

Robin M Winter

W Nance

On April 15, 1976, a young physician wrote to me from England to inquire about the possibility of spending a year in the new Department of Human Genetics I had established at the Medical College of Virginia. We had no funding for postdoctoral positions at that time, but Robin Winter had trained at the Galton Laboratory, and was highly recommended by Gerald Corney and Harry Harris whom I both knew well, so we cobbled together support for a fellowship from research funds and welcomed him to join the department in Richmond. After seemingly interminable delays over his passport, Robin arrived with his wife Joan in June of 1977. He quickly became a favourite in the department and impressed me most by his insatiable desire to learn everything that was known about all aspects of human genetics, even though his bent was clearly towards clinical genetics. During his 18 months in the department, Robin made many friends and acquaintances—Fred Bieber, Cynthia Morton, Wendy Golden, Wendy Segreti, Lindon Eaves, Victor McKusick—some of whom remained close professional colleagues and collaborators throughout his life.

When the end of Robin's first year approached, we tried very hard to persuade him to stay longer, but he was intent on getting back to England to start his career there. After a six month extension, during which he attended Victor McKusick's Bar Harbor course, he returned to take a position at Northwick Park Hospital on the outskirts of London.

When Robin and Joan left Richmond, I asked Robin what his immediate goals were. He told me that he was thinking about developing a computer program to help clinicians to diagnose genetic syndromes. The number of recognisable

syndromes, he said, was already getting out of hand, and it would surely get worse in the future. I remember being vaguely disappointed and thinking to myself that simply cataloguing recognised syndromes, no matter how profusely illustrated they were, was really an unworthy goal for such a promising young geneticist, especially when, by his own admission, there were so many new syndromes yet to be identified. His plans were similar, I thought, to Victor McKusick's unaccountable obsession with nosology so clearly reflected in his burgeoning catalogue of Mendelian diseases. Although taking Victor's first Bar Harbor course, as a medical resident wondering if one could make a living as a human geneticist, had been an important turning point in my career, I began to think that perhaps it had been a mistake to arrange for Robin to take the course.

When Robin's London Dysmorphology Database was finally finished, we bought the system out of a sense of loyalty, but I seldom used it until one day I saw a young man in our clinic who had been referred because he had sustained fractures on multiple occasions while riding his motorcycle. I expected to find someone who either had osteogenesis imperfecta or was a pathological risk taker, and was astonished to encounter a normal looking teenager who was legally blind—a finding that the referring physician had failed to mention—with no vision in the right eye and almost none in the left. When I got back to the department I decided this would be the case that would confirm my prejudice that you couldn't learn anything from the Database that you didn't know already, so I entered "fractures and blindness" as search terms. Up

popped the Osteoporosis – Pseudoglioma syndrome, and when I glanced up from the monitor, I could see Robin looking at me across the Atlantic with that expectant half smile that came across his lips when he had just told you a joke or one of his horrible puns and was waiting to see if you got it. Since then, every time I have used the system, I see him again in my mind's eye.

Over the years, we got to see Robin at meetings, and I visited him at his home in England on at least two occasions. The last time I saw him was at the Genetics Congress in Vienna. At that time I was impressed again with his quiet confidence and the high esteem in which he was obviously held by his students and colleagues.

Many years ago when I decided to go into academic medicine, I asked my grandfather what he thought were the main rewards of an academic career. He had been a Greek and Latin scholar all of his professional life, was President of Soochow University in China for several years at the turn of the century, and was then in his late eighties. I was surprised, and somewhat put off and confused by his answer. He said he really didn't even remember most of the hundreds of students he had taught, but the thought that he had made some small contribution to the later success of his three or four most gifted students is what made his whole life as a teacher seem worthwhile. Now of course, when I think of Robin, I know exactly what he meant.

Robin's untimely death, after the brief span of 53 years that were allotted to him, teaches us all a poignant last lesson about genetic individuality: we will not see his like again, and as I think about him now, I seem to see the half smile again and hear him whisper "Do you get it?"

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Robin M Winter—a colleagues' perspective

E M Rosser, L M Wilson

Like most trainees in clinical genetics we first met Robin at the Dysmorphology Club and would come away

in awe of his encyclopaedic knowledge and amused by his comments. We were both fortunate to spend some time at

Great Ormond Street Hospital (GOS) during our training and were subsequently appointed as consultants there. It has been a privilege to work with Robin and this article concentrates on Robin as a colleague and a friend.

Robin used to say that his interest in malformations and man-mouse homology started during his enforced gap year, spent looking after laboratory rats because he was too young to start medical

school. He went on to do an intercalated BSc in genetics at the Galton Laboratories. After qualifying in medicine from University College, London, Robin began training in paediatrics and it was while he was working at Harperbury Hospital that he first met Michael Baraitser, the visiting neurologist. He persuaded Michael to tutor him for his clinical Membership exams and that was the start of their life-long collaboration and friendship. Michael stimulated Robin's interest in dysmorphology, which Robin followed up by spending 18 months in Virginia with Walter Nance. He returned to the UK in 1978 to take up one of the first three senior registrar posts in the new specialty of clinical genetics. His fellow post holders were Dian Donnai and Ian Young.

