A STROKE SURVIVOR’S PERSPECTIVE OF BRAINSTEM CAVERNOMA BLEEDS
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In Feb 2008 I was married 17 years to my wife Madeleine with whom we had two boys, Gavin and Killian, then aged 12 and 10 respectively. I was 44 years of age and was the Chief Medical Scientist at the National Histocompatibility & Immunogenetics Reference Laboratory (NHIRL), Irish Blood Transfusion Service (IBTS) for over 10 years. I was chairperson of the European Federation for Immunogenetics (EFI) Quality Assurance Committee, a member of the EFI Standards Committee, a recent appointment to the EFI Board and an active EFI laboratory inspector. In 2006 I had completed my doctorate in Multiple Sclerosis genetic susceptibility, disease predispositions and HLA gene frequencies in the Irish population. I had several papers published in scientific journals so was familiar with writing up findings. I was relatively fit exercising once a week in the local gym and pool, mentored and coached a juvenile team several days per week and relished outdoor activities. By the end of April 08 (6 weeks later, following my third bleed) I was struggling for survival on a ventilator in Beaumont ICU, Dublin, Ireland. Professionals have encouraged me to put pen to paper as a means of coming to terms with past demons. Publication was suggested but the objective was to freely help others in a similar predicament.

Prior to my first bleed I was fit and apparently healthy having no medical history of note. I appeared like many companions of the Celtic Tiger generation to be living life in the fast lane. My general ethos was "work hard, play hard". I naively felt invincible. On 27/2/08 it was confirmed that I had a mild stroke. The decisive symptom was a temporary weakness/jelly like feeling in my right leg before the All Ireland club semi final throw in at Navan. My leg movements felt deliberate almost jerky as if the continuity of mind and body had become disrupted. My gait was unstable. I vividly remember the horrifying feeling of standing at the top steps of an almost full stand and realising that I would definitely fall over if I attempted to walk down the steps towards the vacant seats at the very bottom of the stand. I immediately grabbed my brother’s arm to ensure that I would not miss history unfold! My club, St Vincents won in style so the onset of my illness was relegated in priority. I had experienced a
pre/mini stroke (also referred to as TIA - Transient Ischaemic Accident) but although concerned chose not to dwell on it. I even travelled to Bristol the following day to conduct a laboratory accreditation inspection on behalf of the European Federation for Immunogenetics (EFI). I didn’t feel well during my 2 night stay and while my balance buckled on the hotel stairs I assured my fellow inspector, who had travelled from Bulgaria, that my cognition was sufficient to continue. When I got back to Dublin on Wednesday I fulfilled my pre arranged afternoon appointment with my new GP Dr Morrison. Previous to this I had attended several specialists and my original GP with numbness of the right hand, minor but recurring right facial palsy and double vision. Surprisingly, nobody suggested a MRI. Low tolerance of loud music, hoovering and playground spinners in my early years suggest childhood arrival. A progressive reduction in hearing was blamed on premature ageing.

However the symptoms were not linked until Dr Morrison referred me on evening of the 27th to the Mater hospital where my mild stroke was diagnosed by MRI. The stroke was primarily characterised by hemiparesis - weakening/slight paralysis of both limbs on my right hand side. At least I had got my wish. As I waited in A&E I had given myself one of three possibilities. Both, Multiple Sclerosis or a brain tumour had an unenviable prognosis. The scan showed the presence of a ponto/medullary cavernoma (Cerebral Cavernous Malformation - CCM or cavernoma for short) in the critical, lower brainstem. I knew nothing of cavernomas but the location wasn’t ideal. The attending physician observed, with a Scottish grin, that I had been very fortunate. He informed me that had the bleed been another 2 mm lower I would have ended up in a coma. I never really considered how fortunate I had been but instead focussed my attention on resuming where I’d left off. My optimistic predisposition ensured that it didn't feel like I had just experienced a major neurological malfunction that was life threatening.

A stroke is essentially a disturbance in the blood supply to the brain with an associated loss of neurological/brain function. Strokes are also known as cardiovascular accidents (CVA). Although the brain only accounts for 3% (1.5kg) of body weight its oxygen consumption is 20%. Ischaemic strokes are those caused by an interruption of the blood supply by a clot while haemorrhagic strokes are less common (17%) and result from the rupture of a blood vessel or
vascular abnormality (mine). Stroke is the third leading cause of death in the western world. Roughly 10,000 people have strokes in Ireland each year. One in five people have a stroke at some stage in their life. Approximately 30,000 people live with significant difficulty after stroke. Approximately one third of stroke victims die, a third end up in nursing homes and the remaining third improve although disabilities remain. Of those who have haemorrhagic strokes between 40 – 80% will die in the first month. This is because haemorrhages invariably happen at short notice with dramatic consequences. Those who suffer from brainstem strokes have an even worse prognosis. Although brainstem strokes only account for 10% of strokes 65% of victims do not survive. Those that do live invariably survive with a broad spectrum of physical disability, sensory loss, cognitive impairment, behavioural and/or emotional issues. I was extremely fortunate to survive and retain my cognitive faculties. However, it doesn’t always feel that way.

I stayed in the acute stroke unit under the thorough care of Dr O’Rourke and slowly recovered sufficient strength in my right limbs to leave after 10 days rest. During this stay I was referred to the only Neurosurgical hospital in Dublin, at Beaumont, for a cerebral angiogram. This allowed the clinicians to diagnostically eliminate other cerebral vascular malformations as the cause and to confirm their diagnosis as an angiographically occult (not visible because blood flow is low) cavernoma. In Beaumont I was informed by the radiologist in attendance that I had a <5% chance of re bleeding. That sounded fine to me at the time. The scary possibility of a full blown stroke was never mentioned by anyone. I now know that recent research has shown that brainstem cavernomas have a particularly high risk of re bleeding, approximately 18 - 21% per annum (London Symposium 2009), for those patients with a history of recurrent bleeds. Other studies suggest a considerably higher risk. If I knew then, what I know now, I would have immediately requested surgical removal (resection) of the cavernoma. Referral to Sheffield for stereotactic gamma radiation was mentioned but in retrospect I am very glad not to have chosen this option as it is at best controversial for treating brainstem cavernomas. The only legacy from the angiogram was bruising and a sore limp for about one week arising from the injection into the groin. From my bed it was possible to see our largest sporting stadium, Croke Park, where my club would contest the All Ireland final on the 17th March 2008. This huge stadium and the impending date provided
daily motivation for a speedy recovery. For the most part I rested in bed, sneaking a few small bottles of wine to enhance my sleep! I steadily improved and was let home after 10 days. In the final the senior club team gave an inspirational performance, displaying enormous fortitude, to hold out for a narrow but deserved one point victory. I savoured and celebrated our great victory on St Patrick’s Day and vowed to myself that I needed to rest as much as possible and to chill out. Madeleine and I took up yoga and Tai Chi.

Despite my poor knowledge of brainstem cavernomas I didn't overexert myself inquiring about my recent illness. I was naively confident that I had seen the last of it. I had been relatively fortunate in life and empathised with Gary Player's motto "the more I practice the luckier I get". I soon discovered that the brainstem is the critical region which connects the brain to the spinal cord. It includes a number of structures including the mid brain, pons and medulla. The brainstem is clinically regarded as a highly eloquent area and the "highest price real estate" in the brain. I was diagnosed with a ponto / medullary cavernoma which essentially borders these two parts of the brainstem. These structures are responsible for some of the most primitive life functions. Hence even the smallest haemorrhagic events can cause significant neurological deficits. Cavernomas in the brainstem present particular problems for both the affected patient as well as the neurosurgeon. Tightly packed nuclei inhabit the narrow confines of the brainstem. Blood leaks can therefore compress or crush important nerve fibres. The smallest of intrusions can result in significant and life threatening symptoms. The nerves that transverse the brainstem control basic involuntary functions such as gag reflex, body temperature, respiration, alertness, digestion, blood pressure, sleep, heartbeat regulation and pain regulation. In addition the brainstem regulates voluntary functions including eye movement, swallowing, facial muscle control, walking and speech. The brainstem also consists of the 10 of the 12 cranial nerves. Both cranial (cranial nerve 7 controls facial muscle expression and cranial nerve 8 regulates hearing and balance) and long tract (whole body) nerves can also be affected. For the patient, brainstem cavernomas may manifest in a wide variety of symptoms making diagnosis difficult. Brainstem strokes are considered by medical personnel to be a catastrophic event even though cognitive functions, which are located above, are sometimes spared. In retrospect, I now realise that the
brainstem cavernoma was increasingly interfering with my daily life for quite some time prior to becoming symptomatic ie. bleeding.

I googled the net and browsed the Cavernoma Alliance UK website and sister organisation in the USA - Angioma Alliance to find very helpful information for those recently diagnosed with cavernoma(s). Ian Stuart does a superb job coordinating the UK based website and he has been enormously helpful to me since my initial diagnosis. Ian put me in touch with Robert, who works in Dublin. Robert and his wife Caitriona (personal experience) remain wonderful, Irish based "advisors", for those plunged into the dark, unknown world of symptomatic cavernomas. Cavernomas are clusters of abnormal blood vessels (usually capillaries in the brain), which have a raspberry like appearance. They are made of multiple little bubbles (caverns) which are filled with blood and lined by fragile endothelial cells which are prone to leak. Cavernomas can present as seizures, headaches and/or neurological symptoms (I developed the latter). They occur in (prevalence) approximately 1 in 100-200 people. Approximately 30% of those with cavernomas go on to develop symptoms (haemorrhage, migraine, neurological deficits, headaches, seizure etc), usually in their 20s and 30s. Strokes (to my surprise) are a very rare symptom. Fortunately in Ireland recurring bleeds of brainstem cavernomas are rare (0 to 1 case/year) as the symptoms are often devastating. I should know. A search of the Beaumont physio records showed that I was the only symptomatic cavernoma patient on their files. This was requested as it was my intention (naively) to contact other Irish cavernoma patients. A recent study in Scotland has found that, each year, one person out of every 400,000 is diagnosed with a symptomatic cavernoma for the first time in their life. While incidental MRI studies suggest cavernomas are even more common patients with severe symptoms are very rare. I suspect that cavernomas are under diagnosed given the unavailability of specialised MRIs and expertise in Ireland. Cavernomas range in size from 0.25 to 4 inches. Mine (solitary) was approximately 1 inch in size which must have caused considerable traffic congestion in an eloquent area (brainstem) the width of a golf ball.

Cavernomas can bleed in a number of different ways. Initially they may bleed slowly within the walls of the lesion. A small haemorrhage is often reabsorbed by the body. Cavernomas may then bleed more profusely within the walls of the
lesion causing them to increase in size and put pressure on the surrounding brain tissue. Finally the cavernoma may bleed through a weak spot in the vessel wall into the surrounding brain tissue causing an overt haemorrhage. It is likely that my cavernoma travelled a similar journey until it was resected. The presence of blood products (such as haemosiderin deposits) on the MRI can provide evidence of recent bleeds. It is important to note that a ponto / medullary cavernoma can be life threatening as the brainstem is responsible for regulating the critical life processes including breathing and heartbeat.

