

other? It has never been clear to me.

thank you

.....

Martin

What's with these people?

Funnily enough, when you set it out as you have done, it makes one wonder why infected intimates are treated exactly as registrants, since they do not have haemophilia to worry about. We might see if we can review that when get round to looking at regpay at the NSSC (that would be a way of pissing off the Lewis contingent).

P

Martin

Our Emails are crossing. HL knows nothing of this error, and I can see no possible reason for bothering the CC with it. We can put it right (if we wish) next year. There is absolutely no need to write to the CC.

P

Martin

Fine

I have read and re-read the string of attachments and see no reference to the headcount error, which, after all, only came to light at the very end of last week. I suspect that you have given him an unnecessary bit of ammo, but, as said before, I do not see it as serious.

P

----- Original Message -----

From: Martin Harvey

To: Haydn Lewis

Sent: Tuesday, January 25, 2005 10:54 AM

Subject: Re: Accounts request

Haydn

The accounts have been submitted.

The errors in the headcounts have been properly reported to the board and are in the minutes of yesterday's meeting. You are quite at liberty to register any concerns you might have with the Commission.

The minutes will not be made available to you. In **GRO-C** you and all registrants have a first class user trustee, I invite you to consult with him.

Yesterday, a deed of variation was made to the consolidated trust deed. I invite you to consult with Stuart.

Martin Harvey

----- Original Message -----

From: Haydn Lewis

To: Martin Harvey

Sent: Tuesday, January 25, 2005 10:11 AM

Subject: Re: Accounts request

pack if you think I believe either one of you concerning this matter. I will try and clarify this in AOB.

By the time AOB arrived on the agenda I was so angry and frustrated with the whole meeting that I became unable to make my point and get any sensible answers from the Chairman and CE, I lost my temper (which I would like to apologise to all present at the meeting) I ended the matter with a statement of never writing to either the Chairman or the CE again which is a sad conclusion to the whole matter. What I am even sadder about is that the Chairman and CE don't even seem to care that one registrant has now lost all faith in the honesty and integrity of those involved and I'm left with no way of contacting the trust with any belief that what they tell me is true. This also shows how sincere the Chairman's words within his response were.

"I am sorry also that you are worried about MFT. I have no access to the Bulletin Board, of course, but I understand that the number of people participating in the recent discussion is relatively small; however, even one would be something that I would not want, so I am doing what I can to try to set people's fears at rest."

I will end my explanation now and leave any that become party to this to make their own minds up as to who may be telling the whole truth, I should add also that due to the effect on my health concerning this matter my wife has decided to deal with the MFT in the future, so if you think you can breath a sigh of relief at not having to deal with me anymore then think on, because my wife is not a person to appease easily when wronged. I pray for the day when I feel financially secure enough to tell the MFT to stick their benevolent fund where the sun, don't shine!

Yours sincerely

Haydn Lewis (a weary registrant)

-----Original Message-----

From: Peter Stevens [GRO-C]
Sent: 13 December 2004 23:34
To: Martin Harvey
Subject: Stuff

Martin

As I prepare to go to bed I recall that I shall never have a private Email from Haydn Lewis again. Oh happy day! (Indeed, "Calloo! Callay!", but I have not yet discovered if you, too, nurse a Lewis Carroll streak).

Otherwise, what a monumental waste of time - not just this afternoon, but all the previous hours spent nurturing that lot of moaners. As [GRO-C] said, there are some people who want to get on with their lives. However, I guess we have to persevere.

Peter

----- Original Message -----

the meaning) it is a organisation with a specific mission to ALL that qualify as registrants.

Nobody will argue with the sentiment that whatever the amount of money available, registrants do not get sufficient financial support (to recompense for what has happened to them) and that each and every one of them would swap their MFT involvement for a clean bill of health. What we cannot do is meet the all the needs of all of the registrants at any one given time and, again, when registrants determine (for wholly understandable reasons) that the MFT should u meet those needs because of what the NHS did to them, then whatever I or anybody else says will not get a hearing because the emotional dye has been caste.

So, to run a charity like MFT, I have to be a degree detached. If I got personally over-involved with those registrants I have to deal with, it would be wrong. Constructive dialogue, talking etc but I will make sure that all those that look to the Trust for support are treated exactly the same and those same people will be treated in a professional manner that they would expect. So, when talking about personal attacks, it does not really bother me; what would bother me is someone saying he did not approach his job in a professional and transparent fashion.

I look forward to seeing you on the 13th.

Martin

The Chairman of MFT and all

I read most of this in article by Jane Muir in the Guardian last week but it seems to sum up how I am feeling so I have used it, hope she would approve.