In 1981 Robin was appointed to a consultant post at the Kennedy-Galton Centre (KGC), Northwick Park Hospital, Harrow. He organised the department in what was to become a trademark manner, setting up weekly clinical meetings and slide reviews and developing, with Shire, a database for use in the clinical genetics department. During his time at KGC, Robin conducted peripheral clinics throughout northwest London, Hertfordshire, and Bedfordshire. However, his main interest continued to be dysmorphology and he travelled to GOS each week to do the "Thursday" dysmorphology clinic and afternoon ward round with Michael Baraitser.

In 1992, Robin moved to full time to GOS and the Institute of Child Health, dividing his time equally between his clinical work and research. While he said he had done his share of peripheral clinics at KGC, he was always willing to cover outreach clinics where needed and, from the alacrity with which he would volunteer, it seemed that he enjoyed them.

In 1994 Robin was appointed to a personal chair, Professor of Dysmorphology and Clinical Genetics at the Institute of Child Health. He accepted this in his usual understated manner and continued with all his work just as before.

Robin's working relationship with Michael Baraitser was extremely effective and productive. The London dysmorphology and neurogenetics databases (LDDB and LNDB) are the most obvious examples of this, but the partnership also worked at many other levels. They had complementary clinical skills and styles, were responsible for part of the clinical training of many consultant geneticists, and supervised the research of many more. The output of publications from the department during that time speaks for itself.

The Databases were conceived when Robin and Michael decided to embrace technology to aid the diagnostic process and pass on the knowledge they had acquired over the years. They used a three level code and a search programme developed initially by a computer expert at University College, London and continuously improved by Robin. They went through the early volumes of all available journals, recording the information on punched cards. Robin took the punched cards back to KGC to feed them into the mainframe and Michael can recall Robin's great joy on the telephone when he said "it worked". They quickly moved to a desktop computer and the volume of data rose rapidly—so much so that they had a visit from David Danks, who wanted to buy a share of the data for £10 000. Stunned, they accepted the offer and continued with their work. Initially they made the disks themselves and sold them for small sums to colleagues. Then in the late 1980s Oxford University Press offered to publish it and to reprogram the software. The first edition was published in 1990, and it has continued to be modified, developed and updated ever since. Robin worked on the Database largely in his "spare time" and acquired a succession of increasingly sophisticated laptops for the purpose. A dedicated company has recently been established to continue the work. (www.lmdatabases.com)

In 1998, Robin had a myocardial infarct. He made a good recovery but afterwards seemed to reassess his priorities in life. He relinquished the role of lead clinician and declined the role of academic head so that he could focus on clinical work, the Database, and the aspects of academic work that he enjoyed. His clinical work and the Database remained very important to him and he had planned to continue them for many years.

As well as being interested in, and very knowledgeable about, computers and information technology Robin had an excellent instinct about the future potential of emerging technologies. This was evident in many of his projects and achievements, most notably the LDDB but also in various clinical systems that he introduced at KGC and GOS and in the work that is continuing on correlations between genetic diseases in humans and animals. He was the acknowledged computer expert within the department and did not hesitate to express his opinions on the shortcomings of the hospital's and Institute's computer services to the relevant IM&T department.

Robin's clinical and diagnostic skills were important to many patients and families who felt that they had, at last,

found someone who could provide them with a diagnosis or explanation for their own or their child's condition. He was a complete clinician who could not only make rare diagnoses but could also explain their implications to families in a way they could understand. Several patients transferred from KGC to GOS to remain under his care. Robin saw many overseas patients at GOS to provide a diagnostic opinion but did not undertake any private practice. The respect and affection that many parents and colleagues felt for him was marked by a steady trickle of gifts, including a hand made carpet and a tapestry with the hospital logo.

Robin's efficiency and productivity were awesome—during the half time he allotted to clinical work he was able to do as much as most people achieve in a full time post. In this, he was greatly helped by his encyclopaedic knowledge of the literature, which enabled him to dictate most of his letters while still in clinic, without needing to consult the Database! This approach meant that he never acquired a "guilt pile". Despite this, he never perceived himself as being particularly efficient and was anxious that any delays in the typing or sending out of his letters would reflect badly on him. He cared about the welfare of his patients and would worry about any unexpected clinical problems that occurred, even if they were well outside the remit of clinical genetics.

He became increasingly disinterested in and frustrated by all the bureaucracy and changes introduced within the NHS, and involved himself in management issues with decreasing frequency over the years. However, when he could be persuaded to give an opinion, it was usually a pithy and valuable one.