Unfortunately, approximately 6 weeks later on 14th April 2008 I bled coming out of the shower. I suspected this was likely to happen in the days beforehand as I had started to deteriorate and develop weak, neurological stroke like symptoms during an anniversary break in the Roganstown Country Club. In fact I had rung the Mater hospital from the hotel to expect me in again within a week. I tried not to allow the impending destiny to affect my generally positive demeanour. On the following Sunday morning, as increasingly expected, my right leg buckled as I exited the shower. I vomited heavily. I became instantly aware that I was in grave danger. My brother Fergus literally arrived in the house following a shopping trip to New York. He got a lot more than he had bargained for. My eldest son Gavin stood in our bedroom, wearing his club top, as I was helped by the paramedics. I can’t imagine what must have been going through his mind. I remember grabbing his club crest as I was escorted from the room. The club motto is "ferro commitante" which literally translates as iron resolve. How little then, did I realise, that I would need it in the days and months which lay ahead.

I was again brought by ambulance to the Mater but had to wait almost 30 hours in A&E on a chair before being referred to a bed in the acute stroke unit. My experience of a Sunday in a city centre A&E was anything but pleasant. The progressive deterioration of my health seemed irrelevant. The positive CT (CAT scan) confirmed the presence of a fresh bleed in my brainstem. I knew I was in big trouble and requested that I be transferred as soon as possible to the neurosurgery department in Beaumont hospital. The feeling of utter desperation as the life was slowly sucked out of me will last forever. I lay helpless on the hospital bed, surrounded by incredulous friends, as the stroke gathered momentum, slowly but progressively weakening my right limbs and
removing my ability to speak and communicate with those close to me. My right leg and arm felt completely depleted of their intrinsic strength. I had the unfortunate experience of having endured the live, step by step deterioration, of my intricate neurological circuitry. After, what seemed like an eternity, I was eventually transferred to Beaumont Hospital. However I wasn’t long in the high dependency unit (HDU) when I bled again, badly, rendering me completely unconscious. The last thing I remember was very severe coughing as I struggled to breathe. A full blown brainstem stroke ensued. The stroke which originated in the brainstem damaged the left hemisphere and caused hemiparesis of my right side (partial paralysis/weakness). Fortunately I was under the observation of Madeleine and the HDU Nurse Manager Pat(ricia) and was rushed a short distance to the ICU where I was immediately attended to by the ICU team and put on a ventilator to prevent cardiac arrest and subsequent respiratory failure. Needless to say I was totally unconscious for all of this. A recent study of 124 acute stroke patients requiring ventilation showed a 1 year survival rate of 33%. The short proximity of those 10 metres were life saving.

Because of my predisposition to recurring bleeding the neurosurgeon deferred the operation for a further 2.5 weeks. Anadin was a complete no no due to its anti platelet clotting activity. While I played with the grim reaper others pondered my obituary. I was heavily sedated in ICU remaining asleep or enduring very vivid and traumatic nightmares. When I came around the stroke felt like I’d been hit with a massive hammer blow to the rear of the head. I felt like I had awoken from a dull thud. The strokes caused me to lose my ability to swallow so communication with Madeleine and the kids became extremely difficult. I tried to create words by underlining the letters of the alphabet with my left hand. Double vision, inability to speak, impaired hearing, ataxia etc made this a very frustrating experience for all concerned. I naively tried to reassure them with the promise of a family holiday, later in the year, to Africa. During my stay in ICU I was consistently monitored by the Infectious Control team and was heavily sedated so my recollection of events is sketchy - my family and friends have helped here. I recall the early rises, the mandatory cold razor shaves, the wonderful vigilance and care of the ICU staff, nightly paracetemol tablets for painkilling (codeine containing medication like solpadeine is now under regulation), the daily vomiting of the lilac substitute being line fed to me, the intensity of the ward lights, regular physio visits to get me breathing on my
own again, evening nebulizers to enhance respiration, anti-nausea medication, a feeding line inserted directly into my stomach, very short visits by family and close friends, being linked to dozens of tubes and machines and the trauma of events 24/7 around me.

The feeling of sickness had reached every pore in my body with one exception, my mind. When I eventually woke up from the last haemorrhage I felt semi conscious and constantly present within my mind. The ethereal feeling was comforted by a blissful sense of grace. The most striking difference between the pre stroke era and life in ICU was this dramatic inner peace that had taken up residence within my head. As I wandered in and out of sedation I became desperate for silence and minimal sensory stimulation. Social exchange with visitors (although kept to a minimum) used up my negligible energy reserves leaving me completely drained. In my semi conscious condition time escaped me. The absence of my left hemisphere’s (damaged by strokes) analytical judgement allowed me to become embodied in the right brain feelings of euphoria and tranquillity. I genuinely feared that I could end up permanently disabled or worse. For a guy who believed in invincibility this was uneasy, to say the least.

The objective of the sedation was to make me feel mellow and calm thereby reducing the risk of further bleeds. In contrast I repeatedly experienced nightmares none of which were pleasant. I can still recall them now unlike the dreams which I have experienced before and since. However, there was one exception to this nightmare rule. I vividly recall experiencing a dream in ICU when I felt really lousy and the body barely struggled to survive. My mind told me that my body felt almost lifeless. I recall being in the Scottish highlands, soaked to the skin, my body feeling wretched. I was obliged to be in Dublin the following morning for craniotomy. My predicament felt almost impossible to achieve but I rallied myself to make it. I have no recall of the boat trip across the Irish Sea but I fondly recall the warm reception I received, from family members, after I docked in a sheltered bay, akin to Broadmeadows, Co. Dublin. I recall willing myself to this fateful journey. It felt surprising to have reached this destiny. It was to be the only time I felt elation and satisfaction in ICU. Perhaps the surreal experience mimicked reality. No one will ever know. What I do know was that when I came around I genuinely felt a huge sense of relief to be still ticking in anticipation of the surgeon’s knife.
The medical team tried unsuccessfully to encourage me to breathe without the ventilator. The three bleeds (haemorrhages) had obviously impaired the respiratory centre which is located in the medulla. As a date with surgery was due a tracheotomy was required to replace the ventilator. I have no recollection of having my windpipe severed although I do recall being apprehensive about it. Almost 3 weeks later, following admission, I was ready for surgery. I was so heavily sedated that I was oblivious to most of what lay ahead. The thought of finalising a will never entered my head. But I wasn’t apprehensive or nervous. I trusted the surgical team and realised that the future might not be much better than the predicament in which I had found myself. Being a healthcare professional I had faith in the reputation and expertise of the neurosurgeon/hospital staff. I was satisfied to trust my fate in their experienced hands. I had neither the health nor the time to research doctors abroad who specialised in brainstem cavernoma resections (very rare in Ireland). I was fully aware that I had a time bomb ticking inside my head that had to be completely removed. No matter how poorly I felt I fully realised that surgery was my only hope and the sooner the better.

The neurosurgeon would have also been concerned with how best to manage this case and whether the inherent risks of brainstem surgery were worth the potential rewards. There was no doubt that the continued compression of the surrounding brainstem tissue and my repeated haemorrhages (3 bleeds) resulting in progressively worse neurological deficits made this decision easier. Lesions such as mine are normally considered aggressive and need to be removed, assuming the cavernoma is surgically accessible. When considering surgery, pre - surgical patient condition is very important. The better the person’s physical condition prior to surgery, the better the chance of a successful lesion removal and recovery. Fortunately I had maintained a relatively high level of physical fitness. Neurosurgeons allow sufficient time for excess blood absorption and maintenance of lesion integrity before undertaking surgery.

On 8th May 2008, over 6 hours under general anaesthesia, the brainstem cavernoma was expertly removed using microsurgery, by Mr Pidgeon and his team. Image guided surgical navigation (ie. computer assisted) was utilised to
minimise disruption/damage to the rest of the normal brain tissue. I was later informed, by a member of the surgical team, that they only had 1mm to completely remove the cavernoma! The surgical difficulty was compounded by the presence nearby of a large, high pressure venous angioma in the pons (middle of brainstem). This literally could not be touched or the repercussions would have been disastrous. Mr. Pidgeon obviously has an arm with the precision of a Swiss watch. I shall always be indebted to his wonderful surgical skills. Following craniotomy my body temperature rose to 40 degrees celsius due to septicaemia, pneumonia and other infections. I made sure Ed Smyth and the rest of the Infection Control team earned their keep. Whatever optimism was shared by my family about the surgical success of the operation was soon countered by copious amounts of ice cubes being poured down my front to reduce the fever. I survived and remained under constant observation in ICU for a few more days before being transferred to the HDU for 4 weeks.

It was here, in HDU that my post operative recovery began. Each person’s recovery is a unique experience. In HDU I started to restore my swallow reflex and ability to eat, drink, speak and excrete under my control. I never sought access to a mirror but I’m informed that I had the appearance of an African famine victim. I remember waking up one morning in HDU and realised that I was alive and cognitive, minus the cavernoma, having survived the ordeals of craniotomy. Surgery left me with a 6 inch scar from my crown to the base of the neck. Understandably the brainstem area was particularly sensitive for 2 – 3 weeks post surgery. The only reminder of this surgery is a hollow at the base of my skull that a rabbit would be proud of. However my hairline manages to disguise it. From that day on I resolved to pursue my recovery. My body felt limp and very weak. It had been drained of all its energy, like a balloon that had been slowly but comprehensively deflated. I realised that I had to pay close attention to my energy levels. As I had learned to value my experience of inner peace I became sensitive to feeling other people’s (staff, visitors) stress. Fortunately the HDU staff provided a very caring and positive atmosphere for patient recovery. I particularly remember Gavin affectionately massaging my flaking right foot back to life.

I was determined from that day on to eat all around me. Previous to this I had dreamt of some generous person kindly placing a droplet of water on my lower
lur. I literally couldn’t wait to begin eating and drinking on my own again. I don’t remember thinking or dreaming of anything else. I didn’t need a mirror to tell me how I looked and felt. I vowed to restore the nutritional depletion that had occurred over the previous 3-4 weeks. I ate a very large breakfast, two lunches, two dinners, every coffee break, supper and whatever else was going. Norman, the chef was glad to wave me goodbye! But firstly I had to restore my swallow reflex (dysphagia) to allow me to both feed and speak again. Occupational and Speech Therapists made this all possible over an arduous 7-10 day period. This allowed me to speak briefly again. It was this resumption of my first few spoken words that convinced the lads that their dad might recover. Pureed food was ditched sooner than recommended for the real thing.

While in HDU Madeleine and the boys took turns to wheel me outdoors to the bright sunshine. It was at times like this that I became more aware that the adverse affects of an ABI are not just confined to the victim. Fortunately we lived about 5 miles away - I hazard to imagine what travelling long distances, on a daily basis, must be like. A hospital employee even gave Madeleine his car park pass. Every little helped. The wellbeing of the staff enjoying the sunshine and the eternal traffic of rushed ambulances into the A&E area heightened my level of unease about my predicament. Towards the end of my stay in HDU I remember falling over, while drying myself in the bathroom, on top of a slight nurse attendant. She was submerged by a 13 stone telly tubby, unable to reach up to the emergency bell! Fortunately we were rescued by an observant nurse. It was around this time that I began to mock myself, picturing myself as Steve Austen, the Six Million Dollar man. I used to chuckle to myself thinking of him being rebuilt fitter, faster, stronger.....and then the theme music would kick in. I wryly imagined purchasing the bionics on EBay. I always look back positively on my recuperation in HDU and smile.

