

AHCDO 20th Anniversary

One of the few privileges of older age is to be able to reminisce about the old times and the personalities that one has encountered and to some degree unshackle oneself from the fear of failure which I suspect drives and haunts most of us. With the way the economy is at present, in my case, unfortunately the fear of failure persists. So assuming my position as one of the elders, I will reminisce about my journey in the field of haemostasis and haemophilia and if I fail to avoid one of the classical traps of the elderly namely to philosophizing I hope you will forgive me.

My first encounter with haemostasis was in a tutorial on blood coagulation by Jack Hirsh, who was then a registrar and had passed his MRACP exam, in our eyes an exalted human being. I still remember being totally gob smacked by the coagulation cascade of McFarlane and Biggs and wondering on how the heck I was ever going to remember it for the forthcoming exams. I need not have worried since my examiners knew even less than I about McFarlane and Biggs papers and certainly cared even less. And why was that? Because in those days whole blood banked or given by direct donor to patient transfusion and plasma were the only available haemostatic agents and the adage was that when they exsanguinate they will stop bleeding.

My next encounter with haemostasis was during my fellowship training in haematology and oncology in Los Angeles. My senior fellow colleague was Gerry Gilchrist who was South African with family in Sydney. We had a lot in common including strange accents for our USA colleagues, passion for sport including a game totally beyond the comprehension of native Americans, namely cricket and an interest in haemostasis.

Fortunately, LA Children's Hospital had no manual for blood coagulation or platelet function tests and so my ultimate boss, Denny Hammond, decreed that I should spend some time in the lab. of Sam Rappaport. By now I knew that he was some dude but little else about him. The first hurdle was to find my way on the LA freeways to LA County Hospital. Let me remind you that at this time Melbourne had no freeways and I was still pretty new to the LA freeway system since we lived within walking distance of the hospital. So I set out in my little Datsun 1200 full of trepidation and fear of failure and by some miracle managed to negotiate the Pasadena Freeway in downtown LA and take the right exit to the hospital. Next challenge was to find the haematology department of Sam Rappaport. After wandering through the cavernous corridors which could have accommodated a Sherman tank I finally found Sam's office and his secretary.

Sam served in World War II and was acquainted with Australians. I think he was sympathetic but his opinion of Australian achievements in science was not high. To my very good fortune he delegated my training to his chief technician who to me at this stage of my life was an elderly lady, though in retrospect she was probably in her early fifties. She was a splendid teacher and mentor and bequeathed me the lab manual on coagulation which I used for many subsequent years. Her name was Mary Patch. So, I can boast of having done some of my training with the great Rappaport but really it was his technician who trained me and only in my later years did Sam's major contributions to haemostasis influence me.

The next great of Haemostasis I met was Oscar Ratnoff in Cleveland. Again I was sent there by Danny Hammond to further my training and again the trip was eventful. I first stopped in Detroit and attended a 2 day meeting on blood coagulation run by Seegers of the prothrombin fame. I was so baffled by the biochemistry of it all that I and some other fellows of my vintage indulged in a few too many beers at the Detroit airport. I suddenly heard my flight being called and tried to find my departure lounge. It was the first time I had encountered an airport built like the spokes of a wheel and

by the time I had raced through multiple spokes my flight and my luggage had gone without me. It was winter on the east coast and I had no money. Fear of failure was turning to desperation. Fortunately the staff took pity on me and without extra charge I took the next flight to Cleveland and turned up on time in Oscar's lab. He was very kind to me and I spent a whole day in his company seeing patients and visiting the lab. It was here that I met briefly a young investigator who was purifying factor VIII and using it to develop rabbit antibodies to measure factor VIII related antigen, Ted Zimmerman who ended up working with Sam Rappaport and died far too early in San Diego.

LA Children's Hospital looked after some boys with haemophilia A and B and was using cryoprecipitate in their treatment. So, to complete my training I was sent to the LA Orthopaedic Hospital to meet with Shelby Diettrich and Carol Kasper and learnt more about treatment of haemophilia. By now I was an experienced Los Angeleno and despite the hospital being close to skid row have no more travel stories to tell. I learnt a lot about haemophilia center organization and the role of physiotherapy. Most importantly it was a center run by powerful women who could even control orthopaedic surgeons, a novel experience for a young Australian male.

When I returned to the Royal Children's Hospital Melbourne I suffered not future but past shock. There was stasis and not haemostasis. The lab was primitive and children with bleeding disorders were looked after by general paediatricians with little knowledge of haemostasis and even less enthusiasm to learn more. After some pushing and shoving I was allowed to set up a haemophilia conference clinic consisting of orthopods, physiotherapists, nurse and social worker and gradually all patients with haemostatic disorders were referred to me and the "conference". By now cryo was the treatment of choice for haemophilia A and PPSB for Christmas disease. Somehow I managed to set up the first home treatment programme using cryo and car refrigerators and to train the mothers to dissolve the cryo in luke warm water and infuse it to their boys. I still wonder at my "chutzpa" for undertaking this process. By the way I would like to define the word "chutzpa", it is the quality shown by a man who murders his mother and his father then asks the judge to forgive a poor orphan. My praise goes to the parents for urging me to establish it and successfully carrying it to the time when factor VIII concentrates became available.

