



Remembering the Titans

*A Memorial Tribute to Dr. Victor McKusick (1921-2008)
and Dr. Judah Folkman (1933-2008)*

By Frederick S. Kaplan, M.D.

When the lights have shined so brightly and they are finally extinguished, there is an even greater darkness.

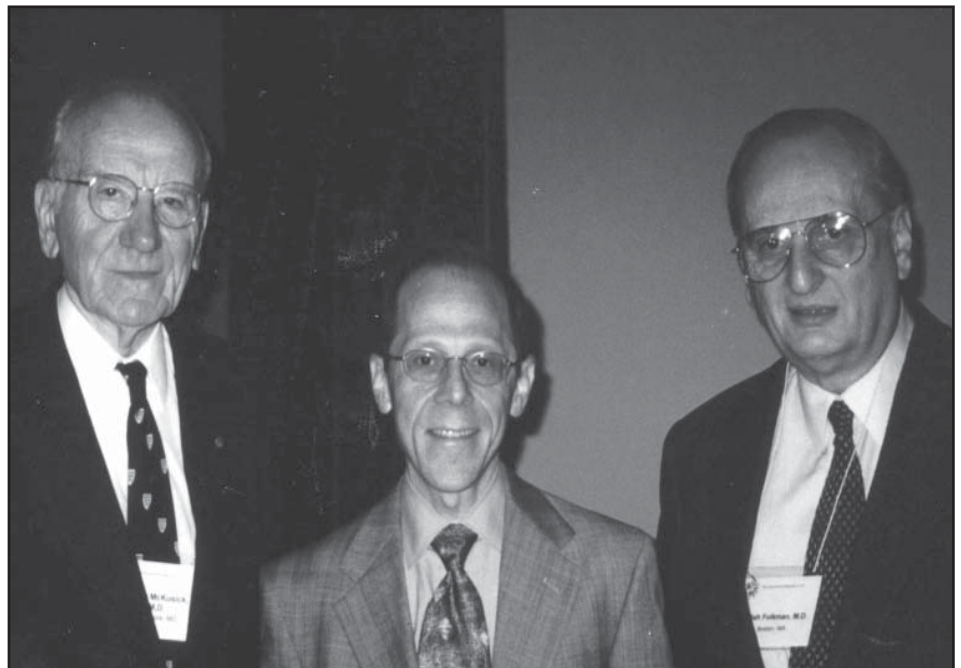
In 2008, the FOP community lost two extraordinary friends: Dr. Victor McKusick and Dr. Judah Folkman. Their names, their lives and their legacies are indelibly linked to the history of medicine and to our FOP community. Here, we remember these great physicians, scientists and friends.

Who was Victor McKusick?

Victor McKusick was the father of medical genetics.

Francis Collins, the director of the human genome project, wrote in *Science*, "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 July 22, 2008, after more than a half-century of pioneering research, mentorship, and leadership."

Victor McKusick began his journey on October 21, 1921 (along with his identical twin, Vincent) in the little village of Parkman, Maine, where he was born to a mother who was an elementary school teacher and a father who was a dairy farmer. Victor McKusick grew up on the dairy farm, led a simple childhood, went



LEFT TO RIGHT: Dr. McKusick, Dr. Kaplan and Dr. Folkman at the Third International Symposium on FOP in 2000.

to grammar school in a one-room schoolhouse, attended a high school that had no science courses, and planned to be a minister.

During the summer of 1937, at 15 years of age, young Victor McKusick developed a severe streptococcus infection under his arm which resulted in a hospitalization at Massachusetts General Hospital in Boston. After many weeks, the infection was successfully treated, with new sulfa antibiotics, and Victor was transformed by that experience. "From what I observed during my illness," he wrote, "I decided I liked what doctors did. I wanted to join them."

After high school, the twins decided that they would pursue different interests. Vincent went on to a distinguished career in law and became Chief Justice of the State of Maine. Victor enrolled in Tufts University in the fall of 1940 and, before finishing college, applied to medical school at the Johns Hopkins University in Baltimore. From its founding in 1893, admission to Johns Hopkins Medical School required an undergraduate degree, the first medical school in the United States to institute such a requirement.

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The International Fibrodysplasia Ossificans Progressiva Association (IFOPA) is a 501(c)(3) charitable organization whose mission is Instilling HOPE through Research, Education and Support while Searching for a CURE for FOP.

The IFOPA was founded by Jeanne Peeper in 1988 and the FOP Connection is its quarterly publication. To help those with FOP and their families, we print information and ideas from our readers on methods of management and care for FOP and its consequences. As an organization, however, we do not support or endorse any particular treatment or therapy. We urge everyone to always contact his or her physician for final approval of any treatment choice.

Open invitation to our readers: The Connection always seeks to improve the content and quality of our newsletter. We encourage our readers to provide us with feedback and comments on the newsletter as well as suggestions for future issues. We also invite anyone interested in providing material such as story ideas, articles, poems and artwork to the editor. Anyone interested in contributing to the Connection is invited to contact Eyal Goldshmid at FOPnews@bellsouth.net.

