



The Birchgrove

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Due South

A Canadian Adventure

A Melson

This was my first international Haemophilia event, and I didn't quite know what to expect. I had been wandering the streets of Montreal on my own for a few days waiting for other UK members to arrive. On the Saturday I booked out of my hotel and got a taxi to where I was supposed to meet Gareth. Unusual I know but we had arranged to meet in the Hotel bar!!!!

Well, roughly 3 hours late due to customs, delays etc, we were at last ensconced in the bar, along with maps and tourist brochures, not to mention our list of relevant seminars that we were attending.

We decided to wander along to the Palais de congress and register, unfortunately Gareth's information (and I lay no blame anywhere in particular) was not on file, whilst I found myself being registered as Dr Melson, a title which we have now adopted

For the main reason being that if some of the people who we met claimed to be Doctors then I am sure I qualify.

After registration we headed off back to the hotel to formulate a plan of action, we earmarked the seminars to attend, and sorted out what we wanted to see in this great city.

I must say I have never seen so many people with a limp gathered in one place for a long time. A relief actually because sometimes I do get a bit self-conscious of my own limp. Anyway back to the bar, we met others from the UK delegation, one in particular whom I cannot mention, mainly because I think any links with Birchgrove may endanger his future career as president of the Haemo Soc, but he knows who he is (don't you Andrew).

Well we sat in the hotel bar getting to know the barman and the majority of the staff all by first name terms (not that we were there that long) and decided we would have an early night to recharge for the following day, this was roughly 1.30am.

I am leaving Gareth to fill you in on the medical aspects of the seminars, I am dealing with the social side, however I must say that the Doctors, nurses health professionals call them what you will, definitely divide in to two categories, those who care, and those who care about corporate hospitality.... I think you all know what I mean.

I think if Birchgrove did have a paramilitary wing then we certainly found a few targets to practice on, in fact I think we would have to expand.

On saying that I did meet a lot of people who do genuinely care and have not forgotten the issues of the past or present which to me was very refreshing.

Let's get back to the social side then. Well, we had tickets to see a gospel

quire, yes a gospel quire, and I must say other than the religious aspect of it they were very good, this however only went on till about 9.30, and as I had found out in the previous week this city does not wake up until midnight.

So Gareth and I and One other, (who must remain nameless) decided to go for a wander. I had found a quiet little club not far away and proposed we went there, yes was the reply. However without blaming myself too much I was somewhat confused by where we were at the time, needless to say we walked quite a distance before it was pointed out to me that the building we had to keep in front of us was now some distance behind...(a minor glitch). Any way I new a shortcut.

We crossed the street (a somewhat dimly lit one) and proceeded to walk past what can only be described as a semi derelict block, with some very choice furniture strewn around the derelict cars, (well you can't stick to the tourist route all the time can you), there was very loud music coming from above, but no one seemed to want to go in?

We crossed over and found an information board, apparently we where 12 blocks astray somehow!!!

On orders given to me in quite a stern voice we hailed a taxi, I must say it did take us about 10 minutes to get there, but on getting there thankfully the owner remembered me and we took a table. We sat there until the early hours putting the world to rights and discussing what was wrong with just about everything.

The next day, or at least a few hours later, we proceeded to the seminars, as I said this subject is being dealt with so I wont go on....sod it yes I will, the HIV seminar we attended that day was I thought quite informative, and dare I say fairly hopeful, as long as we can hang around for about another year or so for the new treatments to come on line.

The next few nights were taken up by much of the same, the odd restaurant and bar and generally seeing the sights, I must however at this point thank Gareth for turning down a free meal with one of the drug companies because I could not attend, cheers.

On the final night of the congress we all had invites to attend the "last supper" as we called it, this was quite a formal event, ball gowns etc, and that's only for us (This relates to a subject that no doubt will be broached in the magazine inferring that most positive Haemophiliacs want to be women,) anyway we attended, the evening went well and finished, albeit quite early on a high note with everyone looking forward to Seville.

The next day we had arranged to hire a car and drive the short distance (yeah rite) up the road to Quebec, it amazes me how anything in North America is "just up the road". We had arranged to collect the car that morning and strolled in to Budget to collect said vehicle, first problem, since my early retirement I don't use credit cards but on travelling on

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my own I thought it was necessary to get one, only thing being I had forgotten to authorise it before leaving blighty...the ultimate embarrassment, it was refused, "not yet valid" was this how the day was going to go.

Luckily one of our number had both credit card and driving license on there person but defiantly did not want to drive, so car paid for keys in hand we bundled into the car like the anthill mob, I slipped it into drive and we screeched out onto the highway, still not quite convinced we had taken the correct car, still no one ran after us so what the hell.

