

Mikey Argy – Dr Craig Millward

24/10/2015 NACAC

01:10:45

MA: Hello everyone and thanks for sitting in and coming to the campaign workshop. I'll stand on here.

What I wanted to do is just give you a brief outline to start off with on what the campaign is really all about and why we're doing what we're doing. I'm sure you read all your letters and I'm sure you all know but if I'm telling you stuff you all know, just stop me. But I just wanted to make it really clear on what we're doing and why we're doing what we're doing.

Originally, we said there were three parties responsible for our thalidomide damage and we said that was Diageo, which is Distillers, we thought it was the British Government and we said it was Grünenthal. But, as I'm sure you're all aware, Grünenthal is untouchable and that just got proven recently in Spain when they won against the Spanish due to time limitation. So it's impossible to get to Grünenthal. Apart from time, we know that they are protected by the German government.

One of the things that we noticed, all around the world, is that no thalidomiders around the world have actually had proper financial justice. So we decided to look into that and, as you know, the archives in Germany were opened after 50 years.

So in we went and what we found was very interesting. First of all we found that the German government really has protected Grünenthal from ever being sued for thalidomide in Germany. That was number one. But we also found a couple of other things which is what the whole campaign is about which is why we're asking the German Government.

Now, we're not asking the German Government for compensation because when I talk to MPs, they use the word compensation and I make it very, very clear to the MPs that what we're actually saying is ... we're not saying the German Government should pay us because we're affected by thalidomide. What we're saying is that we feel the German Government should pay us because we have unmet needs and it is absolutely the responsibility of the German Government that our health needs actually are met and that's the whole focus of the campaign.

Carl ... Craig, I keep calling him Carl, I'm so sorry. Craig is going to talk about strategy a bit later on but I wanted to talk to you just about what we're doing, why we're doing it and how we're doing it in the UK.

So, as with other campaigns, we go into Parliament – and I'm leading on the UK side. We brief MPs one by one. We give them the story. And what we basically tell the MPs is ... first of all, I introduce myself to the MP and I tell them that I'm a member of the National Advisory Council and I tell them that NAC members are democratically elected by all of you so that the MPs know that I'm not a random thalidomider coming to brief them because there's nothing to stop any of you going to Westminster and talking to your MPs but they need to know that there is a national campaign and it is the national campaign we want the MPs to talk with. Otherwise we'll become splintered and that weakens our position.

And then I talk about what the Government did in 2009 / 2010 which is when we received the Health Grant. And so I tailor that, particularly if I'm talking to a Labour MP, I sort of gee up

and thank them very much for their assistance. And I can't really go too far wrong because if I'm talking to a Conservative or a Lib Dem which is ... I've only spoken to one Lib Dem since the Parliament ... new Government. I say, "Oh thank you very much for extending it" which they did in 2012 for the further ten years. I can't really go far wrong and every MP feels thrilled that they had a role in our Health Grant. The new MPs are very intrigued, they want to know and then they want the same participation as previous MPs and so it's all very, very positive. And I've seen probably about over 150 MPs in the last year.

Then I talk to them about the support that we're getting in Westminster and I talk to them about ... sorry, first of all I talk to them about the responsibility of the German Government and I explain to them a couple of things that we found out in the files. There's many things that we found out in the files, but there's two very specific things in the archive files that we found. And that was, first of all, the involvement of the Federal Government and the State Government of Germany in the early termination of the criminal trial.

So, effectively, in 1961 when the drug was removed from the market, the state of North-Rhine Westphalia, where Grünenthal is based, raided the offices of Grünenthal and they confiscated everything. Based on the evidence that they found, they issued criminal proceedings against Grünenthal for criminal negligence. And that was the basis of the court case from 1968 to 1970 in Germany. And then we all know that the court case closed prematurely and a trust fund was set up called the Stiftung and I'm going to refer to it as the Stiftung to separate it from our Trust and that everybody affected by Grünenthal became a member of that and that's, I think, information we all know and I don't think I need to talk about that.

But what we actually found was that the President of the Federal Government of Germany in 1970; a man by the name of President Heinemann and, if I'm correct, he had before that been the Justice Minister. He tried to engage in secret negotiations with the State Government and with Grünenthal themselves, defendants in the criminal trial, and also with the lawyers of Grünenthal to negotiate a payment outside of what was expected.

