Appendix A

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Appendix B

Appendix B  1. Eulogy by Ken McKusick

Ken McKusick
1404 Berwick Road
Towson, MD
21204

On behalf of the family, I’d like to thank all of you for coming today to celebrate the life of my Dad.

I spent a great deal of time talking with Dad over the past couple of months. It was highly satisfying quality time and helped me come to terms with what was happening. I was going to make a list of all the important occurrences and milestones that he felt lucky about. However, that list became very long and I realized that it would take too much time. So I’m going to say just a few things that are most important to me.

First and foremost, Dad’s love for my mother was always very apparent. They had their first date two weeks after she arrived at Hopkins to begin medical school, while he was an intern, in 1946. She’s still here 62 years later. He’d describe her as his best friend, companion, critic and editor, and staunch supporter through all these years. They had very complementary qualities and interests. Mom was the one to go to when you needed help with math homework, and Dad could help more with history and biology. Both of them would continue to correct improper grammar well beyond childhood.

Dad’s devotion to his work, to which you’ve heard several testimonies today, is perhaps even more apparent in terms of what he did not know.

He couldn’t tell you who Barry Bonds is.
He couldn’t name any actor who ever played James Bond.
He couldn’t name any two NFL teams that ever played each other in the Super Bowl.
He couldn’t name any actor or character that played on any of the following TV shows: The Honeymooners, Star Trek, M*A*S*H, Cheers, or Seinfeld.

And...he couldn’t name any member of the Beatles.

The fact that his work was Dad’s greatest passion was apparent in all aspects of his life. His hobbies were his work. After personally accumulating closets full of games and sports equipment, I realize that my dad never bought himself a toy, not a pool table, fishing equipment, golf clubs, sports car, boat, nor electronic gadget. Only when my parents moved into Blakehurst did they pay for cable TV (or get air conditioning). The closest I could come to toys were his camera and computer, both of which were essential for his work.

Nonetheless, Dad did a lot of things just because he loved us. He took my brother and me to the last game of the 1971 World Series despite the fact that he would not have remembered a thing about that game a year later. He drove us to little league, was active in scouting, and would participate in the family games we’d have most summer nights in Nova Scotia, although he always had a pile of reading close at hand. And then, there was the memorable overnight canoe trip Dad and I took down the Annapolis River in Nova Scotia.

Dad told me he was very proud of the fact that he never paid for an overseas trip after his honeymoon. Upon cross-examination that proved to be an exaggeration, he certainly did give us kids the opportunity to travel and experience the world with him. Many of our fondest memories came from these trips. In particular, my brother and I will never forget being pulled out of kindergarten and first grade, respectively, in 1970, to travel around the world via Fiji, Australia, New Zealand, Hong Kong, India, Iran, and England for two full months. On other trips, he took us along to conferences or speaking engagements in the Netherlands, Austria, Yugoslavia, and the Soviet Union at the height of the cold war.

I never thought we’d have a more special family trip, until this year when Mom and Dad took his twin brother, Vincent, Aunt Nancy, Victor, Lori, Maureen, and me to Japan. This trip afforded him a wonderful opportunity to meet with old colleagues, spend time with family, celebrate his life’s work, and provided something to look forward to as his health declined. What made the trip so special for me wasn’t just seeing him win the award but seeing how happy he was to share the experience with family and friends.

Most importantly, I’m grateful to both Dad and Mom, for their unflinching willingness to provide educational opportunities. None of us...Carol, Victor, or I...found our path immediately, but Mom and Dad were always willing to support us on our next goal.

As Dad spoke more about his life, I got a picture of a man thoroughly comfortable with who he was and how he lived. He was not without regrets (as he’d say, “People without regrets just aren’t facing them”), but he was honest with himself, brave, mentally sharp, and cheerful to the end. No one...could ask for anything more.
Appendix B  2. Eulogy by Victor McKusick

Remembering My Dad

The Rev. Victor W. McKusick
933 Westwood Dr.
Herkimer, NY 13350

Pingree Cemetery
Parkman, Maine
August 8, 2008
11:00 AM

I don’t know when I’ve been more proud to be my father’s son.

Over the last month, I’ve been thinking about life and death and about my dad as he straddled that very tenuous line. Also during that time, I rented the recent film: “The Bucket List.” The Bucket List is a tale of two men ailing with cancer in the twilight stages of their disease. The two men head off on an adventure of doing the things they have always wanted to do in life. I think of this film not in the sense that dad should have had great regrets about his life. To the contrary, Victor A. McKusick was a man who lived a full and rich life.

Dad never went on a vacation or a tourist junket. Even trips to Nova Scotia were just a wonderful change of venue to work or to exercise a different kind of work. All the “once in a lifetime” things he did and all the extraordinary places he saw were connected to his lifetime work in genetics and medicine. He never went skydiving as the Jack Nicholson and Morgan Freeman characters in the movie. However, I do remember seeing pictures of him in his bathing suit floating in the Dead Sea. This, of course, took place on a visit to Israel, while visiting with his colleague Dr. Goodman and meeting with the Israeli genetics community.

– He walked on the Great Wall of China on three separate occasions.
– Watched ski jumping competitions in Norway.
– As Ken noted last week, visited the Soviet Union at the height of the Cold War.
– Saw the Lipizzaner Stallions in Vienna.
– Heard the Vienna Boys’ Choir not in concert but street children in the opera Carmen.
– Not only visited Tito’s Yugoslavia but had good family friends whom my brother and I referred to as Aunt Lilliana and Uncle Kreshau.
– And of course dined with the Emperor and Empress of Japan, also on a medical occasion, when he received the prestigious Japan Prize.

These would be “Bucket List experiences” for most of us; for dad, they were happenstance activities on his lifetime journey.