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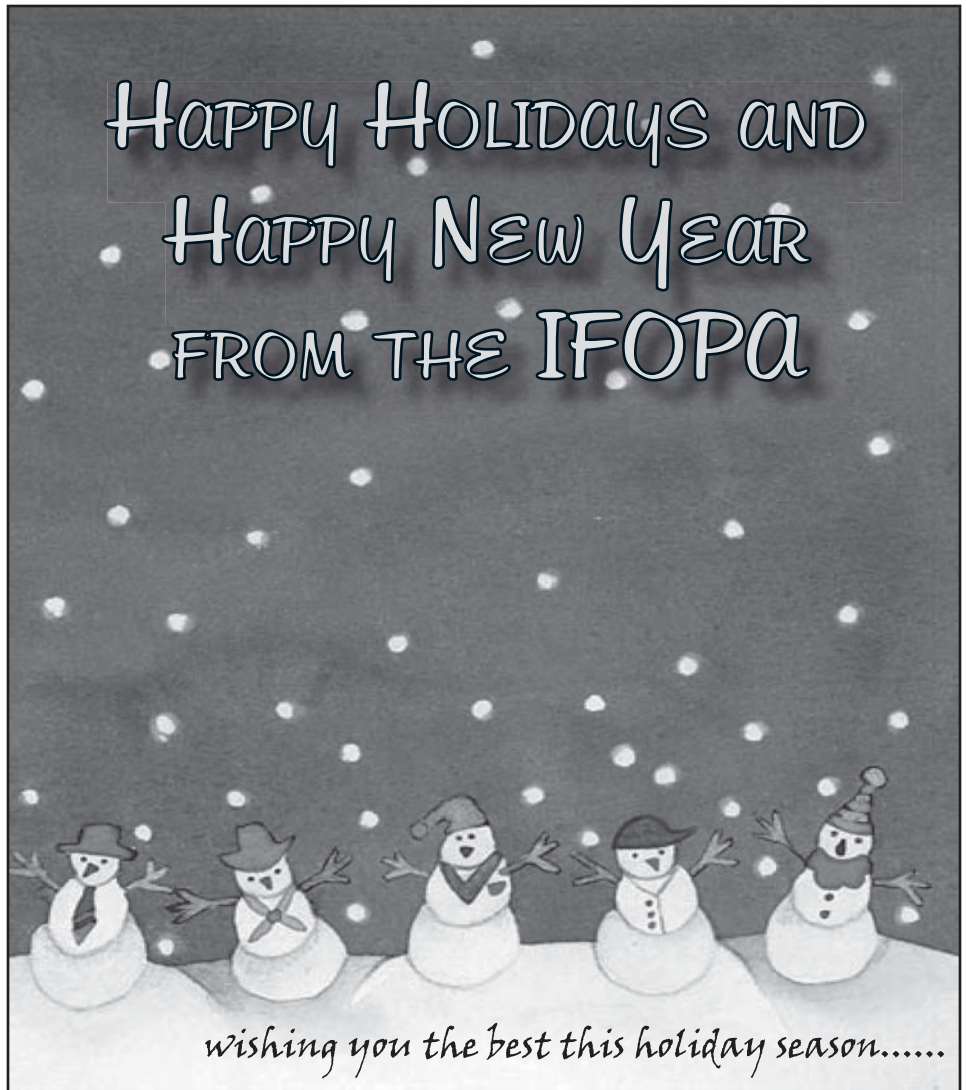


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However, the Second World War was raging, and the school could not fill its class. For the first and only time in its history, Johns Hopkins Medical School admitted a student, Victor McKusick, who did not have an undergraduate degree. Ironically, he would become one of the school's most distinguished graduates.

The entire aura of Johns Hopkins was thrilling to McKusick, and he immersed himself in its studies and its history. After his graduation from medical school, he served his internship and residency at Johns Hopkins and was later invited to join the faculty as a cardiologist. But, cardiology was only a passing interest on the way to other incredible accomplishments.

In 1957, Dr. McKusick created the Division of Medical Genetics at Johns Hopkins, the first of its kind in the world, and became the *de facto* teacher of nearly every medical geneticist in the latter half of the twentieth century. In 1973, he was appointed Physician-in-Chief of Johns Hopkins Hospital and The William Osler Professor of Medicine and Chairman of the Department of Medicine, a position which he held until 1985. Dr. McKusick spent the entire six decades of his medical career at Johns Hopkins, the longest uninterrupted tenure of any faculty member in the history of the medical school.

Dr. McKusick wrote numerous textbooks of international acclaim, including *Heritable Disorders of Connective Tissue* and *Mendelian Inheritance in Man*. The latter became the bible of medical genetics with its online version, *Online Mendelian Inheritance in Man (OMIM)*. He was the editor of many medical journals, president of the most distinguished medical societies, and the guiding light behind the human genome project.

He established and conducted the legendary "Short Course in Experimental Mammalian Genetics," an annual, two-week tutorial at the Jackson Laboratory in Bar Harbor, ME. The "Short Course" was held for medical school faculty every summer for the last 50 years. In fact, on the day of his death, Dr. McKusick was avidly absorbed in a video transmission from the course that he watched from bed at his home near Baltimore, MD. Moments after his death, Edward D. Miller, the Dean of the Medical Faculty and Chief Executive



PHOTO: Dr. McKusick (upper left) and Dr. Kaplan (upper right) meet with Mark Smith (back row, center) and the Smith children (front).