So the total sum of expected needs from the Germans was a figure of 1.2 billion Deutsche Mark but President Heinemann negotiated a secret deal with Grünenthal that was a total of 100 million Deutsche Mark. It was only 13% of their calculated needs and they were so desperate, the parents in Germany that they settled with that and of course they didn't know anything that had gone on behind the scenes.

Now the Cologne prosecution service warned Heinemann to stop interfering in the criminal trial but he continued interfering in the criminal trial and there was this settlement.

Now, where the German Government breached its own constitution was actually some of the evidence we found in the trial, was in the mid-50s Grünenthal gave the drug to a company then called Smith Kline & French to trial it and Smith Kline & French trialled it on about 400 800 members of their staff. Many members of their staff developed peripheral neuritis, which we know is one of the side effects of thalidomide, and they had born to them three thalidomide babies. Based on that evidence alone, they rejected the drug and returned it back to Grünenthal.

Now, Grünenthal had that information and we know that the German government was aware of that information and to terminate a criminal trial with evidence to prove criminal negligence is actually in breach of your own constitution. So that's what we hold the German Government to and that's one of our very strong points. We don't have an issue with Smith Kline & French who are now GlaxoSmithKline, that's a completely separate story and that would be a distraction, they are not responsible for the drug thalidomide. So that's why we believe the German Government is responsible and that's why we are going after them.

So we're using our tactics as usual. Going into Westminster, briefing them one by one, so I've now given them that side of the story. I've already now thanked them for what they did for the Health Grant, and everybody is getting geared up to see what else they can do.

Then I tell them about what we've done so far in the campaign. We've done some things. We have a letter and, just recently, you've all had a letter and you've sent it off to your MPs and, as of ten days ago, 156 of you returned your postcards to the Thalidomide Trust. I mean that is absolutely phenomenal. In the last mail out, I think we had 303 postcards returned. So if you haven't done your letter, please send it off to your MP. It's got an open letter attached and what that open letter is, it's an open letter to Angela Merkel, Chancellor of Germany, and it's asking her to come and meet with the Thalidomide Trust and discuss a package of financial assistance.

We, to date, have 344, because I just had an email last night, 344 MPs have signed up over the letter. So I mean that is a phenomenal amount of work and that is a lot down to you guys writing to your MPs and some of you have awkward MPs and some of you have really challenged your MPs who are refusing to meet the campaign team. It's interesting when you send me your correspondence, it's really exciting seeing some of you taking on the fight for us. Liz Buckle works with me on the phones and on the email system that we have and I'm quite sure Liz is cheering alongside me when we see some of these fantastic emails that we get from you guys saying, "Look what I've written to my MP." It's like, yes! It's not just Liz and me doing it but you guys are as well.

Now, some of you may be aware that there's an Early Day motion out in Parliament at the moment. And that was started by an individual MP and that's absolutely fantastic because what that Early Day Motion is asking for ... is asking for the British Government to support all of us in our campaign.

Now some of you may have seen a little debate about this EDM because somebody was asking ... members were asking all of you, outside of the campaign team, to chase your MPs to sign this Early Day Motion. And the reason I was asking everyone not to chase your MPs is because I want you to chase your MPs for the open letter because it's the open letter that we are looking for in the campaign, that's our strategy. You can ask your MPs to sign that EDM, it's completely fine, but it's not part of our strategy at the moment because we don't want burn out with the MPs at the moment because it's very, very easy for them to say well I've done one, I'm not going to do the other. And actually we have that scenario at the moment; we have MPs who are struggling to sign our open letter because they've signed the EDM and what we want is, we want to get to 400 signatures on that open letter. Actually we want to get to 600 signatures on that open letter. It's probably not going to happen because cabinet and Ministers are not allowed to sign the open letter. So we could get to 400. So we are still pushing with that open letter.

We talk to the MPs about our health needs and I don't know but I'm sure every time I tell an MP the same story as I told a previous MP, it's as fresh as the first time I said it but for me it's getting a bit stale. So if anybody has got any interesting stories you would like me to pass to the MPs, something kind of funny but poignant at the same time; a brief story, please share it with me and I can look at maybe sharing that with an MP. You know, when I talk about knees going, Beneficiaries who use their legs all the time and how that reduces our ability, that fascinates them, and just a little bit more of a story if anybody wants to share anything with me.

So, in the UK Parliament, we've got two campaigns running ... one campaign running. We've got one in the European Parliament and one in the UK, so I'm going to let Craig talk about the European side of it.