I think an even more poignant part of this motion picture, when I think of dad’s life. In the scene, the two crusty characters are perched high above the Valley of the
Kings atop one of the pyramids. The character Carter says to Jack Nicholson character, “The ancient Egyptians believed one was asked two questions at the gates of heaven: Did you experience joy in life? The second question was did you bring joy to others?” And unlike the wealthy hedonistic Jack Nicholson character, who responds, “I guess I’m not getting into Egyptian Heaven then,” by those standards, Victor A. McKusick is unequivocally, absolutely getting into Egyptian heaven. It is this joy and delivery of joy that I find in my memories of my dad.

I have to say I don’t remember hearing many stories from dad about his childhood except the occasional twin story such as the switching of ties with Uncle Vincent at school to confuse their teachers. However, one childhood story was one of dad’s favorite jokes. Grandma McKusick was busy putting the twins to bed one evening. She was having a particularly hard time in settling them down. “Come on boys its time to go bed. I have other fish to fry.” Supposedly, my father responded, “I want to stay up and have the fish.” Such was Dad’s sense of humor.

I’m finding it very difficult to encapsulate mom and dad’s courtship and their 59-year marriage. Mom and dad went on their first date sometime in the late 1940s while they were both at Hopkins. They had dinner together and evidently ordered vanilla ice cream for dessert. My dad stated boldly, as to impress this very attractive woman: “I’ll have ketchup on my ice cream. That’s the way I like it.”

I was reading an interview that described dad’s career before we went to Japan. In the interview, both dad and mom spoke of going through Sir Dr. Jonathan Hutchinson’s (personal physician to Queen Victoria) drawings in the basement of the Welch Library at Hopkins. The interviewer noted, “How romantic.” For them, I’m sure it was. Although different specialties, mom was a partner in dad’s practice of medicine.

There were two very loving acts that my father performed occasionally throughout my parent’s marriage. They seemed to be small and insignificant yet were filled with the love he shared with my mother. I have tried to duplicate them in my own marriage. My dad developed the habit of bringing tea to mom in bed each morning. Although I don’t bring tea to my wife every morning in bed, we have developed the ritual of my always asking as we prepare breakfast together if Lori wants orange juice. Furthermore, dad would frequently wash dishes with mom or make Ken and I do them. In the McKusick household in Herkimer, Lori and I do the dishes together after supper whenever we can.

Dr. Andrea Superti-Furga is a young physician my parents first met in Sestri Levante in 1988. I thought he captured dad’s relationship to mom best when he wrote, “VAM was also a role model for the way he took Mrs. Anne with him as an eye level partner and affectionate spouse, not as the attachment-wife of a famous man.”

Although she is not here, I wanted to share words from my sister Carol in memory of my dad. One time, Carol and I were looking at the black and white framed photo of dad sitting in a chair reading a book. Carol remembered sitting in his lap while he read, and how comfortable, safe, and cozy she had felt sitting on her father’s lap, and the sense that he was always there for her. In truth, my sister adored her father and always will.

There are so many childhood memories of dad’s joy. I remember a game we used to play where I stood on dad’s shoes while facing him as he walked. I remember him
beating me at tennis as teenager and he danced across the court in glee saying, “Game. Game. Game. Game. Game.”

My dad took great joy in my achievements. When he got home from work one day, he proceeded upstairs when I yelled to him that I had gotten into Bates College. He came running down the stairs with a big smile and wanted to hear all about it. That same sense of joy and smile has been repeated many times at graduations, ordination, and installations.

I was interested last week when my brother noted that my father did not consider himself a musical person and that is quite true. However, I will always remember his humming and whistling. And he took great joy in the bagpipes. As a teenager, I went with him to take Cousin John Grant to work: playing the bagpipes outside a Halifax department store. He would hum “Scotland the Brave.” He would hum his favorite hymns as we came home from church. There were two favorites that he sang in the car on our summer trips. (Singing) “My bonnie lies over the ocean. My bonnie lies over the sea. My bonnie lies over the ocean. O, bring back my bonnie to me, to me. O bring back. O bring back, O bring back my Bonnie to me, to me.”

Or…

(Singing) “Down by the old, not the new but the old, mill stream, not the river but the stream. Where I first, not last but first, met you, not me but you. You were sixteen, not seventeen, my high school queen, not king but queen. Down by the old, not the new but the old, mill stream, not the river but the stream.” Dad particularly relished the echo.

I didn’t really have a great sense of what dad did when I was a child. I knew he was a doctor and a geneticist and distinguished in his field, but I don’t think I had the sense of his greatness and his contributions until I was in college. I recall a discussion in high school with friends talking about what their parents did for a living. My friend Gordon (who is here today), when I started to speak, rebuked me by saying, “Shut up, Victor, your father invented DNA!”

My brother and I as kids went on a very memorable trip with my dad on Amtrak to New York and stayed at the Americana Hotel. We never left the hotel. My brother and I stayed in the room and ordered room service. It isn’t like we saw the city or took in a Broadway show. For me, it was just great to be traveling with my dad.

One Washington’s birthday, I traveled with dad and one of his Fellows to Amish Country in Lancaster County, Pennsylvania. I think what was special about that day is he set a personal best for farm visits that day. I believe we made 23, but I could be mistaken. What was memorable for me was meeting Amos Stoltzfus, a fifth grader with a sixth finger on one of his hands. Amos had a very special challenge in learning how to write. Later, I’ve learned that the sixth finger is a symptom of McKusick-type achondroplasia. Don’t ask me to say that again. Amos was a student in the one-room schoolhouse of Sarah Fisher, an Amish teacher who was one of dad’s contacts and hosts in the Amish community. I was always impressed with how dad related with his Amish patients; they seemed to admire him and get such joy at of his visits.

I noticed one of my dad’s little professional quirks. When in book stores, he would take time to sign his own books. He did this not as part of a book signing mind you but just slip a couple of his books from the shelf and sign, “Victor A. McKusick.” I think he liked the idea of the new owner being surprised and happy as
the reader found a signed copy of MIM, or “Green Genes” which was dad’s playful nickname for an early genetics publication.