Officer of Johns Hopkins, said, "We have lost a giant, but his influence and legacy reach around the world."

Dr. McKusick was the recipient of numerous honors and awards. He was elected to the National Academy of Sciences in 1973, received the Albert and Mary Lasker Award (The American Nobel Prize) for Special Achievement in Medical Science in 1977, the Gairdner Foundation Award (Canada's highest scientific accolade), and the U.S. National Medal of Science. He was the founding president of the Human Genome Society, was inducted into the International Pediatrics Hall of Fame, and received the prestigious American Association of Physicians' George M. Kober Medal.

In 2008, just months before his death, he received the Japan Prize in Medical Genomics and Genetics for "original and outstanding achievements in science and technology that have advanced the frontiers of knowledge and served the cause of peace and prosperity for mankind." On receiving the Japan Prize, Dr. McKusick said, "I am deeply appreciative and grateful for this wonderful honor. In my view, it also honors the contributions and support of Johns Hopkins, and of my colleagues and students over many decades."

Dr. Harry Deitz, III, a former McKusick student and the Victor A. McK-

usick Professor of Genetics and Medicine at Johns Hopkins Medical School, wrote, "While I will miss Dr. McKusick deeply, I feel his tangible presence in my clinic, and in my lab on a daily basis. His legacy to medicine is so pervasive, even fundamental, that it will be difficult to pinpoint but impossible to avoid."

Frances H. Collins wrote, "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 at The Hague, Dr. McKusick proposed that mapping all human genes would be useful for understanding basic derangements in birth defects. While the proposal reflected the exuberant mindset that followed the first moon landing by Apollo 11, just weeks before, the idea was met with perplexed silence in part because no one was clear on how this could be achieved. Thankfully, Dr. McKusick was not one to give up easily and was a strong advocate for that project, perhaps its strongest advocate of all."

"Dr. McKusick's vision is reflected in his early recognition of the inherent value to medicine of mapping the human genome," said Aravinda Chakravarti, Director of the McKusick-Nathans Institute

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in a 2002 statement. "His contribution to the practice of genetics in medicine is thus seminal, phenomenal, and ageless."

An obituary in the *New York Times* noted that, "McKusick, a cardiologist went on to become the founder of medical genetics and helped make the discipline a central part of medicine. He influenced the training of the vast majority of medical geneticists, through his textbooks which catalogued thousands of genetic disorders, and through his many lectures and personal visits to clinics throughout the world."

Vincent Gott, a Professor at Johns Hopkins noted, "I have never really known anybody who achieved so much and worked so hard as Dr. McKusick. He was absolutely brilliant and yet very soft spoken and understated."

This legendary man who literally put human genetics on the map not only made history but was deeply influenced by its lessons and took every opportunity to teach it to his students. While recovering from his bacterial infection at 15 years of age, he was absorbed in reading Harvey Cushing's Pulitzer Prize Winning Biography of Sir William Osler, the first Professor of Medicine at Johns Hopkins.

More than a century ago, Sir William Osler wrote, "To rest from the 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 eventually held the Osler Professorship at Johns Hopkins, lived that vision better than any other physician of the twentieth century.

What Did Dr. McKusick Mean to the FOP Community?

Dr. McKusick had a deep and lifelong interest in FOP. He wrote about it extensively, especially in his classic work *Heritable Disorders of Connective Tissue* (1960), and in many revisions and papers that followed. Dr. McKusick was single-handedly responsible for changing the name of the condition from myositis ossificans progressiva to fibrodysplasia ossificans progressiva to acknowledge the fact



PHOTO: Jeannie Peeper and Dr. Kaplan present the IFOPA Lifetime Achievement Award to Dr. Victor McKusick at the Third International Symposium on FOP in Philadelphia in 2000.

that the disease involved not only skeletal muscle but also other soft connective tissues including tendon, ligament, fascia, and aponeuroses (soft tissues that hold large muscles bundles together).

I first met Dr. McKusick when I was a young medical student at Johns Hopkins University School of Medicine in 1973. While he taught our genetics course, but he made a point to teach the indelible lessons of medical history. He lectured to us extensively about the importance of studying medical history and understanding the role that each small discovery plays in the evolving history of medicine. He often asked us questions about doctors who contributed to the history of medicine, quizzing us on their names and contributions and making sure that we recognized that often a single sentence in a medical textbook might have been the distilled focus of a doctor's work for his or her entire lifetime.

Dr. McKusick conveyed the important lesson that cumulative knowledge, built upon by generations of scientists and physicians, allows us to practice medicine as we do today and to move the art and science of medicine forward for the next generation. He not only taught this, he deeply felt it, and it was a message that resonated

with all of my classmates whether or not we pursued academic interests in our own careers. Importantly, he provided the foundation on which all of our learning and practice of medicine would be based.

