

Craig Millward – Deborah Jack

24/10/2015 NACAC

00:28:28

CM: Great, well it's good to be with you. I really should have brought two shirts with me today. The reason being that I'm speaking on my own behalf, what I was originally tasked to speak on, and I'm also speaking on behalf of Nick Dobrik, who very sadly can't be here today. So he does send his apologies as does Guy who was due to take part in this morning but his father is having problems with his care arrangements. So he's going to be here later today. So between us, Mikey and I are not just doing what we planned to do but also speaking on behalf of Nick and Guy.

Nick's asked me, basically, to speak on three things just as we start this conference together. The first one being ... I'm sure you're aware that as part of our partnership or part of our relationship with Diageo, there is built in, every six years, a review, a conversation. It's not just a single conversation, it's something that's likely to last for the whole of 2016. But next year we are due to begin conversations with Diageo again.

It's confused a little because, since our last review six years ago, we actually had an additional conversation with them because once the SOF and the Firefly reports were released, our health needs were shocking. I mean it shocked those of us who saw that report for the first time. And, on that basis, we actually stepped in and said, well, we know we're not due to see you until 2016 but we really think we need to see you earlier. So it might feel like it hasn't been long ago since we've spoken to Diageo and we got an extra payment but that was outside the regular schedule of meetings.

So we have another meeting next year and we're going to be kicking that off with our agenda. Obviously when two sides come together they've always got a slightly different agenda and I'm not by any means the expert on this. I haven't been involved in these negotiations before. I'm going to be working with Nick this time but he says there are a few things in our heads that we want to bring into those conversations.

The first one is we feel we need to securitise the income stream from Diageo, and we want to suggest that to them, which may include possibly a bond or may be achieved in some other way. Essentially what we mean there is we want to make sure that income into the Trust is secure and isn't going to tail off and isn't going to stop at any time.

The second thing is that we want to safeguard Trust assets and this is particularly important because, as we go forward, the Trustees are seeking to change the risk profile of the investments that we currently have to make them less risky in the sense that they will earn less interest. So we're going back to Diageo and we're saying, look, this is our long-term strategy and we want to get assurance from them that they are going to meet the needs that we have.

The third thing that we're going to begin negotiations with is to raise the issue of new beneficiaries. Just to make sure that they recognise that as and when, or if, new beneficiaries come forward, that they recognise their commitment to meet additional costs which obviously will be incurred.

Fourthly, we want to address the change of control issues. If you've been reading the financial press or listened to the in-depth news, you'll realise that two of the biggest brewers are talking about a merger, for example, what would happen if somebody made a bid for Diageo. It's not on the cards, we can't see it coming, but who knows? No-one saw the possible merger of Anheuser-Busch and SABMiller, for example. So we want to put that on the table. If it were to happen that Diageo were taken over by somebody else, would our needs be covered.

And finally, of course, the one that we keep on coming back to and the one that's never going to leave the agenda: increased funding for our health needs. That's something that we're going to be bringing yet again to Diageo because reports are being published all the time and I'm sure we'll be touching on some of those this afternoon.

The negotiations with Diageo, they're likely to last through pretty much the whole of 2016; if previous negotiations set the standard, then probably they may even go a bit longer than that so we'll be locked up in negotiations for a good period of time. But that's going to take up a lot of our time next year.

The third theme ... a second theme, sorry, I'm jumping ahead of myself. The second theme that we just wanted to highlight right at the beginning is that we very much see the relationship between the NAC, the Trust and the Trustees as one of increasingly close partnership. And I'm just going to give you a few examples of that really, just to highlight that. Health and wellbeing – all of the afternoon is given over to that and you will see that the health and wellbeing committee at the NAC, I mean Simone and Roland are leading that, but I'm also part of that committee, are just doing a fantastic job in dealing with some really complex issues. But we deal with those issues in relationship with staff and we've got some excellent staff who ... we're very much a team when it comes to tackling these key issues that face us all as we're now well into our 50s.

Staff and the NAC, I just said, we've got a very, very skilled staff and we work closely on a number of projects. So, for example, today is an example of that. This is an NAC event but the staff, again, have done a huge amount of work to help us and we've worked together on putting a day like this on.

You'll be hearing this afternoon about Fit for the Future which is an event we're running next year which, again, is an NAC initiative and we've put a huge amount of work ... I mean that's actually been going on the agenda for a very long time. But, again, we've been working with staff on how to put that together. So, again, we very much see this thalidomide family as a partnership.

And then Trustees. I'm sure you all know, but it's worth reminding the folk that the NAC ... we have an open and respectful relationship with the Trustees. We're observers on each other's committees but we also work increasingly closely together and it's a real privilege to be on an NAC which is respected by staff and Trustees and, likewise, we respect and are very grateful for what they do for us.