It was during my recuperation in HDU that I was discouraged to hear that this was only the start of a long road to recovery. I vaguely recall meeting Dr Morgan and Dr. Delargy from the NRH. They assessed my suitability for rehabilitation at the NRH. At the time I was learning again to speak so Madeleine ably substituted. Even though I now know that the NRH greatly accelerated my recovery, my initial apprehensions, about undertaking this period of rehabilitation, were demoralising. It felt like completing a marathon only to
be told, at the finish line, that there were several more miles to go. I had
naively begun to imagine an upcoming welcome home party in the Porterhouse.
This dream was only that.

I was then transferred by ambulance to the National Rehabilitation Hospital
(NRH also known as REHAB) for 9 weeks during which I received extensive
physiotherapy, occupational therapy and physical redevelopment. I was also
rehabilitated on essential functions for day to day living in the house and
community. These included tasks as diverse as cooking, grooming, household
care, computerisation and meditation. Since most of the damage of brainstem
strokes is to the motor rather than the cognitive skills patients can become
more actively involved in their rehabilitation. Challenges were recuperative and
compensatory. I was apprehensive about this stay in the NRH but I found the
staff to be superb and to this day I am always glad to receive the sound clinical
advice of my Consultant in Rehabilitation Medicine, Dr. Morgan. I soon
discovered that the clinical staff had great faith in my continued ability to
learn, heal and grow. I had to relearn basic personal care including how to dress
myself. Scientists are now aware, that by the process of neuroplasticity, the
brain can respond to incoming stimulations and recover its lost functions. The
motto "use it or lose it" is very appropriate to brain recovery. I was fortunately
placed under the attentive supervision of Allison. I soon realised that you only
got out of the rehabilitation process what you were prepared to put in. Recovery
was the difficult decision I had to make several times each day. The bottom line
was I prepared to endure the painful agony of recovery? Notions of vanity,
dignity and humility would require compromise too. In contrast to many of the
other patients present I was fortunate to have relative youth on my side, no
cognitive disability and physical damage, some of which, was recoverable. The
staff knew that it was especially important to challenge my brain systems
immediately. It was important for my recovery to prioritise those areas in which
recovery was possible so as to maximise my valuable energy reserves.

Unfortunately in the first week I awoke to find that I was suffering from
another bout of pneumonia and my body temperature had reached 39.7 degrees!
Luckily my immune system (memory T cells) swatted it like a fly. My cognition
was also assessed initially by an arduous 3 hour test on memory, concentration
and IQ. Fortunately, no impairment of my cognitive functions was detected. I
particularly relished the rough and tumble (tongue in cheek) physio sessions with Leslie, my circuit training which restored some of my original energy and meeting so many acquired brain injury (ABI) patients. Leslie and Allison were particularly encouraging. They realised that by collectively celebrating my successes, no matter how small, they inspired me to push myself further. Within a couple of days I realised, that relative to so many of the other patients, I had been very fortunate. I learned to get around by pushing the wheelchair with "my left foot" as my ataxic right hand would have got caught in the wheel spokes. Going to the bathroom, showering, feeding etc had all to be relearned from the difficult platform of a wheelchair. There was plenty of spare time to relearn such essential functions so I committed myself to extra gym visits to build up my core strength and daily bed exercises. Observing many of the other patients I became increasingly aware of the devastation that intellectual disabilities can impose on an already physically disabled body. My stay at the NRH reinforced this feeling of good fortune. Despite residing in a rehabilitation centre these generally positive feelings allowed me to squash feelings of self pity and depression. In my efforts to attain recovery I became reluctant to accept help from adult visitors. I needed visitors to bring their positive energy. The depleted energy reserves meant that it became difficult for me to cope with people who exuded a negative or anxious energy. There were and still are stressful emotions such as frustration, anger and anxiety which feel uncomfortable and are counterproductive to my recovery.

For the first few weeks Gavin and Killian wheeled me up the road to Baker's Corner for Sunday dinner. After 3 weeks I was allowed to return home every weekend. We treated ourselves by visiting Butler's cake shop on the way home. The daily commute across the city by Madeleine and the boys must have been monotonous and tiring. The "weekending" at home proved very beneficial especially when I intentionally left my wheelchair behind on departure day. Walking aids were similarly dispatched as a statement of independent intent. I remember, on departure day, heading to the Porterhouse with Madeleine for a pint of my favourite Oyster Stout. Fortunately we had a barbecue invitation to Portmarnock. If I had stayed for another only a JCB would have removed me. Although on departing I was only able to manage a few steps indoors (with the help of safety railings in REHAB) the rehabilitation process had been so successful that within 6 weeks I was walking/staggering approximately 1 mile,
twice a week, around the local park accompanied by Madeleine. After almost five months hospitalisation I couldn’t wait to get home. I have no doubt that Madeleine and the boys were glad to see an end to the travel too. The local health centre, together with the NRH OT nurse, recommended that a stairs hand rail and downstairs loo be installed to facilitate this return.

Neuroplasticity is a relatively new concept. Studies have conclusively shown that the brain is not a hard wired organ that is incapable of change. Instead it is “plastic” and the wiring (circuitry between brain cells) is changed every time we perform a new thought or action. Experience shapes the brain so it can adapt, memorise and better predict the future. In essence the plastic connections form and reform in response to both learning and brain injury. Hence, brain cells that “fire together, wire together”. When sections of the brain are damaged or destroyed by injury this is not a disaster. The brain is very plastic and its capacity to recover from injury is vast. Hence in the case of brain trauma we have the ability to continually adapt and/or improvise. “Use it or lose it” comes into play following brain damage. The more active your brain is pre injury, the more resilient it will be afterwards (Roche, University of Maynooth).

However, I suffered a major setback/relapse in October 08 when my entire right leg went stone dead and stiff with numbness restricting me to very short walks to the bathroom and back. This was an enormous downer both mentally and physically as I had begun to see some light at the end of the tunnel. I had even attended my first social event the previous Friday. I was referred back to Beaumont hospital for two stays totalling one month. As I was now post surgery, I was placed under the watchful eye of the Neurologist Dr Delanty. Despite numerous different MRI’s the medical staff were unable to agree on a reason although gliosis (surgical scarring) was suggested. Very little came of these two stays except that quite a few of my fellow neurology patients suffered from brain tumours. The continuous waiting for surgery, test results and prognosis suspended our lives. If I didn’t already feel lucky I certainly did by the time I left hospital, emotionally drained.

What I remember of 2008 was the fantastic support we received from so many. The lads particularly relished their regular excursions, with club friends, to see matches both locally and down the country. The winter of 2008/09 was dark in
the extreme. When I review my personal diaries I am immediately struck by the constant severe headaches, in several locations and the aggravated tinnitus. I was on a multitude of medications and in hind sight the dosages alone would have contributed to my tense condition. Social events were a disaster as the high pitched frequencies of plates, cutlery, glassware and voices became unbearable. My poor health meant that I was forced to quit gym for 6 months till end April 09. One of my few pleasant memories of this period was playing catch ball with Killian to improve my hand to eye coordination. I also remember the amusement playing darts with the boys and particularly the mock celebrations when I, very occasionally, managed to win with my left.

I felt almost desperate for some reprieve. I was prepared to chance anything and in February 09 began (and have maintained) the Cambridge diet based on food intolerance. In my case intolerance was to dairy, eggs, brazil and pine nuts. I hoped that by excluding these foods from my diet that my immune system could then focus on other foreigners! I also tried acupuncture and reflexology with Tina which prior to my injury had been an effective relaxant and energiser. In April 09 I tried Constraint Induced (CI) therapy which involved me wearing an oven glove, in reverse, on my unaffected hand. This was beneficial to my affected right arm for about 6 weeks (on 2 occasions). In fact writing with my right hand became legible. Unfortunately, on both occasions my brain rejected (induced onset of bad headaches) activation of my right hand. In June 09 I commenced the Volvic 1.5L/day water challenge for 6 weeks. In May 09 I purchased knee supports to help my legs tackle the burden of mobility. In the summer I took to swimming at Low Rock seashore with my Portmarnock relatives. Getting in and out of the water was by far the biggest problem. Shoulder assistance was required from others. Once I got in I found it hard to get out. In June 09 I developed recurring right big toe infections (probably due to my weight distribution) which required antibiotics, toe nail excision and unsuccessful attempts at podiatry. In June 09 I replaced the crutches with a walking stick and ventured for the first time into town on the local bus with Gavin and Killian. In August 09 a shoulder impingment was diagnosed probably due to inactivity in my right side. It was in Sept 09 that my right hip started to feel sore. This was most likely due to lopsided weight carriage of an increasingly mobile body. In August I tried TOGI ear treatment at the Wellmar clinic in Raheny, but nothing came of it. By the end of August I began walking short
distances unaided and by October I had this up to 1,000m. This coincided with a rear extension to our house from 14th September till I returned from our apartment in Santry on 27th November. The building was a constant source of mental stimulation but I couldn’t wait for it to finish and return home. A frustrated desperation pervaded my essence throughout 2009.

After I left Beaumont in October 08 I did regular physio there with Michelle and Roisin over an 8 month period. To address my balance deficit this physiotherapy concentrated on the computerised EQI machine. However, even this clever device failed to significantly improve either my motor or sensory balance even though I had also committed myself to a vigorous, daily home exercise programme with the emphasis on gaze stabilisation. In March 09 I was referred to Dr McConn Walsh where tests indicated that my tinnitus was central but had become less troublesome. In June Gavin (captain) and Killian both played on the victorious school hurling team in Croke Park. In July we took an enjoyable two week family holiday in Lanzarote. I brought the two crutches with me. The adjacent beach and pool in Peurto del Carmen provided me with daily opportunities to exercise. I followed the family holiday with a five day retreat in Cloona, county Mayo.

In August 09 I was then referred to Prof Luxon, Neuro-Otologist, in Wimpole Street, London. I was given a thorough assessment but found that retelling my recent neurological history, for the first time in a year, was unexpectedly difficult. On the same day I was also referred to Dr. Pavlou, a vestibular (balance) specialist in Harley Street and for extensive (9) neurology tests in the neighbouring Queen Square, National Neurology hospital (UK) where I had two MRIs in the afternoon. With Dr. Pavlou I learnt to focus my balance on the ball of my foot. Madeleine and I treated ourselves to a night in the beautiful Irish run Marybowlane Hotel and dinner in a recommended Indian. This was a highly productive day confirming that my inner ear activity was only 15%, I had bilateral inner ear damage especially to the left ear and damage to both the vestibular (balance) and auditory (hearing) nerves. The bleeds had impaired both sides of the brainstem, the left side of my brain and some of the proprioception pathways in the neck feeding into the nearby cerebellum. Unfortunately the latter controls coordination of movement so the resulting ataxia of both right limbs gives the impression of someone who’s fond of the
bottle! As well as controlling balance and equilibrium the cerebellum also regulates eye movement, coordination of voluntary movement, postural control and motor coordination. I was also posted a detailed report synopsising the results and interpretations, something that was foreign from my Irish experience. The presence of another venous malformation in my pons (venous angioma) was first mentioned in this report. I did Dr Pavlou’s home vestibular (balance) exercise programme on a daily basis. This together with core training in my local gym improved my strength, posture and walking. Fortunately a local vestibular physio (Ailbhe) was located in Dublin’s Temple bar district so I attended classes until early Nov 09 and continued to exercise at home. I suffered another significant setback in October 09, similar to 08, but not as devastating physically or mentally. I have only been able to walk outdoors again, for short distances, since Spring 10. The treacherous underfoot conditions in winters 2009/10 and 2010/11 have contributed significantly to my house confinement since I have been left with very poor grip/touch in my right sole. Being reliant on others to escort me to the car (see later) and de ice the vehicle is also limiting.