Soon after I met Dr. McKusick, he was appointed Physician-in-Chief of the Johns Hopkins Hospital and Chairman of the Department of Medicine. In his new academic role, he made hospital rounds with us regularly. He frequently invited us back to his office, often with guests – retired professors and sometimes even patients themselves – to recount stories about how they contributed to the history of medicine. I recall the morning on ward rounds that I introduced Dr. McKusick to an elderly secretary, nearly 100 years of age, who I had admitted to the hospital the weekend before because she was experiencing "blackout spells." However, it was not her clinical history that was most interesting to Dr. McKusick but rather the fact that as a young woman she was a medical secretary to Dr. William Osler, the founding physician of The Johns Hopkins University School of Medicine and the namesake of his Professorship. He mentioned it to me often and spent many hours at her bedside, asking her questions and recording interviews with her on audiotape. He

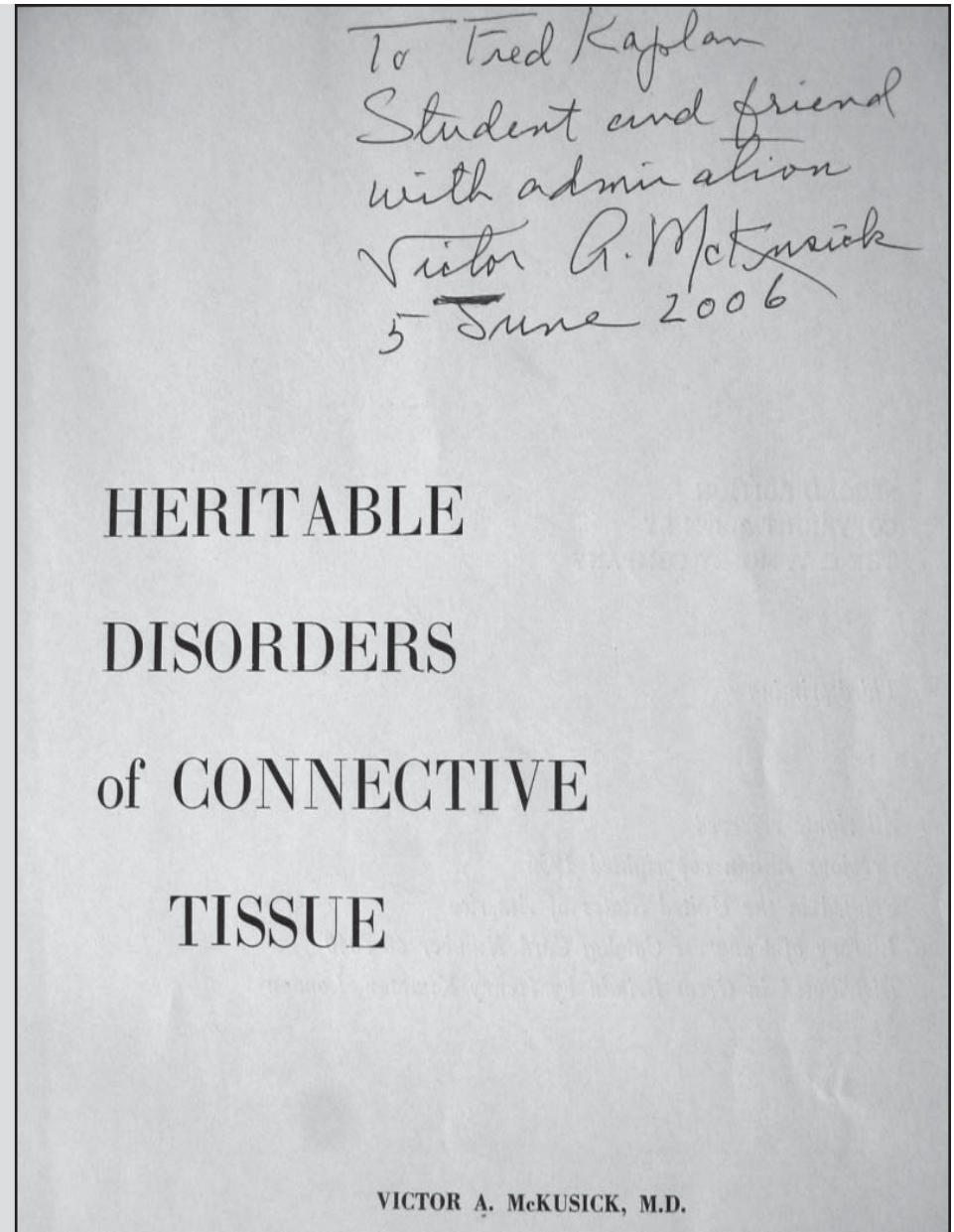
was thrilled with the experience and was grateful to the patient. I remember what he told her. He said, "Thank you for sharing your wonderful memories with us, and I hope your stay here is not too unpleasant."

As a young medical student, I frequently attended Genetics Clinic with Dr. McKusick. Many years later, I truly understood that not every medical student had such an extraordinary opportunity to study with a truly great mentor and pioneer. It was in this context that Dr. McKusick taught me another valuable lesson of my professional life, the importance of studying rare diseases. He introduced me to the writings of Dr. William Harvey, the discoverer of the circulatory system. He showed me a letter, from the late 1600s, that Dr. Harvey wrote in response to a letter he had received from a Dutch physician asking him to see a patient who had a rare disease. At the time he wrote the letter, Dr. Harvey was an old man and could not make the trip to see the patient, but implored the young Dutch physician to study rare diseases for their intrinsic educational value. He wrote, "Nature is nowhere more likely to display her secret mysteries than in cases where she shows traces of her workings apart from the beaten path. Nor is there any better way to advance the proper practice of medicine than to give your mind to the study of the rarer forms of disease. For it has been found in almost all things that what they contain that is useful or applicable is hardly perceived unless we are deprived of them, or they become deranged in some way." (London, April 24, 1657).