It's no fun when you need to go cap in hand to charity for help, you can often end up feeling patronised, humiliated and exploited. I'd almost rather be sitting on a street corner, with cap in hand.

You can see why some people believe that is where the word "handicap" originated.

The statutory bodies - NHS, social services and education - have no ethos to give the best, but only to give the absolutely necessary. We need more than merely the "necessary" for registrant's to realise their potential.

But worst of all is the means test. You are required to list your expenditure per week in detail. How much do you spend on food? On clothing? - On your phone and TV? - Household bills? - Insurance? Do you have debts or savings? Do you live with anyone else, or do you have other children? Intrusive questions to say the least, when you already feel uncomfortable enough, being on benefits. They don't do much for your self-esteem. The fact that you've been means tested already just to be eligible for state benefits seems to count for nothing at the MFT.

Maybe we need to jettison the very concept of need for

registrants of the MFT, or perhaps we could just start looking in that direction, because when I think of the MFT, I find that I am looking the gift horse in the mouth and finding far too many rotten teeth.

Below you will find my personal perspective of the chain of events which lead to this unfortunate situation, please feel free to comment on any of the content if you have problems with any not being factual.

If you do not respond I can only assume that you agree with the following content of this summary of events.

(FAO) - The Chairman, (CE)

Quote from my original email (28/11/04) and reason why Chairman decided it necessary to break my request to keep correspondence private

"I would also like to request the total spent in personal expenses over the first 12 months by the past CEO (Ann) and the same total for the first 12 months of the current CEO (Martin)"

Response from Chairman (29-11-04) concerning above question, (comment) the Chairman implies no reason to contact the CE about query.

"Unless there is a compelling reason for doing so, I am not going to divert our scarce office resources on to this question. In any case, operating costs are, as you know, funded by a Section 64 grant, and I do not see the relevance of these numbers to anybody except those who have the responsibility of running the Trust, which is the Board of Trustees."

Two Quote's from my second email to Chairman, (8-12-04)

(1)

"I personally have no concerns about the RSW's as it would be folly of the trust to employ staff with an agenda of economics, as they would never save the trust the cost of their salary. They will no doubt have a large effect on registrant's dignity, but most of us lost ours when we signed up to receive money's from this benevolent fund in the first place".

(2)

"You seem to have assumed rather a lot from my brief letter, your comments about my lack of confidence in the current CE are incorrect I have only met him twice and know nothing about his CV but I'm sure if you choose him he is more then capable of implementing any policy the trustees instruct him to comply with. As I have mentioned before you cannot blame the messenger he is there to serve you, your trustees and implement policy's to the registrants.

My motive for inquiring into the personal expenses of the CE while performing his duties was to see if the responses you received from registrant's concerning the very same issue and your response were in any way similar, this as I thought was the case which proves my point. No one likes people intruding into their personal affairs."

----- Original Message -----

From: Haydn Lewis

To: Peter Stevens

Sent: Sunday, November 28, 2004 11:22 PM

Subject: Private letter chairman MFT

(Private and confidential)

Peter

Hope you and your family are keeping well, as you can see by the time this email was sent I am not finding sleep that easy to achieve at the moment.

I believe you have already been made aware by other registrants of the MFT that there are signs of storm clouds on the horizon. I would like to find out if the concerns of the many entry's I read on the bulletin board are the opinion of the majority of our trust registrants. The message I am getting from the comments made are mainly concerns about the intrusion and fears that the DoH are proceeding with a policy which was rather crudely described in the strategic review of 1999 (final report) as a some what inevitable MFT "farewell symphony". My best guess based on the LTR, re; stat's income, suggests this may be the case.

Martin Harvey stated at the Birmingham meeting that a business case when completed will be put before the DoH for an additional capital sum to meets the needs of the remaining registrants perceived longevity.

May I suggest a simple solution, look back to the original formular used when calculating the lump sums made by the second special payment scheme but change the entry concerning life expectancy from 3/5 years to shall we say 20/30 years and see what the balance will provide in monitory terms for all registrants. This will take into account the vast age difference of registrants at time of infection, while also at the same time recognising the years widows and partners have sacrificed and continue to spend looking after their loved one's.

You may not agree with this suggestion but really it should not be your view or the trustees that matter, as you rightly stated, "it is our trust" so I would ask you to provide a mail out to all registrants with a questionnaire which I will provide to obtain a democratic policy for the first time in the history of the MFT.