In Jan 2010 I had left eye surgery in the Mater hospital (under the skilful knife of Ms Logan) for the second time (previously 9th March 09) to overcome the problems relating to eye position and movement (nystagmus) which arose from damage to cranial nerve 6. I had never thought of myself as a potential candidate for botox treatment but in summer 09 I submitted myself to needle injections directly into my left eyeball. This unpleasant experience has distanced all pretensions of vanity restoration. The eye operations were a huge success correcting the head misalignment from 45 to 30 and then to 6 degrees. In fact in summer 2010 I was informed that the head alignment was now 0 degrees - absolutely perfect! A further assessment of my vision in early March 2011 confirmed that the operations were an “excellent” success. My primary problem is the lack of left lateral movement in my left eye which needs care, when driving (see later) or crossing the road, to avoid “blind spots”. However, the rewiring of my circuitry, especially the juggling of my eyes relative to how they interact with my ears and brain, is particularly notable with gaze stabilisation exercises. This is most evident by the blurring of vision when my head is moved during walking or viewing. This eye operation also improved my visual acuity, obviated double vision (diplopia), allowed me to apply for a driving
assessmen and removed the requirement to wear reading glasses (resumed occasionally in January 2011). Fortunately, fortune favoured the brave. The eye surgeon had spelt it out to me beforehand that the operation carried the risk of using the last of my eyeball muscles. This eye had a chequered history as its repair required me to request the nursing staff in Beaumont and the NRH to nightly apply a special ointment. I did it too, to avoid a squeamish proposal to sew my eyelids together! I realised that I had enough health problems and the thoughts of an additional corneal transplant was a sufficient deterrent for me to remain resolute. However my eyes, particularly my left, remain especially sensitive to a variety of exposures including UV light, salt, chlorine, glare, shampoo, over sensory stimulation, stress etc.

Due to impairment of vestibular function, dynamic (mobile) imbalance, with ataxia and increased muscle tone, still remains the most apparent physical symptom. Balance is achieved and maintained by sensory input from the inner ear vestibular system (motion, equilibrium, spatial orientation), eyes (sight) and proprioception (touch). Sensory information from the eyes, ears and joints/muscles is received and integrated by the brainstem. The cerebellum coordinates movement, posture and balance. The cerebral cortex contributes higher level thinking and memory. As sensory integration takes place the brainstem transmits motor impulses to the muscles and joints that control movements of the eyes, head, neck, trunk and legs. The stroke definitely damaged the brainstem and neurons feeding the cerebellum. Damage to the left hemisphere has also impacted on the cerebral cortex although the extent has not been definitively established My international contacts, through the Cavernoma Alliance UK website and hub, have helped me to employ the Cross Country Skiing exercise machine (without hands) to improve this. Regular home balance exercises with a foam pad and wobble board (with additional challenges - feet together, eyes closed, barefoot etc) have enabled me to further stimulate the brain to activate/restore vestibular/proprinoception receptors on my injured right leg and sole. However the constant fatigue to maintain balance when mobile and the depleted energy levels caused by the acquired brain injury (ABI) and repeated setbacks are highly frustrating. I would love to have Lucozade Sport's ability to bottle this energy. I could then focus on the first 45 and leave the last 15 to Ronan (O'Gara)!
I had to endure very severe and painful headaches (possibly migraine) during winter 2008/09 but their frequency and severity are reduced now. I cringe when I reflect on those dark days. Tinnitus is permanent but more tolerable and only bothersome in the late evenings and at bedtime. As the left side of my face and the right limbs were primarily affected by the strokes I have no sense of smell in my left nostril, poor hearing in both ears especially high frequencies in my left ear (even with a digital aid), poor coordination (ataxia) and increased muscle tone in both right limbs, reduced feeling/sensation in my right palm and sole, occasional facial palsy and twitching, very slight slurring (dysarthria), vertigo, swelling of my right foot and impaired temperature regulation in both right limbs especially my fingers and toes. Cold weather and saunas are avoided, if possible. I remain sensitive to sensory (bright light, small print, noise) overstimulation. Reflux problems (probably because I was in a rush to relearn how to swallow and eat in HDU) were frequent in the first year or so (embarrassing regurgitation, in public) but rarely now. Yawning lockjaw, irregular heartbeat, repeated setbacks/relapses, disturbed sleep, scary darts across the brain, pain in the vicinity of the brainstem, temporal throbbing and painful cramp in lower right leg at night all serve as further reminders that it hasn’t gone away. A doctor has indicated to me that a clicking sound is a warning sign for strokes. Whenever I hear this rattle from the back of my throat (approximately monthly in the vicinity of brainstem) I immediately become wary and relax instinctively. Initially this clicking was scary but over time I have learned to take them in my stride. Similarly with a burning taste at the back of my throat which heightens anxiety about breathing. Neck muscle stiffness and right shoulder impingement remain a nuisance despite regular exercise.

Proprioception, particularly of the two right limbs, remains markedly impaired. Proprioception, has been referred to as the "sixth sense" and is the ability to be aware of where your limbs are relative to the space around us - somatosensory system. This may also manifest as unconscious arm and leg movements, particularly in bed at night. Masochists will be glad to hear that thick lips, bloodied gums and a busted nose are the annoying consequences of impaired right hand control.

The symptoms of vertigo have become progressively more pronounced with time, especially over the last year or so. This may be a reflection of reality or their
emergence beneath others. It is quite frequent in the elderly. Vertigo is defined as a whirling or spinning movement (type of dizziness) where there is a feeling of motion when one is stationery. I have been noticing and monitoring this when lying on a pillow and noticing the ceiling lights spinning around. The head feels like it has a mild shake. The car also gives the impression of moving when it comes to a standstill. Second checking the brake is a minor complaint. The symptoms are due to a dysfunction of the vestibular system in the inner ear and it is often associated with standing/walking balance difficulties (unsteadiness), ringing in the ears (tinnitus), intra cranial pressure or fullness (relieved involuntarily through my ears or by intentionally blowing through squeezed nose), hearing loss, motion sickness, occasional night sweats and accompanying neurologic defects. Vertigo frequently and increasingly impairs the quality of my life. In fact I now gauge my overall neurological status, each morning, by the extent of these symptoms. The symptoms of vertigo have a variety of causes including brainstem stroke. Excessive alcohol consumption can also produce these symptoms. Repetitive spinning can induce short term vertigo and probably explains why I always hated such childhood/adolescent games/rides. Similarly, common respiratory infections such as influenza and the common cold may involve the inner ear causing transient vertigo. When vertigo arises from the balance centres of the brain the resulting pathology causes a sensation of disequilibrium (light headedness/off balance). This unsteady feeling is uncomfortable and slightly nauseas. I have tried the Epley manoeuvre, with little therapeutic benefit. Besides alcohol and infections, stress and vigorous exercise (possibly similar to motion sickness) aggravate these symptoms. To overcome the symptoms of vertigo my walking has become more deliberate (slower, feet wider and steps shorter).

In Aug 10 I met Kieran O'Reilly, a chartered physio with the Dublin football and Irish cricket teams. He put me on a series of exercises to strengthen my right glutus muscle and hip flexor muscles. The positive effects reduced but didn't eliminate the grating pain that I experienced in my right hip when mobile. The ataxia in my right hand has improved since Nov 10 when I began daily shoulder stabilisation exercises. This appointment, with Graham Byrne, from the local university (DCU) sports science department, has, through a daily core/resistance exercise programme had the most beneficial effect on my health since my ABI. Core training has rebuilt my right hand side, reduced the
aching hip pain associated with movement and in strengthening my right side has reduced the burden on my left hip. In Sept 10 Madeleine purchased a Circulation Booster to improve my right foot/sole. This Australian device was, given their excellent medico/scientific reputation, a valuable addition. In fact the regular sending (initially daily) of electric currents (while watching TV) through the soles of my feet has had a great success by “reviving” the touch/grip receptors in the soles of my right foot. I can now feel and grip floors. Similarly within 2 weeks of wrapping, the provided electrical pads, around the fingers my apparently dead hand was able to feel and hold a ball. However, since then I have discovered that the benefit of the booster is short term and obviated by periods of poor health.

In Sept 10 I purchased a tailored splint/prosthetic in the NRH to reduce the numbing/deadening effect in my right leg. From my perspective this symptom is THE characteristic symptom of setbacks/relapses and considerably affects my quality of life. I wore this relatively cumbersome device for many hours each day, with disdain, but after approximately 2 months the deadening in my leg is such that I only need to wear the splint every fortnight or so. Wearing this splint has also taught me how to reduce the deadness in my leg by promptly resting it in an elevated position with the foot curled towards me. However it is awkward to put on, uncomfortable to wear and aggravates my hip. I dislike putting it on now as it invariably means my right leg is deadening and my choice is limited. I purchased a wobble board in Jan 10 and had a room reassigned for home exercise purposes. However, since Christmas 10 this room has become home to the lad’s drums! These developments together with a daily home vestibular exercise improved my static sensory balance but had a negligible effect on my motor balance. The vestibular contribution has risen to 35% (0% in April 09) suggesting that the rigorous home exercise regimen has enhanced this balance function by neuroplasticity (cerebral adaptability to repair, replace and retrain the human brain to perform functions previously not performed by that part of the brain).

In the Autumn of 2011 I had 2 consecutive appointments in Beaumont separated by 1 hour. I had regularly visited Beaumont physio and eye departments not to mention the NRH with absolutely no fear. But today I had an hour to spare and decided to visit Richmond HDU in the Neurosurgery unit. I warily made my way
by foot becoming more and more apprehensive the closer I got. I entered via the back door of ICU which is linked to HDU. The sight of so many patients struggling for life was very uncomfortable. I immediately rushed through ICU to the nurse’s station in HDU. Unfortunately, the Nurse Managers, Patricia and Mary were on leave. I spoke to a nurse who had attended me. She didn’t remember me. I wasn’t exactly a pin up and hundreds of patients have passed through since. I had a gift for the staff and just wanted to say thank you. But I couldn’t. I hurriedly departed, vowing never to return to this centre of traumatic turmoil.