I never really understood what *Aequanimitas* meant until this last year of dad’s life. From what I understand of William Osler, dad’s idol, the great physician spoke of *Aequanimitas* as a balance—a balance between engagement with the patient or student and yet a professional detachment of expertise. When I read the 2000 interview with dad about his life’s work, I figured out what it meant: it is not only something he lived, it is not only what many of us seek in life, but I can understand it as a goal that I seek as a pastor. In 1957, A McGee Harvey named dad as Director of the Moore Clinic, a clinic that had studied syphilis. Because of Dr. Moore’s fundraising, grants, and various endowments, dad and his enterprise which laid ahead was independently funded. He had the opportunity to follow his intellectual curiosity and did. Furthermore, as the story goes, there were many naysayers of the genetic endeavor, yet dad stuck to the course of his life. He went about it with *Aequanimitas*.

Why then is *Aequanimitas* so important for us all? Despite all the distractions, despite all of our desires to be reactive, to carry the day, when we can stay on course and follow that balance, follow that center, we are at our most meaningful. Last night, my cousin Paul mentioned that the necessity for equanimity is really present in many professions. I know as a pastor; I find the most satisfaction and meaning when I am visiting someone or in a meeting, and I am not only aware of myself and but engaged with those around me. I think this is *Aequanimitas*.

The last Saturday of his life I said goodbye to dad for the last time. “Dad I love you, and thank you for everything that you have done for me” and then kissed him on his forehead. I was feeling woefully inadequate for not having had long and deep, meaningful talks with him in his last months of life. Then Lori reminded me that my dad had read an article by a writer in Central New York. The author had scribed an article about my dad and me for Father’s Day in a local paper. Somehow, that would always have been a better medium for dad to hear what I thought and felt about him, rather than any long heartfelt talk. So Good-bye dad. I love you!
Appendix B

3. Eulogy by Clair A. Francomano

Eulogy for Victor A. McKusick, M.D.
Teacher, Mentor, and Role Model

Clair A. Francomano

We are here to commemorate, and to celebrate, a remarkable life. Others have discussed Dr. Victor McKusick’s prodigious contributions to medicine, to the field of medical genetics, and to Johns Hopkins. My task, as he requested, is to discuss Dr. Victor McKusick’s legacy as a teacher, mentor, and role model.

I first met Dr. Victor McKusick when I was a high school student participating in the Jackson Laboratory summer program in Bar Harbor, Maine. During that heady summer of first exposure to the principles of genetics and scientific research, we students had the privilege of attending the Short Course on Medical Genetics, which Dr. McKusick had cofounded with Dr. Thomas Roderick of the Jackson Laboratory in 1960. There was a cocktail party during the course, and I was selected, by virtue of my legible penmanship, to write the nametags for attendees. A secondary assignment was to serve hors d’oeuvres. And so it was, in 1971, that a high school genetics neophyte from Yonkers, New York, first encountered the Drs. McKusick face to face, on the lawn of the Drs. Earl and Margaret Green overlooking beautiful Frenchman’s Bay in Bar Harbor, Maine.

Eventually, I came to know him as a medical student, a house officer on the Osler medical service, a genetics fellow, and a faculty member at Johns Hopkins. He sent me to Lancaster County, Pennsylvania, and Holmes County, Ohio, to research the Amish. He introduced me to the little people and the tall people with Marfan syndrome and their support groups, and to dozens of colleagues from around the world. He was unstintingly generous of his time and whatever resources he had at his disposal. He encouraged my research and supported my career in every imaginable way. I know that he did this for every one of the many who came before me. There are 121 people on the list of genetics trainees supervised by Victor A. McKusick, M.D. We have all been gifted by his enthusiasm, his innate curiosity, his life, and his work. By his example and the opportunities he made available to us, he taught us to explore deeply, to think critically, and to write clearly. He molded us into the professionals we became.

As I thought about the fundamental lessons that Dr. Victor McKusick left us as a teacher, mentor, and role model, three essential teachings emerged:

1. Work very hard
2. Always stay positive
3. Share what you know

I would like to take a few minutes to elaborate on each of these lessons. I should say that he never would have told us directly to do any of these things—his teaching was always by example rather than by exhortation.
1. Work very hard. Truly, Victor was always working. He just kept at it, day in and day out. An avowed Lark (as opposed to a night owl), he would awaken early in the morning and start working at 5 A.M. He worked on the way to the hospital when Anne would drive him in the car. He worked on the weekends. He worked while he was away and he worked at home. He was never not working. When I was a fellow, we were making rounds one Monday, and he said to me, “I wrote a book this weekend.” Just like that. He accomplished great things, in part, because he worked very, very hard, all the time. It gave him his greatest joy and pleasure.

He expected hard work from his students and trainees, but never more than he gave himself. Dr. Judith Hall told me a story of revising her manuscript on Thrombocytopenia-Absent Radius Syndrome when she was working with him as a fellow. She was on the 13th draft and really slogging it out, and she asked Dr. McKusick, “Is it always this hard?” With his characteristic brevity, he replied, “Yes.” Nonetheless, it was exhilarating to share in his passion, his enthusiasm, and his commitment.

Dr. Michael Bliss, in his essay about Sir William Osler on the 150th anniversary of his birth [1], wrote: “No one has ever loved the medical life more than William Osler did. From the day he decided to become a doctor until the day of his death he lived, breathed, ate, slept, talked and wrote medicine.” Dr. Victor McKusick, who was an avid Osler historian, followed closely in this path. The morning of the day he died, he watched the streaming video from his beloved Short Course in Bar Harbor.

2. Always stay positive. I have known Dr. Victor McKusick for 37 years, and I worked very closely with him for over 20 of those years. In all that time, I never heard him complain or say anything negative about a situation or another person. I do not believe that I know another person about whom I could say the same thing. He was truly remarkable in that way. He was truly remarkable in that way. If he saw a situation that was not to his liking, he worked to change it, quietly, without rancor, and without discord. I never heard him raise his voice.