Failing that I think a extraordinary general meeting should be held, open to all registrants willing and able to attend and a show of hands asked for, concerning which way we proceed with the construction of a business case to the powers that be. They seem to have forgotten their part in the reasons why the MFT evolved in the first place!

I would also like to request the total spent in personal expenses over the first 12 months by the past CEO (Ann) and the same total for the first 12 months of the current CEO (Martin)

Hope you will be able to provide me with answers to my requests and suggestions.

Kind (but weary) regards

Haydn

ps I would be most grateful if you would give me your opinion about the merits of a question I intend to submit at the next public meeting of SEAC which is being held in Cardiff this coming Tuesday. " How much longer do the panel think the Haemophilia community will need to wait before a blood test is available for vCJD"? (or have they already been tested, becuase nothing would surprise me anymore!!)

----- Original Message -----

From: Peter Stevens

To: Martin Harvey

Sent: Monday, November 29, 2004 9:52 AM

Subject: Fw: Private letter chairman MFT

Martin.

Notwithstanding the heading I thought you'd love to join me in starting the week with an insight into the thoughts of Haydn Lewis.

I shall try to compose a reply in the course of the day. I shall point out to him that I am unable to provide him with information about expenses without asking you.

It is irritating that someboyd so thick can come up with such meddlesome suggestions.

MFT getting compensated for expenditure on behalf of other agencies.

Tax status of interest on MFT or other "group" money

VAT issues

Skipton

Progress to date.

Views on probable out-turn of total applications.

Natural clearers

Timetable for new directors.

VAT

Operating costs (do we have enough info?)

Appeals Panel

I have thought about whether we should ask to take Keith along and am undecided.
What do you reckon?

I expect you'll have other things. These are not in any particular order.

P

-----Original Message-----

From: Peter Stevens

GRO-C

Sent: 08 December 2004 15:44

To: Martin Harvey

Subject: MFT agenda 24/1

Martin

Not a lot of comment. I assume that your report will cover the Bulletin Board/ITN/March/
etc crap.

162.05 will obviously now be different. (We might invite Connon along rather than
Zubeda).

166.05 might also be different by then. In any case I cannot believe that it will be
relevant to circulate your letter.

In both agenda and the Trust Deed paper there are the usual (in the sense that we both
do it) form/from typos. In the latter document you might add to the 3rd para that
proposals for further amendment to the Deed, relating to the appointment of Trustees
and, maybe, other things, will be put to the April meeting, at which stage the Society and
DoH will have been told about them.

Will you report on Claudette in your report?

Nothing else occurs at the moment.

P

----- Original Message -----

----- Original Message -----

From: Peter Stevens

To: Haydn Lewis

Cc: Martin Harvey

Sent: Tuesday, December 21, 2004 2:07 PM

Subject: Re: PG meeting 13th/AOB

Haydn

Thank you for your message. I am sorry I could not reply earlier, but I have been in the middle of a botched computer up-grade and have had technicians here yesterday afternoon and this morning.

I have little else to say, I fear. You summarise various correspondence and conversations, and I am not going to dispute your record. I should point out, however, that your assessment of the amount of time that Martin and I might have spent considering and reviewing what you said earlier does not take into full account all that we were then concerned with. Having failed, both then and subsequently, to understand your reason for asking about his expenses in your first Email, it was certainly not something for further discussion after your second.

I am not sure what particular aspect of the Trust's work is your *casus belli*, but I shall continue, with Martin's help and with the support and guidance of the other Trustees, to work for the benefit of the registrants of the Trust and their families. If you wish to contest my qualifications for doing so, you are welcome: the Society appointed me, so they can, I imagine, ask me to step down if they believe that that is warranted. So, I expect, can the Charity Commission, although I believe that would be an exceedingly rare action.

I would support Martin in asking you to keep this from the media. Over recent weeks, as was made plain at the PG, much anxiety and stress has been caused to registrants because of ill-informed and, at times, malicious rumour-mongering about the possible changes to the way the Trust delivers its services, which were covered in full at the PG and in the recent Newsletter. I believe that media coverage of your particular issue with Martin and me would only resurrect, most cruelly, similar worries. We have already heard from a totally unconnected third party who has heard of your complaint; I trust that this is not evidence of a general policy of publicity.

Presumably you will also take into account any possible political implications of making your views public; any risk of damage to the continuing support the Trust receives from the Government would be serious indeed.

You have had my apology, privately and publicly, for breaching your confidence, and you said that you accepted that. You have been told my Martin and myself what happened. I have no more to say except to hope, with, I fear, little confidence, that, especially at this particular time of year, you might draw a line under the whole episode.

Peter

-----Original Message-----