Depression is an unfortunate but inevitable consequence of brain surgery. Unfortunately for the majority of patients it doesn’t go away. Strangely I never suffered from depression throughout my stay in Beaumont or the NRH. However, it soon became established with the onset of my first setback in October 08. Advice emphasises that depression should be viewed as an inevitable stage of adjustment following an acquired brain injury (ABI) and should be regarded as a sign of progress and moving forward. Rehabilitation personnel view the onset of depression as an insight, understanding and awareness of one’s ABI condition. I have gradually and consciously reduced this medication (under medical supervision). In October 09 I developed disturbing myoclonus but this disappeared with the withdrawal of a specific medication. I have voluntarily attempted to address mental aspects of an ABI with Headway and Prof. Cotter at Beaumont hospital. Headway provides services for ABI patients and their families and specialises in brain injury rehabilitation. I also contacted BRI who provide an advocacy service that represents and negotiates on behalf of ABI patients. I am indebted to Suvi, Senior Clinical Neuropsychologist at Headway for helping me overcome many of the constant frustrations of living with an ABI, the anger which is an inevitable consequence of an ABI and anxieties regarding the future. As a professional I suspect she understands me a lot better than I now know myself. I have always enjoyed those sessions. She helped me to learn about my new self and have a good laugh (at myself) too. I also volunteered for an exhausting 9 hour cognitive assessment at Headway, with Conor, over 4 sessions.

In 4th May 2010 I was plodding along making slow but almost indiscernible progress when I was informed by Beaumont that there was evidence of a "small,
residual cavernoma" in a recent MRI. Needless to say this was very traumatic as further surgical intervention would then be a consideration. Fortunately professional colleagues in Beaumont were frequently able to assist me with hospital related matters. I sought a second opinion from Prof Bertalanffy, Zurich. He had until summer 2010 successfully removed 137 brainstem cavernomas from patients throughout Europe and Asia. He is arguably the foremost international Neurosurgeon on this matter. I flew to see him at his clinic in Switzerland in June. It was ironical that I should book the same outward flight as Robert and his wife Caitriona who was returning for her check up having had a troublesome deep brain cavernoma successfully removed, in the recent past, by surgery in Zurich. In fact Caitriona was an advertisement for her wonderful surgical treatment. Her exuberant health compared very favourably with mine. I had an MRI there, with and without dye, to improve resolution. We assessed it immediately in his office and he disagreed with the reappearance of the cavernoma but highlighted an associated "huge" venous angioma in the pons. While this was welcome news he also pointed out another ischaemic area in my medulla which he indicated was probably responsible for the majority of my neurological symptoms. This damage to the medulla was permanent and irreversible by surgery. At least I knew the pertinent neurological story. I am now resigned to my balance deficit though I will continue to perform vestibular exercises on a regular basis to maintain and if possible to improve my balance by neuroplasticity. His offer to promptly respond to subsequent queries and discs (MRIs) from me has been invaluable.

At least 2010 was a progressive improvement from the two previous years. I have some fond memories of a family holiday in Balmadena, a trip to beautiful Florence for a work related EFI conference in May (exhausted for several weeks afterwards), attendance at the WMDA conference in Trinity College, Dublin in June which gave me an opportunity to catch up with visiting foreign friends and a relaxing and enjoyable weekend at Rathsallagh House (won a radio quiz!) where Madeleine and I were whisked by helicopter to the Irish Derby at the Curragh to savour the splendour of the hospitality suite. Summer Sundays (thanks to tickets from relatives and friends) were often spent in the premium seats of Croke Park watching the sporting drama unfold. In Autumn 10 I flew over to a one day Cavernoma Alliance UK meeting at Queen Square, London. Prof Bertalanffy presented to the audience for about 90 minutes. What I
particularly remember was the unselfish manner in which he then made time to address patient concerns, review MRI discs and offer clinical advice on possible avenues. Neurosurgical ambassadors are enormously precious to patients diagnosed with symptomatic cavernomas.

My current physiological objectives are on maximising muscle and joint strength to maintain balance especially when mobile, to enhance core body strength and improve stability/flexibility, avoid recurring setbacks/relapses, reduce right limb ataxia, improve muscle tone in my right limbs, enhance the coordinating function of the cerebellum, minimise vertigo, improve fine motor movements of my right arm and to reduce the grating right hip pain when moving. The recent development of a piercing, arthritic pain in the back of my right knee is of ominous concern. Similarly a very mild shake in my vital left hand is notable as it has become the most used limb in my body. The frustratingly deficient energy levels are tackled by weekly swimming and daily exercising/stretching/walking (when possible) to improve my aerobic fitness. The energy required for pain suppression and overriding my imbalance, especially when mobile, is a constant drain on my enthusiasm for recovery. Since my bleeds I direct my life, almost entirely, towards how people, places and things feel energetically. I am fully cognisant of the requirement to protect my precious energy with cautious vigilance. The incredible resilience and endurance of the heart to haul a traumatised body from challenge to challenge never ceases to amaze me.

I was also called in August 2010 to the Irish Wheelchair Association (IWA) for a driving assessment. This was passed following a driving suitability assessment for over 1 hour. I then took 5 driving classes before putting a deposit on a Nissan Qashqai. This car, following advice from the IWA, was then adapted (infra red spinner, left accelerator and extended rear view mirror) for use. This automatic car has completely transformed my life. The sense of new found independence is palpable. It takes about 2 months to recondition the brain to now using a left foot accelerator. Driving has provided me with the freedom to consider domestic, social and sporting avenues that were less accessible in the last 3 years. The impact of glare at night, reduced optical and peripheral vision, treacherous walking surfaces to and from the car in icy conditions, the need to de ice the car and managing the whole driving process with one hand have only
slightly impacted on, what has largely been, a tremendously positive development.

Driving also gave me the opportunity to consider some form of return to the work environment. Prior to this, commuting to and from the National Blood Centre had been a major concern. With this in mind I met Samantha, Headway’s employment officer with a view to returning to part time work, if possible, sometime in 2011. My employers, the Irish Blood Transfusion Service (IBTS) have been very supportive over the last 3 years. I was fortunate in that both my Consultant and Laboratory Manager have been particularly encouraging, keeping me up to date with progress in the work environment. I have consistently kept in contact with work colleagues, managed to coordinate and complete European Standards for Transfusion (from home by e mail) and have attended two work related conferences in Florence May 10 and Trinity College, June 10. The spirit in the laboratory (NHIRL) is excellent and has meant that the bone marrow transplant recipients in St James’s Hospital (adult) and OLHSC Crumlin (paediatric) receive excellent care from a committed team of Consultants, Transplant Coordinators, the Irish Unrelated Bone Marrow Registry (IUBMR) and the laboratory staff. The staff worked hard with me to build an excellent team ethos in the laboratory. I was very proud of their achievements and the high quality of service provided. Work was always very busy but seldom less than stimulating and rewarding. The adverse impact of the recession on the Irish healthcare service has been especially significant in recent times. The scientific staff have always been willing to provide additional commitment and expertise in response to various emergencies. It is particularly regretful that the workload continues to increase but I can’t be present to contribute to the “all hands on deck” effort.

On 19th January 2011 I was diagnosed with shingles. Since the 14th I had begun to note an area of increased sensitivity around my left knee. Four days later I observed painful blistering along the full length of my left leg from groin to foot. My GP immediately diagnosed the illness and prescribed FAMVIR, an antiviral agent. I later required a second course of treatment. The harmful varicella zoster virus causes chicken pox in children but unfortunately this latent virus remains dormant in nerve cell bodies when it can re emerge, more virulently in adults, as shingles. This nasty virus caused further deflation of an
already energy depleted body and destabilised my balance by weakening my strongest leg and left lower back. The beneficial effects of the medication were soon evident. I significantly reduced the frequency of heart palpitations within 16 hours of commencing therapy. This was highly significant as this symptom had been troubling me for about 6 - 8 weeks, particularly when stressed or tired. A heart screen in April 2011 was fine but my cholesterol levels had risen above normal since my bleeds and the critical LDL levels were particularly high. Reduced outdoor exercise and regular periods of enforced indoor inactivity have obviously contributed to these results. While my blood pressure was normal it was interesting to note that it was 10 mmHg lower in my affected right arm. Perhaps the stroke has also impaired circulation in this limb. My cardiologist, Dr. Brown, prescribed Lipitor. Fortunately, I have been reassured by a hub member that statin trials, in the USA, suggest that they may prevent cavernoma bleeds. While the medication (together with lifestyle and benecol foodstuffs) succeeded in reducing my lipid levels to normal the progressive breathlessness and low tolerance of exercise meant that I had to discontinue it. The shingles leg rash continues to last (incredibly for >20 weeks) but the lower left back arthralgia has subsided. Madeleine purchased back supports in early April 11 to reduce this discomfort.

The shingles rash fluctuated in intensity and seemed to be greatest when a setback ensued and/or my energy levels were particularly low. The virus seemed opportunistic, causative or both. I was extremely glad when I thought the rash had disappeared on 20th May 2011. However, this was short lived. In May/June 11 I picked up a head cold which took me 13 days to clear. Surprisingly the shingles rash has also returned till present. Towards the end of April 11 I had also picked up a gastric flu bug which completely drained me for 24 hours with cramps for another 3 days. At times, it can feel like being repeatedly kicked when down. Obviously my immune system is not as strong as it was before in 2009 and 2010 when it successfully dealt with all comers post surgery. This development is of concern. After these three infections and the adverse medication reaction I needed plenty of rest and energy tonics to revive my deflated body from the depths of fatigue. My residual energy levels got so low that I had to abstain from reading and writing for 4 weeks for fear of headache inducement. At the time of writing the return of the energy levels and inner neurological strength that I experienced in 2010 seem very distant. This
will take several months, if I'm lucky. I began a course of acupuncture in May to restore my energy. I was forced to cancel an intended trip in early May to attend the EFI Standards meeting in Prague. EFI had kindly offered me a financial bursary but my welfare regretfully had other ideas. However, with the aid of modern technology (Skype) I was able to video link with the 5 hour EFI Standards meeting.

On the 24th January 2011 I had a gradient echo MRI, with gadolinium dye, to monitor my progress. As no result was forthcoming from Beaumont I referred it on disc to Prof Bertalanffy, now in Hannover, Germany. I was understandably apprehensive about the results as I endured another setback (the first since Oct 09) at this time (see below) so was very relieved to hear that there had been no significant change to my MRI status since June 10. It was suggested that some of my neurological problems may relate to the presence of the high pressure, “large”, venous angioma (another venous malformation!) which is present in my pons. The altered physiology of the brainstem resulting from the bleeds has also made this region more susceptible to stress and depression. The advice was to continue with the physiotherapy.

In January 2011 I met with Samantha and Suvi to review their recent visit to my place of employment at the National Blood Centre. My employers continue to show flexibility but my circumstances have compromised a return to the post. This position was tactfully relayed to me. As I sat there in Headway the realisation that I would not be in a position to return to my original fulltime, laboratory post, in a meaningful way, was traumatic. I had naively assumed that the previous 3 years had prepared me for repeated exposures to the school of hard knocks. The quest to return to my original job, in some capacity, had served as a distant target during my recovery. It was said to me that I needed time to grieve. I now appreciate this but at the time it felt like encouraging the cats to bark. I now realise that optimism rather than realism governed my outlook. I remember, at 34, having to give up playing hurling. The body had had enough. There was nothing voluntary about this battle between what the mind wanted but the body couldn’t do. A survey of UK stroke survivors in 2000 showed that 27% returned to their original or modified jobs. 12% became students or undertook voluntary work and 6% obtained a different job than before their stroke. Over half did not return to work. If/when my health
improves I hope to be able to make a meaningful contribution to my professional field of immunogenetics in haematopoietic stem cell (bone marrow) transplantation and/or transfusion science.