And then we're engaged in some consultations going forwards. There is a survey which we're going to be sending out next year to ask your opinions on ... not just on the NAC, but on all things thalidomide and we want to get your opinions on how we can do better, any ideas that are out there that we can pick up on. We just want to get your feedback. But consultation happens within our relationship with staff and Trustees as well and so, just for example, we're beginning a consultation on the

effectiveness of the IBR process and that's something we, as NAC, are fully involved in and we're currently debating it, more or less as I speak.

The final heading is the heading of change. Within the NAC, we're constantly asking the question: are we effective? How can we become more effective? Three of us have been involved in leading a process led by Roland and Carl and I've been involved in that as well of just looking at how effective our guidelines ... or our operating guidelines are and as to how responsive we are as an NAC. And we've actually changed those guidelines quite significantly and they've just been approved by the Trustees.

I've mentioned the survey. We're also beginning to ... no, that will come up this afternoon. I won't mention that now. I've pretty much come to the end of what I want to say. The final two things I do want to say are ... the NAC, look, it's a very busy environment. There's a huge amount of work. I mean, I've been Deputy Chair at the NAC now for three years and, honestly, sometimes it feels like it's taken over my life. But that isn't a bad thing. I mean, I do have other things I do, I have a paid job as well but there are times when a whole week can be taken over by NAC things. But, I have to say, looking back almost four years at all the things we've achieved and the huge amount of activity and work that's gone on, I look back with some pride and think, as a team, we've achieved a massive amount. And if you're sitting there thinking, I'd really like to be part of that or I think there's a skill I have or an ability that I can throw into this mix, I want to encourage you to stand for election when the invitation comes round at the beginning of next year. Because we are a dynamic team and there's a massive amount of work that needs doing but we may well need your skills. So I'd like to encourage you to consider standing if you think you've got something to contribute.

And then, finally, please communicate with us. If there's any question that you've got, anything you want us to answer, anything you'd like us to help you with or give our opinion on or anything you want to tell us. Please communicate and we will do all we can to work with you.

Thanks a lot. Deborah.

DJ: Okay. I wanted to start by saying that I actually find it hard to believe that it's twelve months since I was standing in Stansted talking at an NAC conference just because the year has gone by so fast. This time last year, I'd been in the role for less than six months and, at the time, I think I probably felt a bit like a sponge. I was just there soaking up information, asking a lot of questions, trying to really understand Beneficiaries and your experiences and understand thalidomide.

So what do I feel like now? Twelve months on, I think I've moved on from being a sponge and I think perhaps I feel a bit more like a ... taking the sea theme, an octopus, with lots of arms stretching out all over the place, trying to have fingers in lots of pies or even one of those plate spinners who's got plates spinning all over the place and trying to stop them all dropping to the ground and keep them all going at the same time. It's been a really busy year with lots of different things going on.

So, thinking about the things I've been doing over the last twelve months ... because what the NAC asked me to do was to say what's been happening over the last twelve months and what am I going to be doing going forward. *[Ooh, look, I've finally got slides. You missed all my pictures of sponges and octopuses and plate spinners but there you go!]*.

So I think the first thing I've been doing over the last year is really looking at how we develop the staff team. I think probably all of you are aware that we had a large number of Trust staff that all reached retirement age at around the same time over the last, two years. So one of the important things has been recruiting new staff and supporting them to get them fully up to speed quickly. And I know that some Beneficiaries were quite anxious about all the changes in the staff team. People they'd known for years were suddenly disappearing and I think that was quite unsettling. So I've been really pleased by how much positive feedback I've had from Beneficiaries about how friendly, how helpful and how approachable the staff at the Trust are.

But one change to the staff team that no-one was expecting was obviously the tragic loss of Michelle Hodson-Curren in the summer and her sudden and unexpected death really hit the staff team hard. She was an absolutely wonderful colleague. She was not only very knowledgeable and professional but she was also really warm, really sensitive and actually really great fun to work with. So I think that has been something that has very much marked the last year and I know from some of the emails and letters I've had from you that a lot of you were really shocked and saddened by her death too.

So I'm really delighted that we have Katy Sagoe as our new Director of Health and Wellbeing. Katy is over there and I know that she is going to do a brilliant job - but I just wanted to record my thanks for everything that Michelle did in terms of improving the sort of Health and Wellbeing support for beneficiaries.