Again, I would like to quote Dr. Bliss [1], who wrote about Osler: “Someone has said that the real trouble with Osler as a role model is that he never had a bad day, and no one can come close to matching him.” I believe the same could be said for Victor McKusick. He epitomized Osler’s principle of aequanimitas.

3. Share what you know. Surely this is his greatest legacy. All of us who trained with him benefited from this essential aspect of his being. It was simply a part of who he was. He took legions of house officers up to the Hopkins Dome to share his knowledge of Hopkins history. Mendelian Inheritance in Man, now OMIM, was his way of making the entire evolving knowledge base of human genetics available to the widest possible audience. Not only did he share what he knew, freely and without reservation, he brought people together to share what they knew with each other. The Birth Defects meetings and Short Stature Symposia at Johns Hopkins, the Bar Harbor and Italian genetics courses, and even the Human Genome Organization were born of his innate understanding that for a body of
knowledge to survive and prosper, it must be shared, discussed, written about, and preserved.

If I may be allowed one final quote from Dr. Bliss concerning Sir William Osler [1], it is this: “Few of us are as fortunate or as gifted in our strivings to take the good of every hour and contribute to human betterment.” Certainly, Victor McKusick was one of the very few.

I had the opportunity to enjoy Anne and Victor’s hospitality on many occasions. Together they were two parts of a grander whole. I would like to take this opportunity to thank Dr. Anne McKusick for sharing him with us, and especially for her kindness, hospitality, and warm friendship these many years.

The last time I saw him, 1 week before his death, I asked Victor if he had any thoughts about the afterlife. He smiled and said, “I’m keeping an open mind.” This was so typical of him. Wherever he is now, I am sure he is taking notes in one of those little brown books.

He has been an integral part of my entire professional life, as he has for so many others. For those of us fortunate enough to be able to say that, it is difficult to imagine a world without Victor A. McKusick. Perhaps the best way we can honor his memory is to perpetuate that which he taught us, and lived by: Work very hard, always stay positive, and share what we know, widely and deeply, with whoever will stop to listen and learn.

Although these simple words cannot begin to express the magnitude of our debt to you, Thank you, Victor, from all of us.

Clair A. Francomano, M.D.
August 2, 2008

Bibliography

Appendix B  4. Eulogy by Stephen C. Achuff

Eulogy for Victor Almon McKusick
Stephen C. Achuff

It was my great good fortune to be Chief Resident, along with Tom Inui, during Victor's first year as Chairman of Medicine 1973–1974. We did not really know him before that, other than by reputation, and he certainly did not know us, as we had been foisted on him by his predecessor, A. McGehee Harvey. Frankly we thought he must have been a little rusty as a clinician having spent the previous 20 years or so studying all those strange and uncommon genetic disorders. Being perhaps a bit cocky, we saw it as our duty to bring him back into mainstream medicine—and, we had a little help from Philip Tumulty, who was probably the master clinician and teacher of that era. Every weekday morning, the four of us would meet in Victor's office on Blalock 10 and discuss the patients who had been admitted the previous day. Needless to say, Victor was a quick study, and when something came up that was unfamiliar or that piqued his insatiable curiosity, he would pull out one of his little brown books and make notes to himself for later reference or research. It was in those informal meetings and bull sessions that usually followed, that the concept of the Firm System was born—one of Victor's most enduring innovations and of which he was justifiably proud. The Housestaff had grown larger over the years to the point of not only being unwieldy, but something of the sense of camaraderie and family that Victor remembered and cherished from his own days as an intern and resident were in danger of being lost. Plus, medicine on a larger scale had changed what with a new focus on intensive care, shortened hospital stays, governmental regulation, and so forth. So over the next couple years, Victor reorganized the Medical Service—retaining what was good about traditional Osler training and also adapting to the exigencies of medicine in the 1970s. As we came to know Victor on a personal level, it was nothing short of mind-boggling to witness firsthand his encyclopedic knowledge, his phenomenal powers of recall, and his prodigious work habits. This last was brought home early in the year when his secretary called me over to her desk one morning as she was transcribing his letters and papers and had me listen to the cassette—In the background behind his dictation was the unmistakable twittering of song birds—as usual, he was up before dawn accomplishing more before the sun rose than most of us do in a full day—something undoubtedly ingrained during his youth growing up on a dairy farm in Maine.

And then there was Victor's passion for history and his commitment to remind us all of the great heritage of the department and the responsibility we shared to continue and promote that heritage. As best I can tell, he never really explained why he took students and residents to the top of the Dome, talked more knowledgeably than anyone about the great Hopkins physicians of the past, and showed the room where Osler wrote the first edition of his Principles and Practice of Medicine in 1892. He did not force this on us, he just did it, he obviously loved doing it, and nobody could do it better. One tangible sign that will live on as long as there is a Department of
This photo was taken in the room where Osler wrote the first edition of his textbook, “Principles and Practice of Medicine”, in 1892. Dr. McKusick is sitting in a high-backed desk chair that was Osler’s. Dr. Stephen Achuff is sitting on Osler’s desk and in the background is a photo of Osler writing the textbook. Both are wearing the Osler tie—“Aequanimitas” which was created by Dr. McKusick in 1977–78. Everyone who trained on the Osler Medical Service is obliged to wear the tie on Fridays (Courtesy of Stephen C. Achuff and Andrew Harrison [Alan Mason Chesney Archives of the Johns Hopkins Medical Institutions])

Medicine at Johns Hopkins is the Osler tie for men and scarf for women with the word Aequanimitas on a shield—the idea having been suggested by one of his residents, John Beary, after he had spent an elective at the Radcliffe Infirmary in Oxford. Victor, ever the incurable Anglophile, leapt at the idea and started a tradition that has been emulated by virtually all the other departments at Hopkins as well as many around the country. Incidentally, one of the picture boards here today (in the narthex) is a photo of a very contented Victor wearing his Osler tie, sitting in Osler’s chair (appropriately), in the Osler Textbook Room.