Towards February 2011 I experienced another setback/relapse. As 2010 passed reasonably smoothly I had passionately wished that such events were a thing of the past. This was particularly so as I had invested in a prosthetic and felt I had become increasingly aware of the balance between exercise and proper rest. However, multiple infections including protracted shingles and occupational developments pushed an already depleted body into relapse mode. I tried over January to prevent the inevitable but setbacks are invariably stealthy. While the characteristic symptom of a setback is deadness in my right leg I can also include numbness and a drubbing sound in the right side of my head, grating pain in my right hip, exacerbated vertigo, worsening balance, blurred vision, increased muscle tone in both right limbs, shoulder socket rigidity which generates an audible sound when moved, heightened ataxia in right arm, worsening muscle tone in both right limbs, sensory sensitivity, disrupted sleep patterns, scary headaches, fatigue and facial twitching. In essence a setback/relapse feels like a stroke coming back for another bash. In fact the NRH recently (April 11) referred to these temporary ischemic episodes as “mini” strokes. The only treatment is rest and more rest. Endless hours are spent in bed or resting in a comfortable armchair with my right leg elevated on a cushioned table. Mobility is restricted in the house to 10 – 20 feet. One is forced to wear the leg splint each day for weeks, sometimes more. When energy eventually returns one often wishes to catch up with exercises and attending events. Being forced, by circumstances, to exercise restraint and do nothing is often enormously difficult. Energy conservation isn’t just the preserve of electricity suppliers.

In early April 11 I purchased a compression stocking to improve blood circulation but this was discontinued soon after. Since April 11 I have placed a pillow under my mattress to elevate my foot at night. Such setbacks/relapses stretch one’s mental fortitude to the very limit. Setbacks force one to switch almost exclusively to the unaffected side forcing one to neglect the weakened side which you have been exercising to build up. This is enormously infuriating and a constant test of resolve. Setbacks are also highly demoralising as they
ruthlessly extinguish hopes of a perceived recovery. Depression is an inevitable consequence of such setbacks. This repetitive cycle of “normality”, distress, setback, depression and normality again becomes reality. Relapses can also be destructive undoing the neurological benefits of home/gym exercises to improve balance and touch/grip sensors in the right sole. One is left with the choice of anonymous resignation or rebuilding again. In reality there is no choice but the body is only designed to take so many knock out blows. Setbacks hover like a dark cloud over an already vulnerable body. Although I did and have accepted my disability I feel that I will not be able to exert control over the quality of my life until I learn (if possible) to manage these setbacks. Besides stress my condition is also exacerbated by certain drugs, alcohol, over physical exertion, infections (such as shingles, colds, flu), depression, over sensory stimulation, headaches, tiredness (both physical and mental), sleep deprivation etc. Other members of the UK cavernoma hub have also mentioned high blood pressure and head trauma which fortunately have not affected me to date. However, it is not improbable that some of the above cause spikes of hypertension (high blood pressure).

Since mid January 2011 I have experienced several blows including persistent shingles, infections, a setback from early February to mid May, occupational reverses, cholesterolaemia, an adverse reaction to medication, cancellation of scheduled attendance in Prague and house confinement over 95% of the time for almost 3 months. Until mid May the car resided in the driveway with the general exception of occasional medical appointments and school drop offs. When things were poor walking more than 10 metres left me breathless with a low tolerance of gentle exercise. Similarly, I have been unable to do any gentle gym work since early January. On 11th May I began a course of acupuncture (8 sessions) with a view to restoring the energy levels I had in 2010. I also managed to track down a vestibular research specialist (Dr. Dara Meldrum) at the Royal College of Surgeons, Dublin who recommended the nearby Balance Centre. On the 13th May I attended Dr. Douglas Duffy, at the Balance Centre, Leeson Street, Dublin. My vestibular (balance) system was thoroughly assessed. For the first time in 3 years my motor balance showed signs of improvement (?) plasticity). Similarly my centre of gravity and leg weight distribution was good suggesting that the core and strengthening exercises, particularly on my right side, were bearing fruit. My rewired brain, restricted eye movements, ataxia,
leg muscle tone, reduced grip sensitivity and disrupted vestibular communication will continue to manifest as balance problems. However, he put me on a tailored home exercise programme that was specific for my balance difficulties. It is early days yet but it is a pity I didn't meet him before now.

On 20th May 2011 I had my second appointment (private) with my new neurologist Dr. Moorhouse, Bon Secours Hospital, Dublin. He assured me that on the basis of my recent brain and cervical (neck) MRI status that I could continue to improve but to expect repeated setbacks. Something as simple as the common cold could induce stroke like symptoms. Other stressors such as medication and stress could induce setbacks. He enquired whether I could prepare myself mentally for these inevitable setbacks. I explained that such recurring relapses were understandably proving difficult to my disposition and ambition. However, at least I was relieved to receive a medical opinion and report outlining what to anticipate. He assured me that my relapse symptoms were not uncommon for stroke victims. I had at long last found a credible opinion for them. He explained that the bleeds probably caused damage to my cortico spinal nerves which run from the cerebral cortex (brain) to the spinal cord through the injured brainstem. The cortico spinal tract is primarily concerned with discrete, voluntary, skilled movements especially of the distal (fingers, toes) parts of my limbs.

I explained that the primary factor affecting quality of life was the deadening of my right leg. He referred to this as tightness of the leg muscles due to an increase in muscle tone - hypertonia. He expressed surprise that nobody had previously brought this to my attention. ABI patients whose muscles are similarly affected have performance alterations including muscle weakness, decreased movement control and reduced endurance of muscle fatigue/over – exertion (deadness!). He prescribed a low dose medication to address muscle tone. Already (after a few weeks) the improvements are mild but discernible. He also recommended that I consider acupuncture to restore energy. As luck would have it I had already begun 2 recent sessions with this specific objective in mind. My optimistic disposition suggests things can only get better. In contrast, the realist warns not to become too deluded by optimism.
My personal experience of the Irish Health system has been extensive over the last 3 years. I also sought health care in London and Zurich. My impressions are that the level of healthcare provided by medical, nursing and related paramedical staff is of the highest quality but access, due mainly to administrative bureaucracy, remains the biggest problem. The number of patients residing on A&E trolleys in Irish hospitals is a sad testament of this reality. I hate to think of the problems that ABI patients might encounter if they have intellectual disabilities, severe physical disabilities, are aged, live in remote locations, dependent on carers etc. The treatment I received in Beaumont and the NRH was and still is very good. Unfortunately, once Irish stroke patients leave the public health system as an inpatient healthcare often becomes only accessible through significant expense either locally or abroad. In Ireland, private health insurers steer well clear of covering neurological care. Tackling the Irish health care system has been a simple question of perseverance. I remain sceptical about what would have been achieved without relentlessly knocking on doors until they opened.

The picture looks a lot rosier now than many originally thought possible when I lay in ICU three years ago. My physical disability (according to the Rankin scale) has travelled from severe (grade 5) to slight (grade 2). The probability of the cavernoma reforming is <1%. In the last couple of years my eyesight, mobility, gait, equilibrium and static balance have all improved considerably. The car has given me independence. I am now functionally independent with the exception of fine, dual hand tasks such as opening tight lids, slicing steak, buttering toast, transcribing phone messages, cutting tablets etc. It seems that my immune system is less robust and the ataxia and muscle tone in my right limbs (esp. my hand) have gradually worsened since I left NRH inpatient care in 2008. Successive setbacks have also progressively depleted my energy reserves. The associated and gradual increase in neurological susceptibility to stress, infections, alcohol, fatigue, physical and/or mental over exertion have frustratingly compromised me further. In essence while I am physically, cognitively, emotionally and behaviourally stronger I am energetically, immunologically and neurologically more vulnerable. I have become increasingly dependent on online shopping. Towards the end of March 2011 I fell on concrete for the first time. Indoor tumbles have been occasional. However, only for the fact that I managed to grab some seats, to buffer the fall, bruising to my right
arm and hip wouldn’t have been the only consequence. I realise that the next time I may not be so fortunate.

My recovery has been hugely influenced by the incredible work of a number of people who I never knew existed. If these wonderful people could make so many sacrifices to improve my well being then the very least I could do was reciprocate this effort. When I lay in ICU the motivation “to hang in there” was provided by a refusal to allow two vulnerable young boys to tackle life without their dad. Luck played a huge role too. Google data suggests that those who experience three brainstem injuries have a <1% chance of functional independence. I have ceased reading the harrowing stories, from loved ones, concerning the utterly devastating effects of brainstem strokes. The cruelty that such injuries can inflict on survivors and their carers is beyond belief.

I was fortunate in that I was relatively young, fit, with no evident impairment of cognitive and intellectual capacities. I had a scientific/clinical background, great and continuing support from family and friends and a determined and motivated mentality. However surviving and recovering from these brainstem haemorrhages has taken and placed a very substantial toll on the human frame. I fully realise that I will never be the old me. This has proved especially difficult for my immediate family who have been forced to accept that this new personality differs from what existed before. Disability unfortunately forces a switch in emphasis towards oneself reducing in priority other concerns that were previously important. While the financial costs have been very considerable they pale in comparison to the devastating physical and emotional consequences that remain an unfortunate reality for ABI victims and their loved ones. The reality is if I was offered the Euro lotto or a resumption of my original good health I would immediately choose the latter. You can never put a price on your personal health but most of us never fully value it till it is taken from us. The cost to the state has also been substantial. However, given the amount of tax I have contributed to the exchequer over the years they should retire me to the Seychelles for rest and recuperation!

Prior to my ABI, life, for the most part, was busy and lived in the fast lane with little time to reflect. In contrast, since the ABI, I have had plenty of opportunities to focus on the past. Perhaps the only important thing about the
past is to learn from it. Although I will bring the neurological/physical consequences to my grave the last 3 years have given me the opportunity to learn more about my physiology and enhance the wisdom of my mind. Recovery, particularly of my right side, has uncovered muscles and connective tissue that I never knew existed. I have also learned how the brain works. Perhaps I should be more definitive and say that I now have a better understanding of why it doesn’t necessarily do what you want of it. I have learnt that to resume lost functions one needs to work slowly but steadily on the brain and get it to reactivate/refine existing pathways or though the process of plasticity “patiently encourage” other regions in the brain to create new neuronal pathways and replace those irreversibly damaged by the ABI.