Now we had two navigators sat in the back, and I was suddenly taken back to when my estranged wife and I used to drive abroad, there is something inherent in the female of the species (sorry not trying to be sexist) when giving directions that they tell you to turn when you are doing about 70 and you have to cross 5 lanes of traffic to get to the junction which is about 10yards ahead!!!!

Needless to say we missed the junction, we ended up taking the scenic route, still it's only "up the road". We decided to keep the St Lawrence River on our right and we couldn't go far wrong. We went through quite a few picturesque little towns and decided to stop at a truck stop for breakfast. Here we took a look on the map, this short trip up the road suddenly looked something reminiscent of the Paris -Dakar, still we've got 24 hours to get the car back.

We eventually got on the interstate, heading in roughly the rite direction, I set the cruise control and we were of.

I think it was about 4 hours later we arrived in Quebec, all I new was I had seen a picture of a castle that looked nice so lets find it. Bad move really, I think Quebec must have more castles than Disneyland. We did find some interesting places however, and luckily found a car park in the middle of town, which was as it turned out quite convenient seeing as though Quebec to a Haemophilic with a dodgy knee was a cross between San Francisco and Mount killamanjaro (yes it was very hilly).

We must have been down every street ally road lane and anywhere else you could think of, but it's a beautiful city and well worth it. By the time we got back to the car I required at least one knee replacement, 2 ankle joints and a bottle of neat oxygen, and don't ask me why, but I suggested going further on to see the water fall rumoured to be 30 meters higher than Niagara.

I was taken up on the suggestion (aghhh), we hit the interstate once again, luckily by this time one of the navigators sitting behind had sussed out that you don't cross the red traffic lights....many thanks that's obviously were I have been going wrong all these years!!!!.

We drove for about 30 minutes (whilst I contemplated how long a UK citizen would get for manslaughter of one of his passengers, and how deep the St Lawrence was) when we reached the falls. They were impressive, with a cable car climbing the cliff face to restaurant on top. We decided to eat, probably a bad move in hindsight, there was a wedding going on at the same time, and the restaurant was basically dress for

dinner type...we hadn't.

Now we got there at about 7.30 I think, and the cable car (the only method of getting home) closed at 9.00 sharp, to say that this restaurant was not the speediest of eating establishments was at least an understatement, it got to around 8.30 and we had just been given the main course. By this time I was contemplating the trip home and wondering when my "second wind" of energy would start, (it had to be soon).

Any way I decided to leave and grab the cable car and skip the goats cheesecake, after all these goats are quick on there feet and it could have been at least another two or three hours before they were milked!!!!

All safely at the car park and the cable car now closing for the night we wandered towards the car, now when we picked it up, the very nice lady said take the RED one, well this was about as close to red as, the pope is a rabbi, still the keys fit and we've got to get home, sod it to late now anyway.

Rite everybody in "doors to manual" as they say, and we are off again, now I was honest and did mention that I wear glasses at night because I have poor night vision, this was greeted with laughter from the rest of the explorers, well I warned them.

Headlights on, in fact all the lights I could find to switch on (every little helps), we set of back on to the interstate towards Quebec.... into Quebec.... out of Quebec. around Quebec....you get the picture, yes the navigators were in fine harmony telling me this time on a six lane carriageway (and I am in the sixth lane), yes this is the junction coming up, yep there it goes, now I did suggest that although the vehicle we were in did have approximately 12 airbags I thought it was prudent not to use them just because they were fitted (perhaps that's just me, I am old fashioned).

After seeing Quebec and the surrounding wilderness several times on the way home

The interstate for about 2 hours, when I herd a noise, now this is were I have to be very careful because it's not like me to offend!!!! But the noise turned out to be one of our navigators snoring. Now it was suggested to me that we did an emergency stop, but people who know me, and know that I am a kind humanitarian wouldn't do such a thing, and anyway this person had there seat belt on so it would have been a waste of time.

Now I don't know what time it was when we reached Montreal, I think it was about 2.00am or something...and by this time I wanted something to eat. I had my second wind, and I was now on a mission....it was to hunt for junk food, it was easy really, we swerved into the "golden arches" restaurant, (I was told this description of McDonalds by a fellow passenger and found it amusing, thanks E.R) were I pulled up at the microphone and tried to order, for some reason we all started crying with laughter, which I think somewhat annoyed the attendant, especially when I told him I didn't want the drink that comes free with the meal.