Haemophilia treatment in Australia at this stage was fundamentally run on Marxist economics, by which I mean, Government controlled and funded centralised means of production and distribution by CSL & ARCBS, absolute and enforced adherence to a fundamental principles of self sufficiency and volunteer donors, and rationing of resources which meant a permanent shortage of coagulation products, particularly factor VIII.

Into this Marxist system was introduced a bunch of USA trained "rugged individualists". They are all here and are all my respected colleagues so I must not tell tales out of school, but I will.

I first truly met Kevin Rickard at a meeting of the ASMR of which I was then the secretary. The meeting was in Surfers Paradise and the annual dinner was a heady mixture of wine and beer. Kevin who had returned to Sydney instead of Melbourne had to establish himself at RPA, by no means an easy task for a Melbournian and Aussie rules footballer. Anyhow, while wandering along the foreshore in an inebriated state he abused me for being in Melbourne and I abused him for being in Sydney. Having got our parochial prejudices out of the way in just one evening we became the best of friends.

Kevin was what I call a real refusenik in the Solzhenitsyn's meaning of the word. He was brave and outspoken about the evils of rationing of resources and didn't allow the chief commissars to brow beat him. Unlike Solzhenitsyn he was not imprisoned in a gulag and expelled from Australia but he did become our emissary abroad attending and contributing to the many meetings of the WFH and in a published and presented paper he compared our access to plasma for production of factor VIII to that of Bangladesh. While Kevin never risked imprisonment in Australia he and Jenny

Ross had to be rescued from the bandidos running the Mexico City WFH meeting who did threaten to imprison them, the only time I have seen Kevin genuinely shaken. Kevin's role has now been taken by Alison Street who can now be a diplomat, that is she can practice the gentle art of telling someone to go to hell in such a way that he looks forward to the trip.

Others such as Alison Street, John Lloyd, John Rowell, Jamie Price and Ross Baker preferred to work behind the screen of respectability but with the same aim and determination to stop rationing of product and to achieve a system of distribution which addressed clinical needs of all persons with haemophilia A & B and stop the hoarding of products within state boundaries.

At this pleasant occasion I will not talk about the impact of HIV and HCV on our system except to say that it ushered the most profound changes. There were quite a few heroes in those days but none greater than Jenny Ross who managed to conciliate between patients and their families, clinicians and the government to achieve over time a balance which I believe is the best in the world. The bitterness of this era is epitomized in Bryce Courtney's book April Fool's Day

Like the Berlin wall the rationing wall fell with the availability of recombinant factor VIII and IX. Capitalism was now the dominant system by which I mean that the only restraint on unlimited use of resources was the availability of money and not product. Now Governments suddenly became aware of the true expense of treatment of haemophilia as they bore the cost of compensation for HIV and the cost of recombinant product used at optimum doses consistent with developed world standards.

There was clearly a need to control expense and to plan for the future. To the amazement of some we didn't even know how many persons with haemophilia were in Australia and how much product they required. This is when Ross Baker's foresight in fighting for the ABDR became crucial and with the conquest of the NSW department of health reluctance to submit data and with the assistance of the NBA has provided an essential resource for the haemophilia community and the Government.

Meanwhile the Ninian Stephen's report gave rise to the establishment of the NBA, a sort of "Reserve Bank" institution without the right to set interest rates but with the ability to control the flow of capital ie products to HTC's ie banks and ultimately the customers, namely the patients. Led by Alison Turner the NBA has been responsive to customers needs for quantity and choice of products.

This is all very well but HTC were run by rugged individualists, some with bad habits. They met at conferences every 2 years or so spent time as the MAP of the HFA discussing a variety of agenda items which while interesting had little impact on treatments in various centres. This unsatisfactory state of affairs became apparent to John Lloyd, recently returned from sabbatical leave at the Oxford haemophilia center and he together with the other HTC directors as well as the HFA at a meeting in Fremantle 20 years ago were determined to change it. Together with Jenny Ross and the HFA they agreed to a consensual divorce of the MAP from the HFA and the creation a new independent organization to be known as AHCDO under the chairmanship of John Lloyd..

AHCDO is now past its adolescence and from what I hear is a responsible and mature partner of the NBA and a coordinator of uniform haemophilia care in Australia. We now have a well regulated system and almost a market based approach to supply and distribution. There appear to be no hidden underperforming assets and sub prime mortgages and well covered risk management.

Is there still room for the rugged individualist? Is there space for nonconformism? Ground breaking change requires freedom for individual action and enterprise. AHCDO in its mature years should sustain freedom of action by new and young associates and ensure that regulation never exceeds its proper boundaries.