befriending service in Northamptonshire which is where I used to work. I live on the edge of Northamptonshire and Cambridgeshire and that's a really worthwhile organisation and gives me some insight into the challenges facing volunteers and giving them the help and support that they need.

I'm really pleased to be here. I'm really pleased to be joining the Thalidomide Trust. This is only the end of my second week. So I was only the new girl for a week because Emily arrived, so I am no longer the new girl so I'm pleased about that.

I've started to build my 'to do' list, as you do. It's up to four pages and I've reviewed it with a lot of what I've heard today. But sort of some highlights of areas that I'll be focusing on.

First of all, one of my key roles is to support, develop and encourage the HealthLink team. And that part of my role is a real blessing. You met them all a bit earlier, and they are a fantastic team so I'm envisaging that that part of my job will be my nurturing and light relief part really because they're great to work with. Other than that, what I see as the role of the health and wellbeing part of the Trust is to ... and some of this you've heard a few times today, it's quite a strong message, to respond to what you're telling us about your health needs and the changing needs and to respond to that by providing information, by looking at what services we can provide, but also by looking at what's going on outside; how we can connect in to get our voices heard a bit stronger ... or your voices heard a bit stronger and to add value to what the Trust can do. And also, as the message has come through several times, and it's a really important one, is to get the evidence, get your stories and use that as leverage to secure your futures going forward and secure funding so that the Department of Health and Diageo really understand the picture in terms of health needs.

The other bit that Deborah has mentioned earlier and that I really strongly endorse and want to make sure happens is about bringing the Trust out to you. So this involves the IBR review, that you don't need to come and ask us for help, we try to come out and meet you, understand people's individual needs, be a more local and accessible presence where we can have the information more readily available so that it's easy to find on the website. This is all the stuff we've been talking about. Having information ready prepared, gathering as much information and acting as a single repository and point of contact for that. If you can give us that information we can make it accessible to everybody.

And to look at how we can harness your own skills and experiences and help you develop peer support networks where you can talk to each other, volunteer and support each other, bring your enormous skills and experience to the Trust for the benefit of everybody. So that's an area I will be focusing on.

And one other area; Dee isn't here but it's been talked about a lot, but in my role as Director of Health & Wellbeing, I'll obviously be working really closely with Dee to make sure that the health work that she does is supported and, whilst she does individual confidential work, the learning from that is brought back and used for the benefit of everybody.

That's quite a broad overview; there's quite a few meaty chunks of work to be done in there and I hope that you'll see the Health and Wellbeing role of the Trust will improve a bit more. There's some fantastic work being done and for the first time in a while, there's a full team on board and I think for the next few months and hopefully years you'll see continued benefit to yourself from that area of work. So that's me. Thank you.

MW: Thank you Katy and just going back to the Trustees for a moment, I should say that we have a third new Trustee called Mark Benstead, who's a Senior Investment Manager at Legal & General, and I hope you'll have a chance to meet him, possibly next year.

CG I am Chair of the Trust Research Committee; we oversee all of the research that the Trust commissions, apart from the Beneficiary survey which you are doing yourselves.

And I just wanted to say two things. One is an alert about a number of things that are coming up. And the other is to issue an invitation. First, some Beneficiaries have approached staff and Trustees and said, "Look, we're really concerned about the fact that thalidomide survivors are increasingly, because of their health problems, giving up work early." So whereas you would perhaps normally expect to be working until you're 60/65, people are increasingly stopping work in their 50s or they're cutting down their hours, going for part time jobs, perhaps looking for jobs that are less physically demanding and therefore also less well paid. And this has an impact on your quality of life at the moment as your needs are increasing and as you need more expensive equipment for example. But it also has a knock on effect on pensions as well. So if you're contributing to an occupational pension scheme and give up work, your pension in old age is going to be reduced.

So one of the pieces of work that the Research Committee is planning at the moment, with the help of Liz Buckle and Stuart Kenworthy, is to look at the extent to which thalidomide is causing you to lose earnings beyond what you would normally have expected to earn. We are going to be following up the survey that Liz has outlined and asking Liz to do some very, very detailed analysis of the answers that you have given to the Firefly survey about your work and your earnings and we will probably be coming back to ask some of you some more detailed questions. As Liz said, we're really, really grateful that many of you have said you're welcome to take part in further research and we may well be contacting you to ask you for much more detailed information on the jobs you've been doing, the earnings you've had and the extent to which your thalidomide problems and health problems have affected your earnings.

And then we'll be taking that and, with the help of David Body, with his expertise in calculating lost income, we will try to build up a picture of the amount of earnings that have been lost by thalidomiders as a whole. And this will be really, really, really important in terms of next year's discussions with Diageo. Because Liz and Stuart Kenworthy have sort of said, well, while the original settlement with Diageo was finalised ... you were young and people didn't think about your future earnings and there's a general feeling that earnings loss wasn't factored in properly to the settlement with Distillers. So that's a piece of work that we're going on to do. So, we'll be coming back to some of you and, if you're willing, we'll be asking you for detailed figures. Of course we'll keep all of those figures confidential so that people won't be able to be identified.

The other thing I just wanted to say more generally in my role as Chair of the Research Committee, the Research Committee got set up in a fairly ad-hoc way and people occasionally pop up and say, "Oh, I'd like to do a bit of research on that" or "I found somebody who says they'd do a project on the other." If there are things that you think the Trust should be doing research on, let us know, talk to the NAC, talk to the staff because, you know, we will listen but we can only know what research to plan and to undertake if you tell us. So it's an invitation ... if there are pieces of research that you think the Trust should be carrying out on your behalf, then please say so.

Thank you.

DJ: Thank you Caroline. After that, does anybody have any questions for Caroline? Or anyone else? Okay, well, when I Chair the Trustees Health & Wellbeing Committee, Simone always keeps a very careful check on my time, so I'm going to point at my time-keeping, so I'm going to point out that this session has finished ten minutes early, Simone.

So anyway thank you all very much. It's been really good to see you all today.

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