



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.