It was in Dr. McKusick's genetics clinic that I was first introduced to another rare condition, FOP. At first, I was rather perplexed by it, as I did not yet have a background in molecular genetics (because the field was not yet invented) to know how to explore it. That would come years later when I met a dear friend and colleague, Michael Zasloff, M.D., Ph.D., another disciple of Dr. McKusick.

When I left Hopkins for Penn, I frequently called upon Dr. McKusick for guidance and advice. He was a great mentor who gave me the confidence to pursue my career in my own way, often against the advice of more skeptical colleagues. He was a beacon in the dark.

When I met Dr. Zasloff in 1988, I was extremely excited to learn that he too



had studied with Dr. McKusick, not as a medical student as I had but as a post-doctoral fellow in medical genetics at Johns Hopkins. Immediately, we had much in common. I soon learned that most of the geneticists and physicians who I would work with closely over the next decade were either taught directly by Dr. McKusick or were deeply influenced by him. These included the likes of Michael Zasloff (United States), Eileen Shore (United States) Michael Whyte (United States), Michael Levine (United States), Julie Hoover-Fong (United States), Martine Le Merrer (France), Jon Andoni Urtizberea (France), Michael Connor (United Kingdom), Roger Smith (United Kingdom), John Rogers (Australia), Jim McGill (Australia), David Silence (Australia), Roberto Ravazzolo (Italy), Jean Lin (Tai-

wan), Stefan Mundlos (Germany), Gabriel Gillesson-Kasebach (Germany), In Ho Choi (Korea), Max Muenke, Olli Morhart (Germany), and many many more.

Dr. McKusick was an honored guest at the first three FOP symposia in 1991, 1995, and 2000. He spoke on all three occasions, and in 2000 he was presented a Lifetime Achievement Award by the IFOPA for his pioneering work and research on FOP. He spoke at the banquet that evening, in the presence of many of his patients, students and nearly all of those whom he had inspired to work on FOP. He told us that it was heartwarming for him to see how the FOP community had come together under the leadership of Jeannie Peeper, Michael Zasloff and oth-

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ers. At each of the three medical symposia, Dr. McKusick saw patients with me and Dr. Zasloff, often stopping in the hallways and at the dinner tables to speak with families whom he had seen before, or with new ones who he so eagerly wanted to meet.

When we discovered the FOP gene in 2006, I called Dr. McKusick to tell him the exciting news several days before it became public. He was ecstatic about the discovery and grateful that we showed him that honor. "Please send me the paper," he said, "and I'll make sure that geneticists around the world know about it immediately." That, he did.

One of the most meaningful days I ever spent in my medical career was in April 2007, exactly a year after the discovery of the FOP gene. Several months earlier, I had been invited to give a major lecture on our work on FOP at Johns Hopkins. Dr. McKusick was looking forward to my visit, but unfortunately fell ill on the day of the lecture and was unable to attend. When I returned home to Philadelphia later that evening, I opened my computer and found an email from Dr. McKusick expressing his regrets and asking if I would be willing to return to speak with him personally (and perhaps a few others) when he was feeling better. I responded immediately that I would love to do that, and he responded that same night by asking me for possible dates on which I might return to Hopkins to talk to him. We settled on a date in late April 2007, and thankfully he was feeling well enough to be there. In fact, we spent the entire day together, in a spacious conference room in the McKusick-Nathans Genetics Center, where we were sequestered with comfortable chairs, a PowerPoint projector, and a delicious lunch that we munched on for hours. During that time, Dr. McKusick wanted to hear the entire story of FOP and learn the entire history of our research program over the past 17 years. He was not only interested, he paid attention to every detail, asking probing questions and engaging me and the three other professors in the room in the type of discussion that I have rarely experienced before. It was exhilarating and thrilling. I felt that I had made a Papal visit to the Vatican of Medicine and had my last private audience with one of the great physicians of the twentieth century -- a favorite teacher, mentor, and friend.



PHOTO: Dr. McKusick and Monica Anderson.

The next day, he wrote:

Dear Fred,

I am immensely grateful to you for giving me a chance to hear the FOP story. It is an exciting one, and you and your colleagues are to be congratulated on what you have accomplished.

Thank you, and all best wishes,

Victor

Soon thereafter, Dr. McKusick became ill with a devastating form of cancer. Nevertheless, he continued to work in his office at Johns Hopkins or at home until the day he died. He left behind his beloved wife, Anne, a physician and rheumatologist, three children, and his identical twin brother Vincent, the former Chief Justice of the State of Maine.