Life, since my ABI, is a constant battle. Even small things like dressing, showering, eating, climbing the stairs etc. can be such a chore. I wouldn’t contemplate putting a dog through it. Progress has been agonisingly slow, invariably negligible, occasionally reversible and seldom palpable. Prior to my ABI the healthy body was readily able to absorb the affects of exacerbating external factors. Now such influences are often immediate and invariably pronounced. Unfortunately, I now realise that aspects of my physical and mental rehabilitation will remain, regardless of my resolve. I have learnt with a brainstem stroke to expect the unexpected and then get used to it. Frustration appears to be a constant companion - forever observing, seldom partaking. One yearns for past participation but stark reality soon intervenes. Social events (when I can attend) remain, arguably, the best outlets for escaping from reality. However, appearances can be deceptive and several days can be carefully spent managing the balance between rest and exercise just to attend such events. If only the book was half as good as the cover. Dressing up (well a wee bit anyway) is a drain. I also know that I won’t be able to sustain my current level of exercising. My ABI has and will continue to impede and negatively impact on my domestic life, work at home and abroad, mentoring/coaching juvenile teams, socialising, diet and alcohol consumption and most significantly as a parent. I have fond memories of playing with Gavin and Killian. Finer pursuits such as zoom photography and painting seem quite distant. Instead I have had to be resourceful and adaptable to participate both within and outside the home. Finding sufficient energy to partake remains the greatest challenge by far. I have learnt that life is both fragile and short. Make the most of it.
TIPS (the Do’s and Don’ts - in no particular order)

1. I adapted the pursuit of my "3 P’s" - positivity, patience and perseverance. It is important that one maintains a positive outlook. This is because ABI patients learn to differentiate the mind from the brain and body. When the mind is negative the body follows accordingly. Brains can repair themselves through the power of positive thinking. Neuroplasticity demonstrates the remarkable adaptability of the human brain. It is important to embrace all that is positive in life be they people, challenges or situations. To do this one should make a genuine effort to get out of the house at least once each day, even if only for a short walk. Patience is huge. Expectations may initially be high but the reality, for most ABI victims, is that progress is extremely slow and therefore must be measured in months and years. Brain recovery is generally excruciatingly slow
and frustrating. Retrospective comparisons with life before the ABI are very unhelpful and can lead to a depressive outlook. Instead, progress should be measured by comparison with life since the ABI. If one remains positive and patient the results of one’s perseverance will bear fruit. Progress for the first few years, especially in adults, is often significant initially and tapers off subsequently. However, through the process of neuroplasticity one can continue to challenge the brain to adapt to increasingly difficult circumstances. This undertaking of rigorous exercises (almost daily) takes extra effort and commitment but is rewarding, albeit slowly. A positive, motivated outlook, coupled with patience will reward those with the persistence and determination to continue their recovery.

2. Accept that depression is an almost inevitable consequence of an ABI. In fact depression is seen as a necessary step in the realisation of one’s predicament. Accepting and acknowledging depression can be difficult if one was reared in a sporting environment where the consensus was “have a few pints and you’ll snap out of it”. Depression feels like being in a dark hole from which it is very difficult to escape. It is important to give the body sufficient time to rest and grieve. Depression seems to be more frequent during the dark winter months or when one is off therapy. Anti depressants are often beneficial but their side effects can also have damaging consequences. Follow your doctor but try to wean off them when/if depressive symptoms subside. The SNRIs (anti depressants) act by increasing the levels of the neurotransmitters serotonin and noradrenaline in the brain. Spontaneous responses and/or emotions are not uncommon as the “moody” brain patiently rebuilds the circuitry required to keep these feelings in check. Try not to compare life with how it was before the injury. Instead compare it with how it was immediately after. Omega oils are particularly good at targeting neurological illnesses. I have always regarded these capsules as a daily way of massaging my injured brain. However, omega oils (and ginger) have blood thinning properties! A recent newspaper article described how a patient successfully used the support of family/friends, a good night’s sleep, yoga, exercise/walking and meditation to help climb out of the trough of depression.

3. Address the mental side of things. A disproportionate amount of time is devoted to physical rehabilitation relative to mental wellbeing. It is important
to realise that all ABIs result in some damage to neuronal pathways which will therefore affect your personality no matter how indiscernible. A neuropsychiatric examination is essential if one is to maximise the physical/body recuperation. Occasional impulsive behaviour was bothersome particularly after I left REHAB. However, with patience and time the rewired circuitry has made me less responsive and more tactful. Rebuilding a pause is not easy. The cessation of hospitalisation can be stressful as one tries to manage without the constant support of healthcare staff. Similarly the loss of independence can be daunting and emotional especially when one returns home. Inability to return to work can be crushing. Join a brain injury support group. Get professional assistance if you feel desperate.

4. Stress is highly destructive. Dr Aswad has indicated that stress can alter neurological symptoms after a stroke. Research at Princeton (Jacobs et al) has shown that stress is the greatest precipitor of depression. It may feel like a catch 22 situation with one feeding the other. Prof Bertalanffy is convinced that stress is the primary causative factor in the onset of cavernoma bleeds and re bleeds. From my experience his opinion is widely shared by the cavernoma community. His R&D team is currently actively researching this matter. The effect of stress is not only limited to the onset of the actual symptom(s) but also to the negative role it plays in recovery. For me the most immediate and significant effect of stress was unstable/wobbly balance (vertigo) and blurred vision. Stressful thoughts including anger, frustration and anxiety caused numbing of the affected limbs (progressively leading to deadening - setbacks/relapses), impaired hearing, facial twitching, increased muscle tone, headaches sometimes severe especially in the right temporal lobe, darting pains in vicinity of brainstem, intracranial pressure, heart palpitations, grating pain in right hip, piercing darts at back of right knee, fatigue etc. The onset of symptoms may be instant but the side effects can last for hours, days or even months. Setbacks/relapses can undo the neurological progress made with touch, grip and balance receptors. Stress management is critical to those patients hoping to recover from an ABI. Stress devours energy leaving one depleted. Stress suppression and expression are both potentially harmful. Avoidance of stressful situations (arguments, differences of opinion, upsetting ideas etc) with people becomes the primary solution if one's recovery is to remain on a positive curve. Over sensory stimulation (distance and night driving, excessive
background noise, concentration and/or eye strain reading/writing etc.) has a similar but significantly reduced effect as psychological stress. Over physical exertion may have side effects but they are usually fleeting unless one is already compromised.

5. Abstain from alcohol if cannot permanently restrict it to two units per social night. Alcohol consumption kills neurons in the cerebellum which coordinates movement (staggering drunks!). For ABI victims the effects of alcohol not only include a worsening of coordination but alcohol also inhibits several medications, exerts a strong depressive effect, weakens the immune system and has a dehydrating effect depleting the body of valuable energy reserves. Alcohol can be seductive. Its alluring qualities can override one’s best judgement. For ABIs one learns that some indulgences have a physiological price. Manage it or give it up.

6. Exercise daily. Walk outdoors and perform home exercises every weekday. Give your body a rest at weekends (or more often if necessary). Maintenance of aerobic fitness is essential for everyday life. Wii fitness is now a popular way of exercising indoors.

7. Listen to your body for signs of fatigue, exhaustion and "over doing it". I used the increasing aggravation of tinnitus to call a halt to exercising but other indicators such as the onset of headaches, temporal throbbing, breathing difficulties, sensory overload, perspiration etc indicate that the body has had enough and needs to rest. I now use the symptoms of vertigo as a daily indicator of general wellbeing and my ability to (or not) engage in exercise. Pace yourself. Use gentle exercises and avoid strenuous workouts/weight lifting. This identification of your energy threshold is arguably the most important challenge for ABI patients as it requires much trial and error type scenarios. Knowledge of your energy tolerance is critical to determining what your body is now able to achieve. The battle between what your mind wants to do and what your body can do is constant. Enhanced understanding of one’s limitations may lead to a better undertaking of daily tasks.

8. Join a gym, health club etc. One can improve aerobic fitness by swimming, treadmills, exercise bikes, rowing machines and walking etc. Weights and
appropriate exercise machines can be used, very slowly and gently, to build up one’s muscular strength. However, from my experience, by far the greatest improvements can be achieved through focussing on one’s core region which promotes stability, equilibrium, complete body strength, resistance and flexibility.

9. Perform exercises in the water. The buoyancy and support provided by water considerably reduces the pain associated with floor exercises. If required use the sides, steps, rails, inflatables to perform exercises safely. Be warned, you may look like a wally! People may have looked at me as if I was odd but having damaged my left hemisphere, in which the ego centre resides, meant that I was largely indifferent to their disapproval.

10. Eat a healthy diet and if suffering from a stroke lower your body weight to reduce the load carried by your unaffected hip/leg.

11. Exercise in the morning when your energy levels are greatest. Ensure that you eat a good breakfast with slow energy releasing foods such as oats, bananas, porridge, cereal, fruit etc. Keep the afternoon for less strenuous exercises eg. mental, arm, fingers etc. Take naps during the morning and afternoon and relax in the evening. Try to keep your eating in proportion to your subsequent energy demands. Therefore eat more in the earlier part of the day and try to avoid snacking at night.

12. Eat foods containing tryptophan - banana, yogurt/milk, turkey, meat to increase levels of the neurotransmitter serotonin. Serotonin promotes wellbeing and the feel good factor and is also known as the “happiness hormone” despite not being a hormone. The receptors for serotonin - 5HT are located on the paphe nuclei along the entire length of the brainstem. These foods can also be used to promote sleep. Vitamin B6 improves conversion of tryptophan to serotonin. Nerve cells are sensitive to citrus fruits, coffee, alcohol and excess salt. Employ multivitamins, tonics post ABI to increase and/or maintain your levels of essential metabolites. B complex vitamins are good for energy restoration and the nervous system. Glucosamine/chondroitin strengthens joints. Bob Casey (a professional rugby player with London Irish) writes a weekly
13. Savour sunshine in moderation to improve one’s mood by stimulating serotonin release, increase vitamin D levels and the welcome inflow of fresh air. It is probably no coincidence that sun tanned people often feel good about themselves. I now relish opportunities to sit in the back garden enjoying the sun. Since coming home from the NRH I have begun to watch out for smiling sun symbols on the evening weather forecast. Being greeted by the bright glow of an invigorating sunrise is a good start to the morning.

14. Keep a daily diary – monitor your progress. Dr Delanty encouraged me to keep daily diaries (6 now) since relapse in Oct 08. They detail everything from medication, doses, symptom onset, energy levels, mood, stress, balance, exercises undertaken, vertigo, rest taken, types of headaches etc. By reviewing my diaries in detail I was able to retrospectively assign the numerous, detrimental side effects of different medications/dosage. An additional bonus was helping me to learn and maintain writing with my left hand.

15. Take breaks/holidays whenever feasible. Hotels with a pool and providing full board with a nearby beach/promenade to facilitate exercise/walking are ideal. I enjoyed our family sun holidays in Lanzarote and Belmadena during the summers of 09 and 10. I also took a very beneficial retreat in Cloona, Westport in August 09. This break introduced me to the benefits of raw, vegetarian food and yoga. It was here that I adapted my positive statement "I have the power to heal and be happy". I employ a brief yoga session every morning to (try to) reinvigorate the mind and body.