Well we are off on the final leg, I've eaten and full of energy

From day one we have had a 'tempestuous' relationship as Paul likes to put it. We did however hit crisis point around Christmas and had to really decide whether to work at it or call it a day. Well, here we are....very happy most of the time, and a great little family unit. We have learned to laugh at our differences and most importantly to walk away.

Anyway, back to the weekend, so therefore thinking I'd resolved most issues, come to terms with almost everything, I arrived in Coventry.

Wow!...I thought...nice hotel!

We, the eight partners who attended were given a run down of the proposed agenda for the weekend and introduced to all the 'professionals' present and the facilitator, Fran.

At this very early point I was surprised to find myself feeling anger....about how the whole situation with HIV and hepe, etc had occurred ...and feeling this anger directed to those 'professionals' present.

So, we all introduced ourselves and had to say what if any were our reservations over the weekend. Well, I decided to say how I felt and that whereas I wouldn't physically attack anyone, they could be inline for some 'constructive' criticism....ha!

What pleased me the most was that I could see the other partners nodding in agreement when I said how angry I felt about everything and how let down we all had been by the system, including the Trust, the Society and the medical profession.

All that off my chest, I felt much better....

Lots of issues did indeed come up in discussion groups, such as lack of information/honesty from healthcare professionals. This was quite a 'biggy' for most of us and due to an 'oversight' on the part of the facilitators inviting three members of one partners health authority, we kicked them out for that discussion.!

We said how we were sick of being lied to and treated by many as if we were idiots with no understanding of our partner's health issues. All of us shared at least one story of a bad experience with such professionals, there were also a few positive stories but unfortunately they were thinner on the ground!

Isolation was a huge issue for nearly all, as most families affected by hiv seem to live double lives with few if any others knowing the situation outside of their immediate relations. For myself, this is not an issue but it deeply saddened me to see the problems such couples/families face, such as having to invent cover stories for illness and hospital appointments,etc. More importantly though is the fact that such people often have no-one to talk to or share things with.

The group of us decided that we would all like to keep in touch for this reason....even for those of us who don't lead a double life it was such a relief to meet others who know what its all about and share many of the same worries, fears,etc. We also decided that we wanted to have a voice! As partners we often feel that our needs are overlooked. For example, we do not get 'our own' allowance from the trust. Many of us are stuck in the benefits trap and cant afford to go back to work, even part-time. We get a grant for a taster session of alternative therapies, but then having decided that we like it and it has helped us, we can't afford to carry on with it!

(I subsequently found out on my return to Walsall that we do indeed have representation on the Partnership Group from three partners! For some reason, this wasn't mentioned, but the more of us the better!)

Needless to say this became a very emotional discussion with many tears and tissues.

Another discussion took place about 'preparing for death'. I didn't attend this one so cant really say much about it other than those present said it was very good covering many of the practical issues such as, wills, property,etc that are sometimes difficult to discuss objectively at home.

As a group of strangers(mostly), we all got on really well. I don't think that there was anybody that didn't gel. There was a wonderful atmosphere of warmth and support which was probably the best thing about the whole weekend. The opportunity to discuss and share so many feelings that are for the main part kept bottled up whilst at home so as not to upset our partners or give the game away to others was the best medicine we could have been given.

I don't think we all realised how stressed we were or how much pressure we are at times living under until we had this chance to let it all out.

I know that for myself, I didn't expect to cry or feel so emotional so much of the time. It was an unexpected reaction, and my god...did I ever need it! All that combined with the alternative therapies we had, aromatherapy and spiritual/reiki healing left me feeling very physically relaxed but so emotionally drained that I could have spent at least the next two days asleep!

Fran and Babs were great fun to be around and I have to say....nice people, despite who they work for!

The other professionals present were also very affable.

The only criticism I have about the hotel was that the food was bloody awful!!! I'll never eat fish again!

I do not feel that I have covered even half of what happened, but before I sign off I would like to appeal to other partners out there to try and attend the next one. If the only thing you take from it is the knowledge that you are no longer alone then it's worth it!

So, having got much off my chest, made some friends and recharged my batteries I went home. As great as the weekend was in many ways it was wonderful to see my son and the man I love....even though I had only been away for such a short time. How sad am I?

AN OTHER PARTNER

DISCLAIMER

The views expressed in each of the articles are those of the individual authors, and not necessarily those of the Birchgrove Group.