David L. Rimoin, the Director of Medical Genetics at Cedars-Sinai Medical Center in Los Angeles, wrote, "Dr. McKusick's enormous energy, rigorous work ethic, effective time management, ability to foresee the use of multiple new technologies and rapid response to new findings, coupled with the personality of a sympathetic doctor, devoted teacher, and good

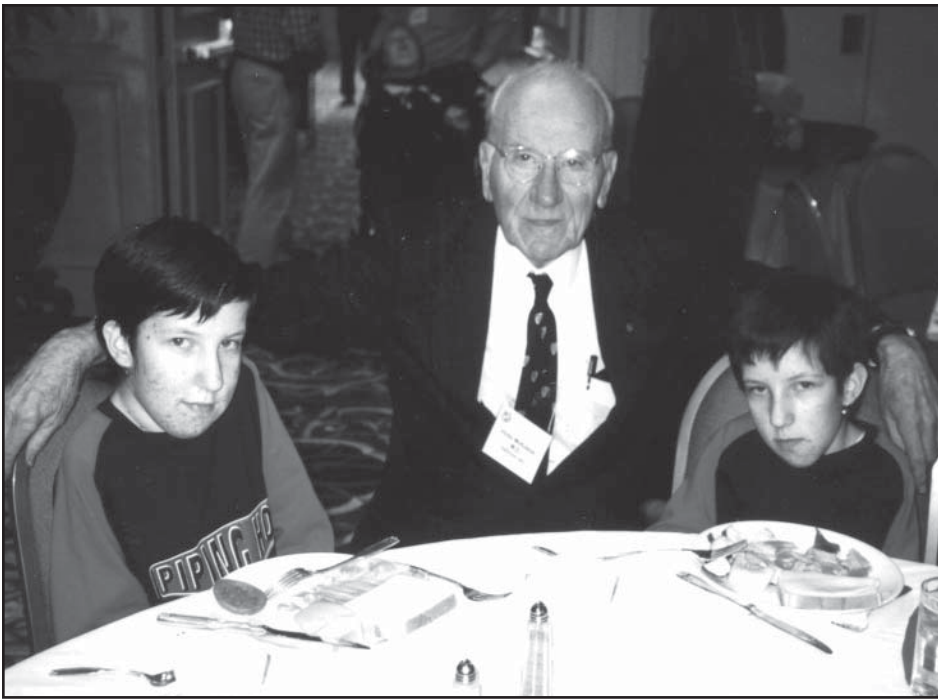


PHOTO: Dr. McKusick visits with identical twins Erika and Nadine Milevoj from Darwin, Australia.

friend, made for a remarkable individual who has inspired thousands of students, doctors, and scientists around the world.”

Kenneth Baughman, a former Hopkins resident and Professor of Medicine at Harvard wrote, “Dr. McKusick was a magnificent man. He was one of those individuals who touched many, many academic lives and influenced them in major ways. And you can never repay that sort of debt.”

Who was Judah Folkman?

Moses Judah Folkman was an American physician who founded the field of anti-angiogenesis research. Early in his career, Dr. Folkman discovered that tumors generate tiny blood vessels (angiogenesis) to nourish themselves and that medications to inhibit the growth of those blood vessels (anti-angiogenesis) might help inhibit the growth of those tumors. As his *New York Times* obituary noted, Dr. Folkman was a “path-breaking cancer researcher who faced years of skepticism before his ideas led to successful treatments.”

Born in 1933 in Cleveland, Ohio, Moses Judah Folkman accompanied his father, a rabbi, on pastoral visits to hospital patients. However, early in life, around the age of seven, he decided he wanted to be a doctor rather than a rabbi, so that he could cure patients in addition to comfort-

ing them. “In that case,” said his father, “you can be a rabbi-like doctor,” something that Dr. Folkman took seriously and incorporated into his academic career.

He graduated from Ohio State University in 1953 and then Harvard Medical School in 1957. He served a surgical residency at Massachusetts General Hospital, and at an early age he started thinking about the role of blood vessels in the growth of tumors. In 1971, he published an article in *The New England Journal of Medicine* postulating that all cancerous tumors were dependent on blood vessels (angiogenesis). At first, his ideas were ridiculed but later were widely accepted as gospel. Dr. Folkman established a laboratory at Harvard University and Children’s Hospital of Boston that was world renowned in its research on angiogenesis. Later in his career, Dr. Folkman discovered the molecular basis of angiogenesis and used this knowledge to develop anti-angiogenic treatments for a myriad of disorders.

He spent his entire professorial career at Boston’s Children’s Hospital, where he was later Chairman of Surgery. He was a member of the National Academy of Sciences, the Institute of Medicine, the National Academy of Arts and Sciences, and the American Philosophical Society. He authored more than 400 papers, 100 book chapters, and countless monographs. He received numerous awards for his dis-

tinguished research, including Canada’s Gairdner Foundation Award, Israel’s Wolf Foundation Prize in Medicine, Germany’s Ernst Schering Prize, Italy’s Association of Cancer Research Gold Medal, United Kingdom’s Society for Endocrinology Dale Medal, and Switzerland’s Josef Steiner Cancer Research Award.

Dr. Folkman died of a heart attack at the Denver Airport on his way to a meeting in Vancouver, Canada on January 14, 2008. He is survived by his wife, Paula, his two daughters, a brother, a sister, and a granddaughter.

What did Dr. Folkman Mean to the FOP Community?