16. Static balance is best improved by a combination of balance and core exercises. I increased the degree of difficulty for balance exercises by performing them with my feet closed, barefoot, on a balance foam pad (akin to standing on a wobbly mattress), with eyes closed, on a wobble board and by searching google for advanced board exercises. Dr Duffy indicated that whereas imbalance was primarily symmetrical on wobble boards it was more random and therefore better on foam pads. With balance exercises it is especially important to ensure safety is maintained throughout.
17. Dynamic (mobile) balance is more difficult to achieve indoors. Walking, treadmills (slow), cross country skiing exercise machines (without hands), threading water (chest high) in pool/beach, foam pads and wobble boards can be helpful. Hard beach sand is arguably the safest surface for one’s initial dynamic walking exercises. I found the wild isolation of the beach on the North Bull Island to be particularly refreshing. I discovered, from walking on pavements, that small paving slabs and freshly laid tarmac provided a safer (better grip) walking surface than large slabs, cobblestones or cement. After early morning school runs I regularly walked (and rested) around the tranquil pavement of Blessington Street Basin in the heart of Dublin City centre. Videos on You Tube demonstrating these exercises are especially helpful. One could start by searching under “stroke rehab”.

18. Keep your friends informed of developments. What amazed me most was the goodwill and generosity of people towards me and the family when the ABI struck. Many wonderful people have nurtured my health. I am very grateful for all the kindness we have received. It is very important for one’s own mental wellbeing and therefore recovery that one makes every effort to meet positive, amusing people on a regular basis. Fortunately, my friends were hugely supportive, tactful yet non intrusive. Every day that I received a message (text, e mail, letter, card, present etc) reinforced who I was before the ABI. The power of this unconditional support gave me the courage to face the challenges of recovery. Unintentionally, I also became a welcome recipient for jokes etc. Well intentioned but negative/stressful people can drain the little energy you have. To minimise stress and physical inconvenience I chose not to answer landline phone calls and unexpected rings on the door. Instead, advanced texting/ e mail have become my modus operandi.

19. Honour the healing power of sleep. Respect the brain’s need for plenty of rest. The need for regular periods of rest cannot be over emphasised. One often is not aware of the level of exhaustion until a bed rest is taken. My appreciation of the importance of rest is greater now than ever. Bed rest during the day, without sleep, is often just as satisfactory providing one’s eyes are closed to sensory stimuli. Sleep is very important as it allows fatigue to abate and renews both alertness and energy levels which are necessary to
tackle each day. The consequences of a poor night's sleep are a very significant deflation of both mental and physical functions. Medication including natural herbal remedies, tryptophan rich foods and moderate mental stimulation such as reading can all assist this important process. If I can't fall asleep at night then I consciously loosen my jaw and then proceed to pass out. I try to avoid going to bed until I am sufficiently tired to do so and have made sure to get up early, where possible, to prevent the harmful effects of rumination. This dwelling on negative thoughts is stressful and can deflate mood. Internal verbal analysis is not ideal behaviour and for the sake of one's mental health it is important to keep these negative thoughts in check.

20. Make sure to seek a second opinion on your cavernoma(s), especially if symptomatic. This is imperative. It is advisable to store your MRI scans on disc to facilitate proper assessment by a recognised neurosurgeon. Gradient echo MRIs provide the best resolution for cavernoma diagnosis. Gadolinium dye injection can be used to enhance MRI contrast. International experts and local/national neurosurgeons can provide second opinions. Submission of the E112 application may allow overseas financial assistance within the European Union. While MRIs remain the gold standard for cavernoma definition CT scans remain the best at detecting bleeds. For those patients with a history of cavernoma bleeds and neurological deficits of unknown cause and who require monitoring CT scans may also be considered.

21. Because of the trauma of an ABI the patient's brain circuitry is rewired. This means that the patient will have (whether he/she likes it or not) a shifted perception of the world with different likes, dislikes and interests. Damage to either or both hemispheres can result in a conflict between what we think (left) and what we feel (right). I like to think of the left mind governing our work, researcher, judging and masculine thoughts whereas the right hemisphere regulates our holiday, diplomatic, perceiving and feminine minds. In my case the left hemisphere was damaged by the strokes. Resurrection of the damaged side over the now dominant hemisphere is an ongoing process. The right mind accurately decodes emotion and is socially adept. It is the observer, higher consciousness and the wiser person. The left hemisphere is excellent at organising information taking responsibility for describing, judging and analyzing everything. Since my ABI I find organisational and physically/mentally
challenging domestic tasks to be difficult. Rushing is particularly stressful as it invariably requires one to speed up doing things which have become difficult. I am most at ease relaxing in an armchair with my elevated right foot at rest. Life has had to become minimally simple.

22. The following books were helpful to my recovery: My Stroke of Insight by Jill Bolte Taylor, Dipped into Oblivion by Sacha Bonsor and The Brain that Changes Itself by Norman Doidge.

23. Relaxation therapy such as yoga, massage, listening to music, Tai Chi, floating in water, showering, ocean breezes, the creative arts, walking in nature and meditation are subjectively beneficial to the recovery of both mind and body. Pets, especially those that enjoy being petted, are a pleasant distraction. With this in mind we got two lap cats, Queen and Chloe, whose mischievous nature is a constant source of family entertainment.

24. Brain training tools are beneficial to cognitive recovery. I also took up learning a new language to stimulate cognitive redevelopment. I am in my second year of learning Italian and enjoy the whole experience. Daily reading, browsing the internet, doing crosswords, playing sudoku, board games, etc. Verbal and written communication with other people can all stimulate your intellectual network. In the Autumn of 2010 I volunteered to coordinate adult player subscription collection for the 2011 season by email. I was grateful for the able assistance of the club's administrative staff to complete this “messy” task.

25. Imagery appears to be an effective tool for regaining the ability to perform physical goals. By dreaming of how to achieve a particular task it becomes easier when attempted. It is now widely used in the sporting arena whereby athletes visualise their performance beforehand. In the ABI recovering environment such “visualisation” can keep the neuronal circuitry alive until the body is ready to make it a reality.

26. Avoid blood thinning or anti– clot medications including Aspirin and Disprin. I naively took Anadin tablets for several months before my first bleed to relieve the symptoms of headache etc. A cavernoma pen pal of mine suggests Viagra may have a similar risk.
27. Hand exercises involving keys, texting, writing, laces, eating, drinking, clothes pegs, coins, scissors, tearing paper, chopping, tweezers, putty, shaving, darts, buttons, zips, etc can be part of a beneficial home exercise programme to improve dexterity and strength. I have found typing on my laptop to be especially good for right hand tone renewal. I am currently playing “ant smasher” on Gavin’s new ipod to improve coordination in my hand. I began mirror box therapy in early May 11 and from initial, brief but daily use would recommend this visualisation procedure, at relatively low expenditure, for improving motor movements and reducing ataxia in affected hands.

28. The new website www.researchandhope is particularly good for information about modern stroke management therapies (can also apply to cavernoma patients with neurological conditions). The UK website “Different Strokes” is extremely informative about all aspects of stroke support for under 65s.

29. The Cavernoma Alliance UK website and its sister organisation in the USA Angioma Alliance are very helpful and enormously informative. I would also recommend joining a cavernoma hub to share experiences and knowledge.

30. Keep up to date with research and developments in the field (Neurology). The Different Strokes newsletter is particularly informative. Recent research has shown that in traumatic brain injuries and strokes that have caused cells to die new neurons may be generated from neural stem cells and travel towards the site of the injured area. Kings Hospital in London has shown that the self repair process of neurogenesis can be enhanced by physical activity, learning new tasks and consumption of blueberries, omega oils and 10 mg zinc daily. In contrast, a high fat/calorie diet, ageing, stress and sleep deprivation adversely affect neurogenesis.

30. Embrace your garden. That is if you don’t live in an apartment! This is particularly so if you are home confined due to disability or mobility/balance problems. Gardens, particularly those in the rear/ with some privacy/ south facing etc can become a sanctuary for relaxation/contemplation/sunshine/fresh air etc. A radio, reading material, music etc can be a good companion. In essence your garden can become an oasis or additional room where the only limit to
enjoyment is one's imagination and relevant privacy legislation! Let's face it immediate family members might be glad of the break too.

31. Distance the past. It is helpful for your redevelopment, following an ABI, to make a decision that one will never return to some aspects associated with the past. To fully accept one's new predicament one should try to ditch the old self. For instance, after 3 years I reluctantly realised that I would never wear many of my clothes again. The deliberate placing of these garments and footwear in a charity bag helped this adaptation. Leisurewear it will have to be.

32. I have to admit that I have some reservations about alternative medicine. However, the provision of relaxation may be therapeutic / beneficial through stress relief alone. I had been going for acupuncture for at least 2 years prior to my ABI. It was largely to provide some relief from the headaches, fatigue and facial spasms that I was regularly experiencing. I now realise that the cavernoma was active long before it bled. My therapist, Tina, has been enormously helpful and regularly included reflexology and homeopathy. As she searched and prodded my skin with needles she mentioned that I had the “heart of a lion”. I didn’t tell her that I had a packet of Kleenex on standby. In May I returned for another course (8 sessions) of acupuncture to revive and reenergise a body weighed down by a stroke, shingles, head cold and a recent dose of a gastric flu. The shingles rash eventually disappeared within 2 weeks of commencing this treatment. However, it soon returned. This latent virus will probably hibernate in my ganglia but the shingles should hopefully soon disappear with the return of energy. It was interesting that my Neurologist also recommended acupuncture for energy restoration. Whether it should be considered as curative, preventative or restorative is subjective.

33. Listen to or read about other people’s stories of success. They are invariably positive. They have often recovered from poor health or triumphed over adversity in life. I have found the endurance of Antarctic explorers and sports persons to be particularly inspirational. Given my background and the relative blanket coverage of sport on television my heroes can be found closer to home. The recent May bank holiday weekend comes to mind. Firstly on Saturday the Leinster rugby team brilliantly overcame the class of Toulouse. Then the following day the Dublin hurlers tore up the form book to beat fancied
Kilkenny and win their first National Hurling title in 72 years. The last time, in 1939, coincided with Hitler’s invasion of Poland! Both teams, although showing no little skill and commitment, were united by one common denominator. Belief. It’s strange, but this is possessed by some but available to everyone. Belief in plasticity has got me this far. I know it can go further. The book “The brain that changes itself” is highly recommended. What amazes me is that the sophisticated machinery in sceptical creatures (humans) is governed by something that isn’t palpable – the mind. The adaptability of the brain is truly remarkable. Progress is tortuously slow but with patience literally anything is possible. ABIs should aspire to becoming achievers too.

Acknowledgments

None of this story would have been possible without the love and support of my family (Madeleine, Gavin and Killian), father (George), brothers (Fergus and Aidan) and all my friends, clubmates in St. Vincents, relatives (esp the Ryans) and colleagues in the IBTS, Beaumont, EFI and abroad. My recovery efforts are devoted to all the wonderful healthcare staff in Beaumont Hospital, National Rehabilitation Hospital, Headway, Mater Hospital, Bon Secours Hospital, Cremore Clinic, London, Zurich, BRI etc. The cavernoma and stroke patients, carers and families provided the motivation for this article. It is my genuine hope that they may benefit, no matter how small, from our shared experiences.

All of the above is personal, subject to change and should not be undertaken without qualified medical advice.

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The 3rd anniversary of my cavernoma excision was on the 8th May.

Production and photography: Killian