Robin's knowledge and skills made him the most highly regarded dysmorphologist of his generation. However, within the department at GOS he enjoyed working as part of a team. He was not the most forceful or the most vocal member of the department but was always available for a clinical opinion or more general advice. During the weekly clinical meeting, as at the Dysmorphology Club, no one really felt secure about a clinical diagnosis until he had approved it. However, he contributed much more than just a clinical opinion, and his dry comments would frequently cause those sitting around him to dissolve into laughter. He usually got the best out of anyone who worked for him, not because he was demanding but because his own workload and standards were so high that others wanted to keep up with him and please him. He was patient in difficult situations though could explode afterwards

and describe his frustration in a few short well chosen phrases. When noisy building work disrupted his clinic for a few weeks in succession Robin made his point to the Head of Estates at the Hospital by e-mailing a picture of himself trying to counsel "patients" (the SpRs) using loudspeakers. This had the desired effect and building work stopped on Thursdays.

Robin was a thorough and conscientious teacher, often taking on the subjects that everyone else preferred to avoid, such as the Bayes theorem. He taught a variety of students on subjects ranging from basic genetics to complex molecular dysmorphology. He was at his best when teaching trainees in genetics on dysmorphology. In this, he was inspirational, less in what he actually said than in the feeling that he was opening a door into a fascinating world. Everyone wanted to develop their skills and knowledge in this field while knowing that they could never really hope to match his abilities and achievements.

Robin was a good colleague. He was always supportive of his academic colleagues, including finding space for them within the increasingly crowded department. He was approachable, though it was sometimes necessary to judge the degree of his preoccupation with other matters, balance this against the nature and urgency of a query, and—if more than a one word answer was required—return another time. However, for important issues he could always be relied upon to listen and advise. E-mail was a means of communication that suited his personality; his messages were invariably brief and to the point and his replies frequently limited to one word answers. Within the department, he usually left instructions written in red or green ink on fluorescent "post-it" notes.

The different facets of Robin's personality were sometimes apparent in his clothes. Always smartly and apparently conventionally dressed, he would wear flamboyant socks or braces and had a pink shirt (the colour of "the pink journal", *Clinical Dysmorphology*) which he wore to Dysmorphology Club meetings.

Robin's family life was extremely important to him. He met his wife, Joan, while they were undergraduates. They were both studying at University College London but actually met in Liverpool during their summer jobs at a local hospital. Joan graduated in

German, then qualified as a teacher. She and Robin married while he was still a medical student and they celebrated their 30th wedding anniversary just before he died. Their two children, Amy and Henry, are both in their final year at University. Amy is studying medicine; having done her preclinical studies at Cambridge, she has now completed her clinical training in Oxford. Henry is studying politics at Warwick University. When the children were younger, Robin always took leave during their holidays to spend as much time as possible with them and he used to take Amy to school on his way to work. He was very proud of his children and their achievements and asking about Amy and Henry was always a safe and effective way of initiating conversation with him. Apart from work and his family, Robin's interests included his garden, particularly his roses and what his family describe as "obscure folk music". He could play the banjo, though did not make this widely known. He enjoyed entertaining and being entertained and had a wide circle of friends, both medical and non-medical. He also enjoyed travelling, taking frequent weekend trips around the UK with Joan, and also venturing further afield on more exotic holidays.

The diagnosis of metastatic gastro-oesophageal cancer came as a great shock to everyone. Robin coped with the diagnosis and treatment in a dignified and courageous manner. He managed to retain his privacy while accepting many letters of sympathy from friends and colleagues from all over the world. He made it clear that his family was his priority, yet also dealt with any outstanding clinical work, delegating when necessary. During the three months of his illness, he came in to work once or twice a week to tie up loose ends or to attend the clinical meeting and the dysmorphology clinic. His efficient and conscientious approach to all clinical and academic issues persisted and he kept in regular and frequent contact by email until a couple of days before he died. He was at the Dysmorphology Club meetings in October and December and participated and contributed as he normally did, manning the computer to project the appropriate parts of the Database and suggesting or refuting diagnoses. His GOS colleagues last saw him at the departmental Christmas lunch where he

ate and drank well and entertained everyone within earshot.

Robin was a man of many talents. He was probably the cleverest man that many of us will meet, but his intelligence was combined with outstanding clinical acumen, kindness, common sense, and dry wit to make a unique personality. He was aware of his abilities but was always so modest and unassuming about his achievements that anyone outside the field of genetics was usually unaware of them.

He was widely admired and respected for his contributions to genetics, but more than that he was universally liked and even loved by patients and colleagues. This has been illustrated in the letters that have been received in the genetics department from patients and families who have heard of his death. Robin's family has also received many letters, and the high regard that people felt for him was evident in the fact that nearly 200 geneticists of all levels from virtually every centre in the United Kingdom attended his funeral, together with colleagues from Ireland, France, Italy, and Holland. Robin himself would probably have been surprised and perhaps embarrassed by this but hopefully he would also have been touched to realise that he meant so much to so many different people.

It is important for us to remember that, even though the genetics world is now without one of its leading members, Robin's family has suffered a much more immediate and personal loss. To quote from Michael Baraitser's oration at Robin's funeral: "Robin was a good man, a kind man and a gentleman, who will be greatly missed."

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