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FACTOR VIII

TO USE IT OR NOT, THAT IS THE QUESTION

Over the last year or so I have been meeting many people with haemophilia and HIV/HCV, discussing shared challenges and problems. Whilst this has been of much benefit to me I have found one aspect of our lives that is very different. I was surprised that most of the guys (and they all are) that I chat to have taken the decision to use as little blood clotting treatment as possible. I say surprised because I use factor on a prophylactic basis and made the assumption that many other people did the same. Although I don't stick a needle in my veins for fun I am determined to never again experience the pain and frustration that comes with a bleed. Therefore I inject myself every other day in order to live a bleed free life. I would like to state at this point that I recognise each individual's choice around their treatment options and am not saying my way is right and others wrong, it just interests me.

Ironically I was just coming to terms with haemophilia when I was diagnosed HIV+ at 29 years of age. Yes it took me a long time and it was a struggle but I had finally realised that I did not have to put up with the pain of a bleed and had begun to treat myself and talk to other people about my condition. I used to live with bleeds as I had done all through my childhood and refused to use factor until it was too late and the pain had begun. Learning to treat myself on a prophylactic basis took most of that pain and uncertainty away and I probably went too far the other way, treating myself more than I needed to, it became almost an addiction.

When I was told I had tested positive for HIV I don't remember treating myself less although that doesn't mean I didn't worry about what was in the syringes at the time, I did. With the lack of knowledge and support from my centre at that time I just assumed it was too late to do anything, the bad blood had got into me and what harm could I do to myself now. The centre staff stuck to the mantra of the benefits outweighing the possible dangers, no mention of HCV of course, they just let history repeat itself. I do remember being given heat-treated product when it became available and feeling relieved as I assumed this was totally safe. Well I say assumed, I was told it was. And now I am battling to get recombinant factor as everyone says it is better. If you look at the issues closely though recombinant still uses human cells or it would not work properly. So, what's the difference? A new recombinant product is due out soon so those of you fighting for this product beware when you get it; it could well be the old one that nobody wants!

As I said earlier many of the men I talk to have made the decision not to treat themselves for many reasons. They reason that their livers have to put up with enough abuse already from the anti HIV/HCV combinations and I can understand that. Also the risk of further infection with varying strains of HIV and CJD are constant worries although our Doctors say its safe to use nowadays. Well, will we ever believe them again? It is not very nice injecting yourself with crap as we all know and it is a constant reminder of what has happened and may happen in the future, I wonder what it is like for those of you with inhibitors, if I think I use a lot of factor Christ knows how you all feel.

I know that my centres policy with newly diagnosed children is to encourage treatment and most parents accept this, I sincerely hope that kids born with haemophilia don't have to go through the pain I experienced as a child but wonder if those parents would still want their children treated with factor if they had half an hours chat with one of us. Some women carriers still have terminations if a scan shows they are pregnant with a male child. How does that make you feel? So, I would be interested in other peoples feelings about this, how often do you use factor, how safe do you feel about your product, do you still get bleeds, is recombinant the saviour, write in and let me know.

In closing I would like to say that although I still stick that needle in me I feel weird every time I do it, and always wonder what they will find in me next.

Please send all comments to

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Partnership Meeting

Thursday 10th Aug 2008

Being very new to actually meeting face to face with the MFT, as for so many yrs you only had access to anyone via the phone, my excitement at the prospect of actually being able to have a proper voice for the first time was initially exciting. This excitement didn't last. It was as if the ghost of John Williams still pervaded over all, a favourite line he frequently spouted "If registrants find out about something they can claim for they will claim regardless of need" Peter Stevens is without doubt a very well educated man although I'm unsure as to who's best interests he has in mind.

Mr Stevens was granted a meeting with Lord Hunt to explain the MFT was going to have to spend more money quicker in the very near future, Lord Hunt was concerned that this may cause problems although he would look into providing the money. WHY oh WHY is Lord Hunt so overly concerned that registrants are asking for some form of help from the MFT when there maybe a local authority, or even another charity we could seek assistance from first?. Should we really have to do this I wonder. Approaching the MFT even now is hard enough without the thought of having to go elsewhere. Wont some one please protect our anonymity from organisations we shouldn't need to contact and disclose our status, thus saving any unneeded stress and worry, PLEASE

Each and every registrants circumstances are going to be different, we are after all individuals with many and varied changing needs. If Lord Hunt feels the Govt dept hasn't kept a closer eye on the way the MFT has spent monies, so much so he is thinking of putting in a civil servant to look into this as soon as possible.

Perhaps Lord Hunt feels we shouldn't still be here, let alone asking or even pleading for our voice and needs to be met. I'm sure more registrant would gladly meet with the MFT Trustee's to talk given an opportunity. So many issues are being discussed, sadly to hear Peter Stevens comment upon how we need to streamline the amount of registrants for further meetings due to the expense was disappointing. The lights maybe on at the MFT, but is anyone really paying any attention, or are they just working hand in glove with Govt Dept's to cut back as much as they can. Thus making life more complicated and frustrating than actually needs be.