But in the UK we have met with David Lidington, who's the Foreign Office Minister, and he has supported us in getting our first meeting with the German Government which was held on the 7th of July. Now, Germany has these hierarchies and we basically met with hierarchy three and hierarchy one is like our Secretary of State and then they have a civil servant who has similar responsibilities. And then hierarchy two is like our Ministers and then they have a civil servant with similar responsibilities. And then they have a hierarchy three and it's kind of like a political appointee and we don't have that position but what that person did was they came, they met, and they advised us that the British government had responsibility for thalidomide and that the German Government would like to tell the British Government of its responsibilities. In other words, the German Government has no responsibility towards thalidomide.

So the Foreign Office is aware of that and we've made it very clear to the Foreign Office and to the Health Department that any meeting that is held between the German Government and the British Government needs to be held with us because one of our founding principles is there's nothing about us without us. Because for the first, pretty much, 45 years of thalidomide, everything was done about us without us and, in the last 13 years we've been there and look at the changes in our fortunes and in our wellbeing.

So we met with George Freeman ... now in the Health Department we have Alistair Burt, who is the Minister. Of course, we have Jeremy Hunt who is the Secretary of State. And Alistair Burt has given the remit to a man called George Freeman, who is also a Minister. And we met with him the other day but we took along with us Norman Lamb and if any of you remember who Norman Lamb is, he was the Lib Dem Minister who brought us our Health Grant for a further ten years. So it was a very emotional moment for him, he came back into the Department of Health, he's one of only six Lib Dems in the whole of Parliament and we were walking down the office to meet George Freeman the other day and we walked past Norman Lamb's old office and he sort of stuck his head in the room and he was going, "Hello boys!" and everyone was very, very happy to see him and he had a little tear in his eye.

But he did say to George Freeman, the Minister, he warned him that he should be audacious within the department and the civil servants, who were there ... we have a very supportive civil servant by the name of Zawar Patel and unfortunately he's just removed himself from our remit ... been taken away from our remit but I suspect he's actually going to keep his eye on all of us and he also advised that David Cameron at Number 10 and the Foreign Office were aware of the current meeting that was being held and they wanted to know what George Freeman's commitment to us was going to be.

So George Freeman didn't give us what his commitment was going to be but he's realising that he's got a massive amount of pressure coming from Number 10 and the Foreign Office to support us as well as from Norman Lamb. Norman Lamb spoke incredibly well to George Freeman and made it pretty clear that he needed to be completely engaged in our campaign. He also warned George Freeman that it wasn't going to be very easy to ignore us because as we write to our MPs and your MPs write to George Freeman, he's going to start getting a pile of letters. And when Norman Lamb took over as MP, his pile of letters was just so big, I think it was coming up off the floor ... I'm not joking, to probably about two foot / three foot high of letters that MPs sent. So we want to do the same to George Freeman and we will let you all know exactly how and when we do it.

That is the thrust of the campaign at the moment. As I said, I phone up the MPs, along with Liz, while we have a couple of other helpers, outsiders, and sometimes we have Miles, who's in the finance meeting and Helen Shore who makes phone calls with me as well, with us as well, and we phone the MPs all the time to get meetings. So if you get an email from

me asking for help, please respond to it and please get in touch with your MPs if you feel like you want to. If you feel like you can't get in touch with your MPs, just get in touch with me and we will push your case further.

On a final note, on the postcards, you're allowed to send back whether you want us to have your details or not. And what I'm aware of is some of you don't want us to know anything about where you live or anything. But it would be so helpful if we just knew your name because when I speak to an MP and I say, yes, your constituent has sent back your letter but I don't know their name, they actually don't know how to start looking for you in their system because they have filed it two months ago or whatever. I very rarely give them, I explain to them that I don't have your details because of data confidentiality and because I'm a Beneficiary. And because I'm a Beneficiary, data confidentiality is, you know, obviously we know what that's all about. But if I could just have your name, they can find you in the pile.

So those of you who've sent back saying no you don't want to share your details, would you just consider saying, on your card, "happy to give my name" something like that so we can find who you are please. Would you agree Liz? Yes. Is there anything else we would like to ask Beneficiaries to do regarding their details? There isn't really is there? No.

Okay, so I think we're doing questions and answers afterwards, is that right Craig? Yes. So if you've got any questions, hold on, and Craig's going to talk about the European side of the Parliament and then I'll come back and talk about the media.