Anne called about 3 weeks ago and said Victor wanted to see me. When I arrived at their apartment at Blakehurst and sat down next to him, I was a little taken aback by his first words—not so much because he asked me to speak at his funeral, that would be a great honor and I told him how much I appreciated it, but more because of what he wanted me to say—and why. I am paraphrasing, but essentially he said
that for a long time he had been disappointed that when people talked or wrote about him, the focus was always on his scientific achievements and what was given short shrift, if any mention at all, were his contributions to education of medical students and young physicians, to preservation of the very best traditions of Hopkins and Oslerian medicine—in his mind, and I think rightfully so, some of his most important and enduring achievements. In point of fact, he had led for more than a decade the largest department in Johns Hopkins University and been Physician-in-Chief at arguably the number 1 hospital in the country. Victor was a modest man—who bore fame and success with uncommon humility, but clearly he took great satisfaction in having been William Osler’s successor and having preserved the best aspects of Oslerian medicine. I think he was undeniably justified in that accomplishment, and I hope I have been able to express some of that this afternoon.
Victor McKusick is a legend among his peers, respected and revered as the “Father of Genetic Medicine,” as well as a master clinician, scientist, medical historian, writer, teacher, and mentor.

Victor wanted me to speak on the establishment of medical genetics as a medical specialty and the vision that he and many of his students have been working toward in the field.

Victor was a physician, first and foremost, and followed the Oslerian tradition of paying close attention to his patients, seeking insight into the cause and management of their disease and problems.

He had become interested in genetics as an undergraduate at Tufts. He also experienced applied biology on the dairy farm as a child, and he wrote a paper with his older brother on coat color inheritance in Jersey cattle, which was submitted but never published.

His first genetic paper was in 1949 which dealt with the Peutz-Jeghers syndrome, characterized by skin pigmentation and intestinal polyps.

He claimed that he then got training in cardiology because there was no such thing as medical genetics. With apologies to Dr. Ross, he said that he found genetics much more challenging, exciting, and novel.

Through his cardiology interests, he came across families with Marfan syndrome and aortic aneurysms and conceived that this was a syndrome in which one could think of the many effects of a single gene that affected one element of connective tissue, wherever it was in the body.

He became interested in the clinical and genetic aspects of the various heritable disorders of connective tissue—a term and concept that he introduced. He published his first book, Heritable Disorders of Connective Tissue, in 1956.

Over the years, he excelled in the clinical nosology of these and many other genetic disorders. Some of his colleagues viewed his research as the medical equivalent of stamp collecting and some wondered if it was even science. But Victor perceived that the future of medicine—and insight into the molecular gears and switches that are the science of life—lay in the direction he was heading. If getting there required going house to house, examining babies, asking about grandparents, etc., he was more than happy to do it. He claimed that he had a great deal of fun tracing hemophilia in early New England families. In jest, he said that we would knock on doors and say, “Take me to your bleeder.”

Victor would travel far and wide to see unusual patients that could teach him about genetic diseases. When I was a fellow, Victor taught me the power of clinical research and the value of studying rare diseases to prove basic biologic principles. I accompanied him to meetings of the Little People of America and even the
Victor did not limit himself to descriptive studies. Enlisting the help of many basic science colleagues, they were able to define the biochemical and molecular defects in many disorders. He was especially effective in crossing basic science and clinical lines and across specialties.

He recently reached his ultimate goal in Marfan syndrome with over 50 years of work, starting with description and natural history, to the exciting work of Hal Dietz, the first McKusick professor, of finding a potential pharmacologic therapy for the aortic disease that first attracted his attention. This is a classic example of clinical genetics at its best.

In 1957, Victor took over the Moore Clinic and started a division of medical genetics within the Department of Medicine. As a general hospital division, this brought genetics into the mainstream of clinical medicine.

Victor built a division of medical genetics with cytogenetics, biochemical genetics, population genetics, and immunogenetics components. His cytogenetic lab was perhaps the earliest clinical cytogenetics laboratory in any large general hospital in this country. Pharmacogenetics also got started in the Moore Clinic with the study of the genetics of metabolism of the antituberculosis drug, INH.

He recruited several hundred fellows in medical genetics from around the world over the years, many of whom became international leaders in the field—he was a true pied piper. A couple of years ago, Victor was in LA and he attended the large Sports Spectacular fundraiser for genetics at which the legendary coach John Wooden was being honored. I introduced Victor to this audience of 1,800 sports fans as the John Wooden of Medical Genetics—Victor really liked that comparison!

Victor started a monthly journal club at his home where each fellow had to review six to seven medical journals and bring in a short description of any new papers on genetic disease. He began publishing an annual review of new findings in medical genetics, which evolved into his classic Mendelian Inheritance in Man, long considered the bible of medical genetics—a constantly updated catalog of genetic diseases and the genes that caused them. This was before the day of the word processor. He put it on the computer in 1964 and then produced a printout book that became one of the first computer-generated medical texts.

His involvement with the Amish was a fringe benefit of university committee work with the Johns Hopkins Press, when in the fall of 1962 he reviewed the manuscript for John Hostetler’s book called Amish Society. His studies of inherited disorders in the Amish uncovered about a dozen previously unrecognized, inherited conditions and served as a model for studies in similarly isolated populations elsewhere.

His involvement with the skeletal dysplasias was an outgrowth of the Amish studies. He was first invited to the National Convention of Little People of America in 1965 as a result of a story about their studies in dwarfism in the Amish in Time Magazine. He was later named an honorary life member of LPA. He was also an honorary fellow of the American Academy of Orthopedic Surgeons and claimed...
that he was the only member of those two organizations who was more than 6 ft tall and did not operate.

The pioneering observations that G6PD and color vision are closely linked on the X chromosome and that the Duffy blood group is located on chromosome no. 1 came from his unit. Victor was clearly a clairvoyant. At the birth defects meeting in 1969 in The Hague, he suggested that mapping the human genome would be the way to go to unravel the mysteries about lots of birth defects and genetic diseases.