WHEN OPTIONS RUN OUT

Last Chance Saloon

After a drugs holiday of some months, The experts, The doctors, The one's who hold the key, it's time to start another regime. your getting weak and ill. Seems quite strange this, as I've had AIDS for over 7 years and HIV+ for what seems like a lifetime. This where the fun starts, What drugs, how many times a day, what are the side affects, do we eat now, after, before, during, or what. Lets call a multi disciplinary meeting we could invite the dietitian and pharmacist and really discuss the shit that comes with combination therapy. Oh and we can have a tasting session first. Great another day a the great UHW Haemophilia Unit, but sounds interesting never been to a drug sampling session before, plenty of wine, whisky, beer tasting events bet never one to see if I will like what's going to save my life. " or not "

After many discussions and a reluctance on my part I decide on a last chance combination, I won't go into names and doses of drugs as some of you might be offered this down the line and I believe everyone reacts differently to drugs and I would not want to put you off talking something by writing about my experience. All I will say is, boy it was a shit full of various big ones, little ones, ones that make cry, and one I've called Lucy because of stories, I've heard about side affects. Offered a week at A7 penthouse suite UHW bed and breakfast, Hospital to start new regime, this would enable closer monitoring and help with the initial weeks of side effects. I agree, drugs are ordered, Ones in liquid form taste like something from an elephants backside and not sure if I can take these over a period of time, but anything for a laugh, big mistake. Taste just lingers for about five hours and sickness is horrendous.

Dates set, bed booked, spent hours and days keeping mentally prepared to start this new all singing all dancing combination, when it's cancelled for a week, You will not believe the problems this caused me, having prepared, my life and that of work and family members for my week in hospital and it's all put on hold, I was close to telling the hospital to stuff their treatment up the same elephants backside " think about it " But agree to wait, reason for delay not important, but made sense to someone. So on a bank holiday Monday book in to my suite ready to start my cocktail at 8.00am Tuesday morning, but what happens drugs not on ward, first cockup and it's only the first dose. So much for they must be taken on time and you must adhere or they won't work and the hospital can't even deliver on time, British Rail or what !

Oh shit, perhaps I should outline the history and how this last option came about. Those of you who know me or who might have been at the conference in Bath 1993 will remember I was not at my best and many thought Oh well that's the last we will see of him ! After driving home from weekend I was rushed into hospital with PCP and started treatment for this and my first combination therapy, reluctantly. Since that time I've tried and become resistant to all

current class of Anti-HIV drug combinations, dealing with rejection and side effects of numerous different regimes only to be told they had failed. The effects on owns mind / pressures failures bring not just for you but for every one around mood swings, anger, death, what happened now, how long do I have, but I've been through this before and I'm still here. All this became to much and for my wellbeing and after nearly 7 years, of hell I decided to have a drugs holiday, which brings me quickly back to the present. The side effects and complications during this time were horrendous with the shits, constipation, itching, bleeding, stomach cramps, stones in kidneys, peeing claret red blood, losing white cell and needing to take another cocktail of drugs just to deal with the problems of supposedly being made better

(load of crap that one I was always better before and after starting and stopping drug treatments) only to be told on every occasion that the drugs don't work. Lets try a different lot. By this time I was living out of sets of different size clothes due to weight loss and gains which happens rapidly, and I found myself with what I called three different sets of clothes, My well set, My Oh shit I'm losing weight set, and my death set. funny I know but this was a fact of life. I even had a room at home called the death room which some people found really hard to deal with. But still fighting and have now changed death room into treatment room, and thats another story.

Also noone told my about the enormous amount of extra money that would be needed during these periods, Your use of toilets rolls increase six fold, your clothes are ruined by blood and steroid creams, sheets and bedding needs to be washed daily and replaced weekly due to excessive bleeding, would you take the risk of asking your partner to sleep on blood infected sheets and bedding. Your food and diet and the times you can eat are all thrown into disarray and family life just come to an end. Your ability to cope with day to day problems is gone your mood swings and tolerance of others is taken away. You take out your anger on those you love, you become a recluse because vanity stops you living a open and honest life, people look and stay and your conscious of spots and scabs all over your body, your next door neighbours child of 7 asks if you have chicken pox, The pox yes that how it feels but I don't think chickens has anything to do with it.