So, moving on, another thing that's taken up quite a lot of my time over the last year has been modernising systems and processes in the office which I know is the slightly dull and boring bit of work. But when I joined ... it was 2014 last year and the office was still using Office 2003 software. We had a server that would probably find its way into a museum somewhere because it was so old and we couldn't get a warranty because it was so old. So we had quite a big job of actually updating both our hardware and our software in the office. And the other thing that is still quite out of date is the sort of database we use with information about all our Beneficiaries and that has really limited what we can do in terms of communication but also in terms of producing reports about what's going on.

So one of the big projects that's going on at the moment is developing a new secure management information system which will allow us to record better information and also allow us to tailor our communications. So just to give you an example, all of you quite regularly get the MPs mailings that are sent out asking you to be part of the campaign. At the moment that takes about two days of someone's time to do because there's so much manual work that has to go into it. The new system that we'll be introducing, going forward, will just, at the touch of a button, be able to produce all the letters and the labels and everything we need. And the other thing is that it will automatically change your MP's details. So if there's an election or if the constituency boundaries change, on your record, your new MP will automatically appear. At the moment someone has to literally go through and put everyone's post codes in and just check that their MP hasn't changed after an election and update it. So the systems were really slow and antiquated and, moving forward, that's one of the things we really want to change.

And I guess it's not just IT that needed updating, we've also had to produce quite a lot of policies. So, on one level, the data protection policy which we didn't have but we now have, which is really about ensuring we keep all your information safe but

also that we don't hold onto information when it's no longer useful or being used. But also we developed a safeguarding policy and that's really about ensuring that all our volunteer visitors and our staff know what to do if they're told that one of our Beneficiaries is being exploited or that they suspect that's happening. And, again, there was never a clear process and I don't think people were really aware of what they should do. So I think it's all that, systems and processes, all that behind the scenes stuff, which is probably not all that interesting but it does keep the staff very busy.

Another important priority and a far more enjoyable part of the job has been getting out of St Neots and meeting Beneficiaries and generally meeting them in their own homes. . And that has been so important to me as a new director in really beginning to understand how thalidomide has affected your lives and also to understand the sort of challenges that people are facing. And also to get feedback on the Trust. I was working out that I've now met more than a third of Beneficiaries but some you I've just met in meetings like this where we don't get much of a chance to talk. But I've now visited more than 60 Beneficiaries in their own homes and that's really useful because you really get a chance to really talk things through and it's helpful for me and the feedback from Beneficiaries is that it's helpful from them too.

Sometimes my visits are prompted by a specific problem that's flagged up but whenever I can, I try to visit a few Beneficiaries at the same time. And what I've tended to do is to f arrange to visit Beneficiaries who've had very little contact with the Trust. Some of them for ten or fifteen years, apart from getting their money each year, we don't really hear from them. And the one thing that has taught me is just because you don't hear from people it doesn't mean that everything is going swimmingly in their lives because some of the people I've gone out and met have been really struggling with health issues, struggling with personal issues and they've been so caught up in their problems they've not thought of contacting the Trust to see if we might be able to help and support them. So that's one of the real lessons that I've taken away.

And that sort of leads me onto my next point which is that, although I've visited sixty Beneficiaries, that's only 13% of the whole Beneficiary body so that's really only a small number. And the IBR process is another way that we find out what the needs of Beneficiaries are. But in the last year, only 2% of Beneficiaries have requested an IBR so we haven't really got good systems in place to ensure we're reaching everybody. And although the NAC is fantastic for ensuring there is Beneficiary involvement in decision-making, we know the members of our NAC aren't necessarily typical of all our Beneficiaries out there. So we need more effective ways of getting an overall picture of what the needs of Beneficiaries are and how they're changing.

So that's why we did the big Firefly survey a few months ago and we were absolutely delighted that 75% of Beneficiaries completed that survey. Now there's going to be a session later on today on it so I won't say much about it apart from to say that we asked questions on a far wider range of topics than we'd ever done before at the Trust. And it's also why, as Craig alluded to, we're going to do a Beneficiary feedback survey early in the year to get views from Beneficiaries. So I've been working with the NAC and the staff of trying to find ways of increasing how we understand Beneficiaries' needs.

Whenever I go and visit Beneficiaries, I always ask them for feedback on the Trust. What do we do that's good? And what could we do better? And probably the most common thing that people say we could we do better is we could communicate

better. That's been the theme that came through from almost everyone. So we've set up a communications working group and we're beginning to look at how we can improve it and I'll talk about that in a minute. But that's certainly been one of the things I've been looking at over the last year.

And I've also been looking at trying to build strong relationships with our funders. So that's Diageo but it's also the four different health departments - and an important thing, for me, is whenever I meet the Departments of Health, we always have Beneficiaries with us and that's really important because we think that it's important that they understand the health needs of Beneficiaries, they understand that needs are growing and they also understand the difference their money is making to the lives of Beneficiaries.