In 1973, together with Frank Ruddle, he began the international workshops on gene mapping in man and pioneered the use of computers for linkage work. He approached the genome as an organ and began writing about the morbid and functional anatomy of the human genome.

The human genome project was strenuously debated because many people thought it was a crazy and very expensive idea, that it really was not science but just brick counting.

As a leading proponent of completely mapping the human genome, Victor served as an enthusiastic advocate, advisor, and kibitzer of the Human Genome Project and served as the founding president of the International Human Genome Organization (HUGO).

Thus, Victor was a true cartographer, whose efforts not only led to the mapping of the human genome, but he also put genetics on the medical map.

Through his fellowship, courses, meetings, and writings, Victor was an extremely effective teacher and salesman of medical genetics.

His annual genetics course at Bar Harbor, Maine, is widely credited with training generations of genetic medicine practitioners and scholars. This course was first given in 1960, and last week, Victor attended the course by computer streaming even to his last day.

This long-standing course attracted a large number of health science faculty members, including a fair collection of the department chairs and even deans. One of the major objectives of the course was to upgrade the teaching of genetics by teaching the teachers. Indeed, a large proportion of people in genetics in this country have attended the course at some stage of their careers. The multiplier effect of this “teaching of teachers” was a catalyst in the development of medical genetics as a specialty.

Victor also created the annual Clinical Delineation of Birth Defects meetings—a yearly meeting dealing with nosology in clinical genetics.

Although at first Victor thought there was no need for a board in medical genetics, he changed his mind and joined us in creating the independent American Board of Medical Genetics. A decade later, the ABMS admitted the ABMG as the first new fully independent medical board in 20 years, and as a full specialty.

We then formed the American College of Medical Genetics that became the 24th recognized medical specialty by the Council of Medical Specialties. We instituted an annual meeting and combined it with the ongoing March of Dimes (MOD) Meeting, which were originally Victor’s Clinical Delineation meetings.

Victor was always one to two decades ahead of his time: creating a division of medical genetics, inventing spectophonocardiography, predicting the usefulness of
linkage and gene mapping, pioneering the use of computers in publishing, and medical use of the internet.

He made major contributions to biochemical, molecular, and population genetics without being in a lab or getting formal training in mathematical genetics or computer technology. He considered his lab to be the clinic and the library.

Thus, enormous energy, a rigorous work ethic, effective time management, the ability to foresee the use of multiple new technologies, rapid response to new findings, coupled with the warm personality of kind and sympathetic doctor, teacher, and friend made for a remarkable individual, who has inspired thousands of students, doctors, and scientists around the globe. Almost every physician in the future will benefit directly or indirectly from his research, teaching, and his persistent and successful championing of the human genome project.

I have been a McKusick disciple for 45 years—he was my teacher, my mentor, my role model, and my champion and was much like a father to me and an uncle to my children. I shall miss him dearly.
Eulogy by Richard S. Ross

August 2, 2008
Richard Starr Ross

I have seen Victor several times since he returned from his trip to receive the Japan prize, and I have never seen him happier. He knew better than the average patient what the future held, but he was happy. He was enthusiastic in describing the presentation ceremony and his conversation with the Emperor and the Empress of Japan. Nova Scotia and Longfellow’s poem, Evangeline, were the subject of discussion with the Empress.

You can sense Victor’s enthusiasm in the photograph taken on that occasion. He was proud and felt that the awarding of the prize represented recognition of his lifetime work as a medical scholar. His pride was obvious and justified by all his accomplishments. We can all be thankful that his health permitted him to attend this ceremony.

I was somewhat startled but greatly honored a few weeks ago when Victor asked me to speak at his funeral. I was selected as someone who had known him for over 60 years and watched him with awe from numerous vantage points.

I first met Victor in 1947 when I came to Hopkins as a lowly intern, and he was a lofty assistant resident. During my first few years at Hopkins, Victor took me under his wing and taught me many things, among which was how to write medical papers. Victor was an absolutely superb writer and editor.

[I even considered the possibility that he asked me to speak at his funeral several weeks in advance so that he could edit this talk. I am sure he could have improved it, but I didn’t ask.]

The secret to his success as a writer was his ability to manage his time and concentrate on the task at hand. He also was blessed with superior intelligence, an awesome memory, a dictionary-size vocabulary, a boundless energy, and the ability to work early in the morning.

We wrote a paper together that was published in 1953. This paper is number 1 on my list of publications, but it is number 26 on Victor’s list. This gives you some indication of how far ahead of the pack he was at the very beginning of his career.

In 1975, when he was considered for the post of physician in chief and chairman of the Department of Medicine, there was a concern that he would not be a good choice because he had moved so far into research on rare, exotic diseases. Questions were raised as to whether he would be able to run a department responsible for training young people in the broad field of internal medicine. These doubters were wrong. He quickly cleaned the rust off the skills acquired as an Osler chief resident and became a superb department leader. The interns and residents stood in awe of his encyclopedic knowledge and loved him as a person. Steve Achuff will speak about this period in more detail.
[In the last few days, I encountered a young woman, at least she was young 60 years ago, who had worked for me and Victor as a technician. She had made charts and graphs and slides for us. She was reflecting on Victor’s death and said that she remembered that he always stood up when she entered his office to show him her work and only sat down after she sat down. I timidly asked her if I stood up when she came to see me and she replied, “I can’t remember.”]

In 1984, Victor was 63 years of age and 2 years from retirement, and he was having trouble filling some of the key positions in his department. Victor did not want to step aside early, but he could see that it would be best for Hopkins if he made it possible for his successor to fill the open slots. Another factor was his recognition that the field of medical genetics was about to explode, and he wanted to be out in front.

I was the dean at this time and have reviewed an exchange of handwritten letters I had with him in 1984 in which the pros and cons were laid out, and it was decided that it would be better for Hopkins and better for him if he gave up the chair of medicine and moved into genetics.