Lets get back to day one, drugs arrive at about 11.00am and first doses taken straight away sickness and the taste of liquids make everything feel like iron your tastebuds are gone and this last for about 4 hrs. So the first dose done, sit and contemplate the next round of drugs and wonder when, if, how, will this regime effect my quality of life. Try to eat some hospital food but that another story. This goes on for 8 weeks and what the F... happens I fail this regime. So no options until the mad scientist come up with new class of drugs.

INSIDE THE CLOSED SHOP

Partners weekend

I recently took part in a Partners weekend promoted by the Macfarlane Trust. It wasn't an easy thing to do, especially as the introductory letters advertising the weekend were only sent out to married partners! Fortunately, through my partner's contacts I did hear about it and the MFT consequently followed with letters to ALL partners irrespective of their marital status!!

I was surprised to discover that only 9 partners had subscribed. Why was that? Did you know about it? Were you not grabbed by the way it was promoted? Do you not feel like 'talking about things'? Would it all be too 'touchy feely' and emotional?

Had you been there, done that?

Some of these thoughts I had but I had not talked about HIV and how it affects my life with very many people for a long time. With all things considered I decided to go for it.

"I must be mad," I thought as I headed off down the motorway straight after work on this particular Friday. "I am spending my first weekend off in ages with a load of strangers!"

What kept me going was the flip side to all this. I knew I was about to meet some people who had at least one thing in common - Our partners all lived with Haemophilia, HIV and/or Hepatitis C and all our lives were affected by that fact.

I hoped that something good would come out of this.

I was fortunate to meet people who could empathise with my feelings and who experienced similar problems with coping as I do sometimes. I also met people who dealt with things very differently. I received lots of positive support and felt a release of tension as I was able to discuss for the first time in public issues such as: HIV, night sweats, combination therapy, telling friends (or not), isolation, families, having children (or not), safe sex, the list was endless and this was just the first evening at dinner.

Representatives were there from the MFT, Haemophilia Society, Newcastle Haemophilia Centre and St Thomas' Hospital. They made us feel at ease and helped the conversation flow

(This process was also admittedly helped by the complimentary wine).

During the weekend various sessions were held where we would be able to discuss, share and explore various factors affecting our lives.

Some of the sessions were pretty heavy and I cried, as did others - but it was a safe environment to do so. Most of the sessions were facilitated well and lots of support was available. I also learned a lot about treatments and felt very much more informed about lots of issues.

We also had the chance to discuss financial matters confidentially with the MFT's financial advisor, Susan Daniels - this I found extremely useful and she was able to advise me with all my financial queries from pensions to mortgages. Susan is available to registrants and partners and will advise you on an individual basis. You do need to get authorisation from the MFT first.

We all received free complimentary therapies on the Saturday. We commented on how happy, revived and relaxed we all looked when we came out of the treatment rooms following our sessions. We were also able to use the hotel's leisure facilities for free. These included a swimming pool, Jacuzzi and sauna. There was also a well-equipped gym for our use.

That evening the wine flowed again and we chatted all evening. I realised that I was relaxed and felt like I was with a group of old friends. I was very glad to have attended.

We looked to the future on the Sunday morning and we had the opportunity to put forward recommendations to the organisations involved. MORE OF THESE EVENTS! Was on the top of the list.

The weekend was such a positive experience for me. I now feel less isolated, more informed and more supported. I also feel like I can contact individuals from the MFT and Haemophilia Society with much more confidence now that I have spent a weekend getting to know them. I also came away with a list of e-mail addresses from the other partners. It is a less obtrusive way to contact someone. I have been in touch with a couple of people since - it feels good but it is not interfering with my day-to-day life. There is also talk of partners meeting up without the attendance of professionals. I shall definitely be there.

A PARTNER

PARTNER'S WEEKEND (2ND ARTICLE)

I was quite excited at the prospect of going on the Partner's weekend. Hee hee, I thought...another excuse to go away for the weekend! This is not meant as a slight against my son or Paul, but I just love going to places on my own. It's a different experience and you can really just be yourself without wearing the mantle of wife, mother or carer.

This particular weekend would not be quite the same however, as by it's nature I was going as a partner.(why do I keep hearing the music to the twilight zone?)

No problem I thought to myself, I can handle this! Before I continue, a brief history is needed I think.

Paul and I have only been together just under two years. I moved very quickly to be with him, bringing with me my son Aaron, who was twelve at the time and my cat...oops..and all my worldly goods of course.