And finally, in terms of the last twelve months, I can probably say I've had more contact with lawyers in the last twelve months than I have in the rest of my life put together. And that's because there's been a number of applications to become a Beneficiary of the Trust that have come via lawyers and it's also because I think most of you are aware that there are a group of 28 individuals who have litigated against Diageo and Grünenthal and their lawyers have been in touch with the Trust to ask us for information about what we know about these individuals and also about the way we assess claims to be new Beneficiaries.

So that's been quite a lot of work. But in addition, all the new Beneficiaries that I've met who've joined the Trust ... a big theme from them is how long and torturous the process is to actually become a Beneficiary of the Trust; it can go on a long time and communication is not great. So both of those factors have led us to look at the process - how we deal with an individual who contacts us and says they think they might be affected by thalidomide - and to try to make that process as smooth and quick and straightforward as possible. And I think that's important because there's increasing media interest in thalidomide. We know that *Call the Midwife* has a thalidomide story line in the new series and whenever there's something on the telly about thalidomide, we suddenly have a whole lot of people contacting the Trust saying 'I think I might be entitled to be a Beneficiary'.

So, looking forward. I'm going to be continuing to work on systems and processes, to really try to make sure that everything is efficient and is fair for everybody. The other big priority will be communications and one of the things that the communications working group is doing is looking at developing what we're calling a communications framework. So we're saying: who are the people that the Trust needs to talk to? What are the messages we want to get across and what are the best ways of getting those messages across? And, of course, the most important audience for the Trust is our Beneficiaries but there are lots of other audiences and the ones that have come to the top of the list are: GPs and practice nurses, politicians and policy-makers, our funders of course, social workers and also OTs and physios who more and more Beneficiaries are looking to for support and realising that they don't really have a good knowledge of thalidomide. And the media has also been identified as a key audience because they are very influential but also because they can help us build understanding, awareness and support from within the general public.

And I mentioned there's been a big increase in media interest. So one of the things we want to do before *Call the Midwife* comes out is pull together a very simple media pack for journalists and also have better systems for dealing with enquiries that come in from journalists. So we're dealing with them efficiently, w We know when there's discussion going on with the media and we're getting the right sort of messages across - including the messages that we're trying to get across to Diageo because

we know that staff at Diageo, as well as meeting with us, they read the papers and they see what's being said.

Another priority for the next year is reaching out to as many Beneficiaries as possible, rather than just responding to the ones that shout the loudest. And we want to ensure that every single Beneficiary is aware of the support that's available from the Trust and also feels comfortable asking for it when they need it. And it's clear that we need to do more to really make that happen.

Another thing I want to do is really develop the role of volunteers and it's clear that you as Beneficiaries and one of the biggest resources that we have because you understand thalidomide, you've come up with lots of creative solutions of dealing with day to day challenges and as a lot of you are reducing your working hours or giving up work, you've also got skills that you're prepared to share with the Trust. So what we want to do is look at how we can use volunteers more. And I think there's some of the needs that are coming out, like the need for more social interaction or the need for more help with benefits, including filling in assessment forms, all of those things are things that volunteers could really play an important role in doing. So we will look at how we can develop new roles for volunteers and how we can get more volunteers involved.

And my final point is that I will be working closely with the NAC on the negotiations with Diageo, which will be starting next year, with the aim of really making sure we can maximise the amount of financial support we receive. But it's fair to say that myself and the other staff will be very much in a supporting role in that process. That process is really being very much led by the campaigns team and the Beneficiaries.

So it's very much a whistle stop tour of what I've been doing since I last came to the NAC and conference and also what I'll be doing over the next twelve months and I wanted to end by just saying: any questions? And that's for Craig or for me. So ...

M1: My mother actually took care of Dominic until much earlier this year but unfortunately sadly she passed away so it's come to me now to pick up the role. And although I've only been, let's say, a third party in that, I've been conscious of the communication and let's say in the last three or four years I've been responsible for that and I can see a huge turnaround so thank you very much for that. Great job. [Applause].

F1: Yes please. Given the recent news about TalkTalk and you did touch on the security of the computer, as the systems at the Trust stand at the moment, are our personal details and banking details encrypted.

DJ: Jenny's probably better than me but yes your financial details are very, very secure and to be honest that's been one of the overriding principles in the way data's been stored which I'm sure you all find reassuring. And what we need to do with the new system is make sure that we maintain that security but, at the same time, make that information more usable and helpful. I suppose you can't say any system is bullet-proof but many steps have been taken to protect that information including encrypting passwords.

END OF RECORDING