He left the position of physician in chief in 1985 while he was ahead and led Hopkins to the lead position in medical genetics. This is the most dramatic example of Victor’s superb timing in switching fields just at the right time.

Friends were very important to Victor. He and nine friends from the Osler house staff of the 1950s and wives met one Saturday night a month for what was called “supper club.” This organization still exists, although diminished in numbers and frequency of meeting, was always very important to Anne and Victor. Victor relaxed and enjoyed the company of old friends. He appreciated a good joke and had a strong, infectious laugh.

No tribute to Victor can be completed without recognition of Anne, in the background when appropriate, but able to move in decisively when needed. On one of my recent visits to see him, he was ruminating about what his life would have been like if he hadn’t come to Hopkins, and first on his list was, “I would not have met Anne.” I can add to that by noting that he would not have been so successful without Anne.

I am wearing the “Osler necktie” designed by Victor and to be discussed later by Steve Achuff. The word on the necktie, Aequanimitas, was used by Dr. William Osler, later Sir William, the first physician and chief at Johns Hopkins, to describe the inner calm that all good physicians must have. Victor was a great admirer of Osler and patterned his own career after this great man of medicine. He was also very fond of the word Aequanimitas and what it stood for.

At this very moment, I can picture Victor and Sir William together, and Osler says, “welcome McKusick, my worthy successor, will you join me on rounds?” They walk together into the ward.

A final word to you, Victor, Aequanimitas forevermore.
Appendix C
Obituary from Francis Collins and Obituary from Aravinda Chakravarti

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Victor A. McKusick (1921–2008)
Francis S. Collins, National Institutes of Health, Bethesda, MD 20892, USA.

It is the rare scientist who is universally recognized as the founder of a field. Even rarer is the one who witnesses his vision evolve from a solitary pursuit into a major discipline. But such was the life of the father of medical genetics, Victor Almon McKusick, who died on July 22 after more than a half-century of pioneering research, mentorship, and leadership.

McKusick was the driving force for moving genetics beyond the tidy realm of flies and mice in the research lab into the messier realm of the medical clinic. In 1957, he established a medical genetics clinic at Johns Hopkins, the model for what would become more than 100 such clinics nationwide, and unleashed a flood of discoveries that demonstrated connections between genes and diseases. Today, thanks largely to McKusick’s creative and tireless contributions, the field of medical genetics is at the center of medicine.

While the influence of some scientific leaders wanes with their passing, McKusick’s will only grow with time. His work created a dynamic legacy that lives on in the thousands of physician researchers he mentored and the marvelous, updateable resources he created. Nearly, every medical geneticist, including myself, can trace his or her scientific lineage back to McKusick.

The first of my many sips from McKusick’s seemingly bottomless well of knowledge came in 1981. As a medical genetics fellow at Yale, I was confronted with a puzzling infant with a congenital intestinal obstruction. The child had a sibling with an identical condition. I was stumped about the diagnosis, as was my attending physician, Uta Francke. So, we consulted McKusick’s landmark text, Mendelian Inheritance in Man, and came upon entry “#243600, familial apple peel jejunal atresia,” a perfect description of the child’s condition. Whereupon, Uta said, “This is wonderful. Victor should win the Nobel Prize!”
Scientific prizes probably were not on anyone’s mind when McKusick and his identical twin, Vincent, were born on October 21, 1921 on a dairy farm in Parkman, Maine. In fact, McKusick considered becoming a minister until age 15, when he developed a serious streptococcal infection and came away inspired by the physicians who saved his life. After spending 3 years as an undergraduate at Tufts, McKusick enrolled in 1943 in the Johns Hopkins School of Medicine, from which he graduated in 1946 and where he held a series of distinguished professorships up until his death.

While he authored many seminal papers and books on genetics, McKusick also delighted in sharing the story of his first encounter with the world of scientific publishing. As a medical student, he and his brother Robert (who became a dairy farmer) wrote a paper on the inheritance pattern of coat color in Jersey cattle, describing how the apparently dominant fawn color was actually a recessive trait. They eagerly sent their genetics paper off to the *Journal of Heredity* but never got a response. Fortunately, both for McKusick and the scientific community, future journal editors would display better judgment.

Among his key publications was a 1966 paper describing the first mapping of a human autosomal gene, the Duffy blood group locus. He also clinically defined a series of connective tissue disorders, the most famous of which is the Marfan syndrome. The tour de force of McKusick’s publications, however, remains his constantly updated *Mendelian Inheritance in Man*, a catalog of human genes and genetic disorders. This classic reference first appeared in print in 1966 and contained about 1,500 entries. Today, an electronic version features nearly 19,000 entries.

No description of McKusick’s impact on science is complete without mentioning his prescient call for mapping the human genome. In August 1969, at the International
Conference on Birth Defects in The Hague, McKusick proposed that mapping all human genes would be useful for understanding basic derangements in birth defects. “The proposal reflected the exuberant mindset that followed the first Moon landing by Apollo 11,” he recalled in a 2006 article. But the idea met with perplexed silence, in part because no one—not even McKusick—was clear on what methods could be used to achieve such an ambitious goal. Thankfully, McKusick was not one to give up easily and was a strong advocate for the Human Genome Project, stepping forward in the mid-1980s to serve as the founding president of the Human Genome Organization.

During a career that spanned an impressive 60 years, McKusick received many accolades, including election to the National Academy of Sciences in 1973, the Albert Lasker Award for Special Achievement in Medical Science in 1997, the National Medal of Science in 2001, and the Japan Prize in Medical Genetics and Genomics in 2008.

Medals and proclamations aside, I suspect that one achievement that McKusick would most want to be remembered for is his role in establishing the legendary “Short Course in Medical and Experimental Mammalian Genetics.” This 2-week event, held each summer at The Jackson Laboratory in Bar Harbor, Maine, has had a profound influence on medical genetics. Since it began in 1960, more than 5,000 clinical specialists, educators, and others have had the privilege of learning about the latest advances from some of the best minds in the field. In fact, according to Anne, McKusick’s physician wife for 59 years, hours before her husband died peacefully of cancer at their home outside Baltimore, Maryland, he had enjoyed watching the live streaming video of this summer’s “Short Course.”