DUE SOUTH CONT

again, so lets go (I'm still wondering about the "red car" situation) we drive past the Olympic stadium, only twice I think, then down some familiar looking streets, not that that's a good thing after all they could be familiar for the wrong reason, oh well the wheels are turning and we are off again, when there is a voice from the back, someone is stirring, they are awake !!!! I have another flight plan passed to me, we stop for petrol, and not a bad idea I suppose we are nearly empty. I pull the limo up at the pumps and ponder whether its like the good old USA were you pay first, well that and rigger-mortis had firmly set in so getting out was a bit of a struggle.

Now this is when I was suddenly thrust into the "wide awake club" as one of the navigators who by now was wide awake had grabbed the petrol pump in their hand, was opening the flap with the right and whilst stuffing the petrol pump nozzle up my nostril with the left, fingers poised on the trigger...a scary moment for someone who smokes I tell you, needless to say the other members of the crew had wound the windows up and were involved in nothing less than hysterics...at this stage the thought of manslaughter came flooding back..(Would it be worth it?? YES).

We managed to refuel without leaving a small crater in the Montreal suburbs and we were of on our final leg, the crew still tittering in the car.

If any one has ever seen "Mrs Bucket" telling her husband not to hit that women...yes you guessed it, the women going in that shop 500 yards up the road, well this is what was happening to me, now I like to think I kept my cool, I think I did, I just kept convincing myself that they still had the death penalty for murder over here, especially for tourists.

You may by now be fairly bored of this story; well bare with it the hotel is not far off.

We hit the main street of downtown Montreal, its most definitely a party city, and unusually safe too, god knows what time it was, it was very late,

or quite early whichever, the streets were alive, traffic jams night clubs roadside bars and cafes, the atmosphere is quite overwhelming really, anyway I am drifting of the subject, the hotel is on the right....yep there it was, this time my mistake, I reverse up to the entrance, and pull in to the budget car park, yes you guessed it I park next to the RED hire car, oops, well no one said any thing.

We all disembark, Gareth by this time is fumbling for the mini bar key (bloody good idea), we all fall silently into the lift which takes us to the hotel foyer, we then get separate lifts to our rooms (a complicated system).

We hit the minibar with a vengeance, as what can only be described as the first rays of the morning come through the curtains. We sit pondering the day, or two days, or however long its been, then the phone rings, there is what can only be described as an hysterical person on the other end of it, who I think if they had laughed any more we would have required an ambulance for them. This person, who cannot be name for legal reasons (chuckle chuckle) was just polishing of a bottle of gin, which was quite obvious as you could hear it clattering against the telephone and spilling on the sheets.

Well that is it my story is at an end, this one anyway, but there are others so keep watching.

On reflection of the Canadian trip, personally I think that it was very fruitful, not only in a medical awareness sort of thing but I feel that I have made new friends within this "Global Family", I think that it can only be of benefit to all of us to use the internet or whatever is at our disposal to keep in touch with others throughout the world, it does help, and although I have bored you with what I hope is one of a few amusing stories, there was and is a serious side to what we do at Birchgrove, at the end of the day we all have to laugh sometimes don't we ?.

BIRCHGROVE CENTRAL PART ONE

Over the past year or so (it seems longer) my self and Paul (Hooper) have been trying to resurrect Birchgrove in the Midlands, it seems lately that more than ever there is a need for such organisations who can offer support and advice to those in need.

We have identified several concerns recently, one of which is something that may offend some but I know not others and that is the level of care from outside the Haemophilia centres i.e. drop in centres where other alternative treatments and counselling may be on offer. Recently I was invited to a meeting at the Birmingham Health authority, where I was astounded to meet a group of social workers that were asking me as a Haemophiliac HIV positive person what I thought of helping to set up a new group. Now this is where I may offend, but frankly "I don't give a damn"(Gone with the wind), The background on why this group is being set up is basically from the concern over HIV positive heterosexuals, yes I said heterosexuals, now there is a large number of these people living and dying in the Midlands who because of one reason or another do not, will not seek treatment and any form of proper counselling, this intern has lead to a rise in the suicide rate amongst these individuals, and for those others isolation. The meeting I attended was to seek some format to establish a positive heterosexual group, which hopefully will grow in size over the next year. Now there are several issues around this subject that you have to deal with. Firstly it will be thought that you are some form of homophobic group, but any one who says this I would ask them to contact HIV heterosexual people living in rural areas, and not somewhere like London or

Manchester before they comment.

The idea of this group is over the next few weeks to extend to the positive woman's groups in the Midlands which are also due to their history woman only groups, and who have expressed concern over why only single sex, why not mixed, indeed if both sexes suffer from HIV then why can they not talk as a mixed group, (what an amazing concept). Now there has also been identified to me (not by name before someone shouts confidentiality) that there are positive Haemophiliacs out there, a few of whom I have spoken to and who have related some quite horrific stories to me over the same types of issues that I've mentioned.