I first met Dr. Folkman at a skeletal biology symposium in Portland, Oregon in 1995. We were both invited as visiting professors and guest speakers to a large audience of physicians and skeletal biologists. Anyone who has ever heard Dr. Folkman lecture knew that he was a riveting speaker who presented bold ideas backed-up by hard core science.

When it was my turn to speak, Dr. Folkman sat quietly in the large audience. After I finished my presentation on FOP, Dr. Folkman rose to ask a question:

“Dr. Kaplan,” he said, “you showed that early FOP lesions have an abundance of blood vessels. It seems that these blood vessels may play an important role in the growth of these lesions or flare-ups. Have you ever investigated the angiogenic factors that might be involved in recruiting such large numbers of blood vessels to these early lesions?”

“No, I have not done that,” I answered.

“Well, would you like to?” he asked.

And, I answered, “Yes.”

And, he said, “Well then, meet me in the hallway after the lecture, and we will discuss this.”

There was a chuckle from the audience but we did just that. Dr. Folkman didn’t have long to talk because he had to return to Boston almost immediately, but he asked me if I would eventually be able to obtain blood or urine samples from FOP patients and then send the specimens to him blindly (without any notation to him of whether the patients were having flare-

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ups) and he would evaluate the levels of angiogenic molecules that might reflect the activity of FOP lesions. He thought that considering the rarity of FOP, it would probably take several years or more to accumulate enough specimens to send to him for evaluation, but he would be happy to evaluate them and then send the results back to me so that I could break the code and see if there was any correlation with flare-ups. He was astonished when I told him that in several weeks we were going to have our Second International Symposium on FOP (1995) and that I would be seeing nearly 60 FOP patients from around the world. I told him that I would be able to accumulate specimens from a large number of FOP children and send them to him promptly. He was a bit shocked that we would be able to accumulate so many specimens so rapidly but he urged me to do so, and we followed-up exactly as he asked. Several months later, when the results returned from Dr. Folkman's laboratory and the code was broken, we were astonished to find that flare-ups of FOP were highly correlated with an intense elevation of specific angiogenic factors in the blood and urine. These factors traced directly back to the bone morphogenetic protein pathway and eventually to the causative

gene mutation. This observation enabled us to identify factors that were responsible for the rapid growth of the lesions. This led to further studies on how to limit the swelling with anti-inflammatory and anti-angiogenic medications (such as steroids, non-steroidal anti-inflammatory medications, and cox-2 inhibitors) that have been a mainstay in controlling many symptoms of FOP flare-ups.

In 2000, Dr. Folkman was invited to attend the Third International Symposium on FOP and to deliver the keynote lecture on "Angiogenesis Research: From Laboratory to Clinic." Dr. Folkman gave a brilliant lecture that left the entire FOP community spellbound.

Dr. Folkman was a giant of medicine who played a vital role in understanding the pathophysiology of cancer and who took time from his work to help us dissect the angiogenic component of FOP lesions. He felt strongly and deeply about understanding the basic mechanisms of cancer and FOP and using that knowledge to develop better treatments and eventually a cure.

Dr. David Nathan, the former President of the Dana Farber Cancer Institute in Boston, noted, "There were very few Roman candles like him. He was indefatigable and unquenchable."

Conclusion

In reflecting on the lives of these two great physicians, Dr. Victor McKusick and Dr. Judah Folkman, we remember them respectfully as founders of new fields in science and medicine and fondly as personal friends and friends of our FOP community. They were medical and scientific pioneers who took time from their lives to teach, inspire, and advance the causes we cherish.

As children, both Victor McKusick and Judah Folkman had dreams of joining the clergy before being inspired and diverted to careers in medicine. Upon learning of their deaths, a patient-member of the FOP community who remembered them fondly remarked: "I'm glad that God had other plans for them."

Those plans aside, what is certain is that the FOP community was privileged to have Drs. McKusick and Folkman as part of our world and privileged to have them make such important contributions to the advancement of our field. To many of us, they were great teachers, mentors, colleagues, and friends, and they will be missed. Their lives made a difference, and their legacies will endure forever.

Thanks

Commemorating the Contributions of Some Departing Members of the IFOPA Board of Directors

**By Don Brister
Chairman of the Board**

One of the strengths of the IFOPA comes from the tireless service provided by those who have agreed to serve on its Board of Directors. Each one is asked to be involved in committee work and fundraising efforts, as well as attending meetings and participating in countless conference calls.

I have been very lucky to have had dedicated people serve with me on the Board. Sadly, four of these people have decided to leave the Board at the end of 2008. I wish to thank them personally for their service.

Monica Anderson served this past year as our Secretary and as Chairperson of the LIFE Committee. Despite the fact that she has FOP, she has managed to earn a Bachelors and Masters Degree and now works a full-time job as a tax analyst. Her insightful contributions to our Board will be sorely missed. I would

be remiss in not thanking her mother for her support as well.

Robin Davis served as our Finance Committee Chairperson. An executive in Cincinnati for E.W. Scripps, Robin's ability to crunch the numbers at Board meetings provided those of us who do not have accounting backgrounds with new perspectives on the budgeting process. She also happens to be the aunt and godparent of FOP member Carli Henrotay.