More than a century ago, the father of modern medicine, Sir William Osler, wrote, “To wrest from nature the secrets which have perplexed philosophers in all ages, to track to their sources the causes of disease, to correlate the vast stores of knowledge, that they may be quickly available for the prevention and cure of disease—these are our ambitions.” Victor McKusick, who appropriately held the Osler Professorship for many years at Johns Hopkins, lived that vision better than any other physician of the last half-century.
Obituary

Victor Almon McKusick (1921–2008)

Quiet Revolutionary in Genetic Medicine


Following the complete sequencing of the human genome, we stand at the beginning of an era that promises medical treatments tailored to an individual’s genetic makeup. No one is more responsible for this revolution than Victor McKusick, who died on July 22. McKusick was the first to understand that systematically mapping human genes predisposing the bearer to disease, which many considered no better than stamp collecting, was a route to a new medicine. In this and other ways, he was instrumental in molding the discipline that we now call genetic medicine and in making genetics the basic science of medicine.

McKusick was born on a dairy farm in Maine in 1921. His early ambition was to enter the ministry. At the age of 15, however, a streptococcal infection of his arm that required a long hospital stay and treatment with one of the first antibiotics made him rethink his future. His identical twin Vincent chose to study law. Victor, by contrast, after initial education at Tufts University, entered Johns Hopkins University in 1943 to pursue medical training, making a name for himself in cardiology.

Like medicine, genetics came to him by chance. His fascination with one teenage patient who suffered from intestinal polyps and melanin spots, and later with three members of a family who exhibited the same syndrome, provided him with firsthand experience of the basic principles of genetics. One was the need to recognize patterns of inheritance, in this case, dominant as opposed to recessive, that suggested mutations at one genetic location. Another was the need to distinguish between mechanisms: in these patients, were two genes involved, one for polyps and one for spots, which were coinherited (linkage), or were polyps and spots different manifestations of the same gene (pleiotropy)? McKusick was thus well armed when he subsequently came across patients with Marfan syndrome—with its dominant inheritance and remarkable pleiotropy affecting the aorta, eye, and skeleton—which, he argued, arose from mutations in a single gene.

Similar patients and their families were to prove pivotal in his conversion to genetics, which was completed by 1957. Asked to direct a chronic-disease clinic by his boss, McKusick argued that “genetic disease is the ultimate chronic disease, since it’s lifelong,” and seized the opportunity to reshape the Moore Clinic at Johns Hopkins to create the first unit devoted to medical genetics. He learned his trade by doing: by using the rudimentary cytogenetic, biochemical, and population (quantitative) genetic methods then available. He soon became convinced of the three guiding principles: the value of knowing a gene’s location in the human genome, the value of accumulated genetic information, and the value of disseminating this new information widely and rapidly.
Given the individual rarity of most hereditary disorders, McKusick knew that he had to learn about the experiences of others and to share his own. He was a prolific organizer, of both ideas and facts, a trait most notably made manifest in 1966 in *Mendelian Inheritance in Man (MIM)*, the first edition of his catalog of all known genes and genetic disorders. The final print edition appeared in 1998, but since 1987, it has also been available as full-text online, with a free database ([www.ncbi.nlm.nih.gov/Omim](http://www.ncbi.nlm.nih.gov/Omim)). It now has some 19,000 entries, with more than 70% of the content having been produced by McKusick himself. This is his most lasting achievement—it is a deep resource and knowledge base, without which clinicians and any manner of biologist would be intellectually orphaned.

One of McKusick’s preoccupations was with cataloguing the location of each human gene associated with a disease and thus to create a disease map of the human genome. He did this not only through his own pioneering studies but by beginning—chiefly with Frank Ruddle—a series of human gene mapping workshops. Subsequently, he was an influential voice in organizing the international community around the Human Genome Organization (HUGO, fondly called Victor’s HUGO). For him, the *raison d’être* of mapping, which he articulated in 1969, well before anyone understood or believed it, was that mapping all human genes was the best way to understand the basic malfunctions causing birth defects.

The existence of *MIM*, together with McKusick’s mapping preoccupation, were the two most persuasive factors in favor of the public project to sequence the human genome. McKusick himself was on the US National Research Council committee that recommended the project and was one of its prime cheer leaders. He was among those who argued for a “map first, sequence later” approach and was a supporter of mapping and sequencing other species and of tackling the whole genome rather than only the known functional genome.
As a pragmatist, however, McKusick was also attracted to Craig Venter’s idea of sequencing expressed sequence tags (nucleic-acid snippets that encode only a portion of functional genes). He supported both the public sequencing project and Venter’s private sequencing effort at Celera (he was a trustee of Venter’s eponymous institute) because he believed that the genome could thus be completed sooner. The leaders of both the public and private sequencing ventures (Francis Collins and Venter, respectively) paid their respects at his funeral service.

McKusick made a research on the human species, despite its poor genetic properties of few offspring and long generation times, a treasure trove for uncovering new genetic mechanisms. He also provided a glimpse of the future for genetic medicine in an interview given in 2001: “I think the medical geneticist will spend much more time overseeing gene screens, or genome screens, interpreting the results to individuals, and designing programs to make the most of the strong points of the genome and to avoid troubles from some of the weak points in the genome.” Spreading the word was a vital part of his legacy—as, for example, in the influential “Short Course” in mammalian genetics, held annually at the Jackson Laboratory in Bar Harbor, Maine, which he founded in 1960 and codirected.

In the long journey to his many accomplishments, Victor McKusick was accompanied by his rheumatologist wife Anne. Those accomplishments are all the more remarkable for having been achieved without his once raising his voice. But then, a man who had genetic institutes named after him in Baltimore, Bologna, and Beijing had no need to draw attention to himself.

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