Now call me what you will, but if there is any way that we as Birchgrove Central can help set this group up and at the same time help these Haemophiliacs their partners, widows or dependents then WE WILL.

The first meeting is being held in Stourbridge on the 25th of this month if anyone is interested then drop me a line and I will give you the details. Now I have advertised this I do expect some negative feed back, but can we please remember one thing, that there are two definite sexualities, homosexuality of which yes I am fully aware has had a hard time being recognised, but the other is heterosexuality, which I am afraid if you are both heterosexual and positive is in some areas an even greater struggle.

comments to :

a.melson@birchgrovegroup.org.uk

BIRCHGROVE IS A FORUM FOR:

- The treatments of haemophilia and HIV
- Taking care of ourselves, through informed debate and argument
- Staying healthy with Haemophilia HIV & AIDS and HEP C
- Ways in which HIV affects love and sexuality
- The social and psychological aspects of haemophilia and HIV

PEOPLE WITH HAEMOPHILIA AND HIV

- Can be empowered and enabled to deal with HIV/AIDS through relevant information and mutual support.
- Can improve their health and extend their lives by expressing feelings and confronting the issues directly
- Should be heard and have their needs recognised and not suffer in fear and isolation
- Have a role in the work of the HIV/AIDS community to inform and challenge the ignorance that exists about HIV

Her Royal Highness

Queen Elizabeth II

Buckingham Palace

London

SW1 1AA

14. August 00

Your Royal Highness.

I feel there is a matter which should be commented on by yourself as head of state.

This involves not only myself but a forgotten community of which your family were apart, I talk of course about the Haemophilia community of this country.

As you are no doubt aware over the past twenty or so years a large number of us within this community have become infected with not only the HIV virus but also Hepatitis C, both of which has been passed to us by contaminated blood products.

I do not have to quote letters from your own family in recent history to tell you what Haemophilia means in itself to the sufferer and the immediate family.

A number of years ago over 1200 Haemophiliacs were infected with HIV, there are at present only 412 of that group left, of which I am one, but we have now all but a few been re-infected with Hepatitis C which means that having a combination of the two viruses leaves us with little or no treatment options.

We have many times approached your Government to seek a public enquiry but with no avail, all we ask is for the evidence to be heard and that the mistakes of the past do not happen in the future.

We have also been told that the enquiry and police action taken in Canada recently was authorised by, and I quote, "Queen Elizabeth II Head of State", if this is true then why can this not happen in this country, we are after all still your subjects and although The House of Windsor may now be free from Haemophilia please consider for one moment if it was not, if for example your grandson was a sufferer how would this make you feel when you know that the life giving treatment given to him has actually shortened his life drastically.

We have as a community embarked on a long struggle over these remaining years for the truth to be heard, I like many have had my chance to be a father and carry on a career taken away from me, we all now live in near isolation thanks to the way we have been treated.

As time goes on there are fewer and fewer of us, but we will make sure that the denial of the past will not be re-enacted in the future, but we do need help, and we need someone such as yourself to recognise the wrong that has

been done.

With the evidence that has now been lodged with our legal representation it is quite obvious what happened in the past, and it will sooner or later be made more public than it already is.

What I am asking is that lessons from other countries be learned and I quote Canada because of its ties to our own United Kingdom, but the same events are actually taking place now in Southern Ireland. There should not be a need to put extremely sick and dying people through a long and traumatic court case when the conclusion is an obvious one.

I am writing this letter to you as our Head of State and as our Sovereign and hope that you may feel either as a member of a family which suffered from Haemophilia in the past, or indeed as our Queen and mother of her own family, that you may be able to pass comment in some way on this subject.

Many thanks for your time and I look forward to a response.

Yours Sincerely

A Melson

Mr Adrian Melson

British Subject

(Ed)

Come on all you people out there lets get similar letters sent too all members of parliament and even as our friend Adrian Melson has done send HRH(Haemophilia Related Highness) a letter aswell.

We are making people look over their shoulders and many MP's and members of organisations who covered up this scandal need to take stock and come clean before we cite them in legal cases that are just around the corner.

We at Birchgrove would like to congratulate all our friends in the North for the articles and personal stories that we have all had the pleasure of reading over the past week.

Hopefully it will kick off in Wales soon with similar bits going into local press as we try and finish this newsletter update.

Oh shit I'm sat here trying to fill this space I'm tired, Married, have two children, It's raining and Melson and hooper are sat on their Arsses and drinking my Lager. If they start to smoke my fags I will kill them. and thats another story.

Gareth Lewis