The two other ladies I wish to thank served me well as Vice-Chair respectively. Jeri Licht and Lori Henrotay are both stepping down, and their efforts and long-time service to our organization have been an inspiration to all of us. Both encapsulate the spirit of dedication and devotion our organization is based on, and I thank them for that.

Even though we will miss their experience, enthusiasm, insight and dedication, I have no doubt that those who have been chosen to serve this coming year on the Board will do so with the same "can do" attitude as Monica, Robin, Jeri and Lori.

A Special Thank You to Jeri Licht

**By Don Brister
Chairman of the Board**

To list all the leadership positions held by Jeri Licht would take an entire *Connection*, but let me highlight a few.

She served as the Vice Chair in 2007, Secretary for four years, served on two Symposium committees, Chair of the Grant Writing Committee and worked tirelessly on the search team to hire our new Executive Director.

When I agreed to serve as Chairman in 2007, it was with the understanding that Jeri would be Vice Chair and would assist me, since she had a vast array of talents and experience. She was outstanding in that role.

She gave up a life as an attorney when her son was diagnosed with FOP. The IFOPA became her place of employment, even though she received no compensation. To say that her life's work is to support, guide and advise parents of children with FOP would be an understatement. There are very few days that I fail to see her response to questions on FOPonline. She has an uncanny ability to be a calming influence on frustrated and anxious parents.

Those who visited the Resource Center at the Fourth International Symposium on FOP in 2007 have Jeri to thank for that; the vast number of adaptive tools displayed there was the result of her vision. Her latest project is to help design, construct and make available a Traveling Resource Center that can be used throughout the world to assist FOP families.

For the last 11 years, Jeri has served our community well in various positions of leadership, has used her legal skills to write and develop the IFOPA policies and procedures manual, has held many fundraisers, has volunteered for almost every project that we have devised, and has been a beacon of support for each Chairman.

She has been there to support me, criticize me if needed -- and believe me there were times when I really did need a dressing down -- and provide innovative proposals. She is truly an inspiration to the entire Board. I will miss her, but she deserves a rest as she guides Daniel through his teenage years.

Thank you, Jeri.



A Special Thank You to Lori Henrotay

**By Don Brister
Chairman of the Board**

I have the utmost respect for parents of children with FOP. I have even more respect for such parents who choose to serve in a leadership position in an organization such as the IFOPA. Lori Henrotay is one of those people.

I first met Lori in Newark, NJ during a weekend planning session for the 2007 International Symposium on FOP. I was attending my first IFOPA meeting at the time, and I was the only man present. Lori and I were assigned to present a marketing plan together and to work on the Symposium budget. She was using two computers simultaneously while carrying on a conversation with me and her daughter at the same time. Despite this apparent chaos, she managed to lay out everything in a clear-cut, organized manner. Talk about multi-tasking!

Of course, I have discovered over the last two years that this is typical of Lori.

We thank her for work on the Symposium Committee, as well as the development of our new logo and branding image due to her role as Chairman of the Marketing Committee. Also, she has assisted in redesigning our website and is currently the Vice Chair of the Board of Directors. She was slated to serve as Chair in the coming year but changes in her personal life necessitated her resignation.

Even though she has decided to resign, she has not lessened her passion to our cause and has not slowed her work for the IFOPA. Recently, she persuaded her employer to produce a series of FOP-based self-help videos that will be available on our website in the coming year. Such a task demonstrates her ongoing dedication to the IFOPA.

In addition, she has been a great sounding board for me this past year, and I will miss her ability to see the big picture, her strategic mind, and her skill in marketing the IFOPA as we continue to grow.



hAPPY hOLIDAYS

Scientific Conference

1st Advances in Rare Bone Diseases

by James McKeever
IFOPA Executive Director

I had the wonderful opportunity to attend the 1st Advances in Rare Bone Diseases conference in Bethesda, MD at the National Institutes of Health from October 22 to 24, 2008. Since this was only my third week as Executive Director of the IFOPA, going to this conference provided me with a great way to see how other organizations deal with their particular bone disease. Additionally, it afforded me the chance to meet some members of IFOPA who were also attending the event.

The first evening consisted of a welcoming dinner, during which I met Hillary Weldon, who has been a long-time member of IFOPA and is the co-Chair of the Rare Bone Disease Patient Network. I learned about her daughter, Whitney, who has FOP, and all that Hillary and her husband, Bill, have done since FOP came into Whitney's life.

Also during the course of the conference, I met Brian Harwell and Monica Anderson and their mothers, and through meeting them I gained great appreciation for the role parents play in helping children with FOP.

Thursday was the first full day of the conference, and during it I attended several presentations and discussions on rare bone diseases. Every talk seemed to supply a great deal of helpful information to the doctors and scientists in the audience.

During this day, Dr. Eileen Shore took participants on a journey through the development of the FOP mouse and how the discovery of the FOP gene had made it all possible. According to Dr. Shore, this project will be one of the research team at the FOP Lab at Penn's top priorities in its search for a cure for FOP.

That evening, roundtable discussions were held for each particular disease. With Dr. Fred Kaplan, Dr. Shore, and Dr. Michael Zasloff in the audience, the talks proved to be lively affairs and positive in spirit. The conversations eventually turned into



LEFT TO RIGHT: Brian Harwell, Dr. Eileen Shore, Dr. Michael Zasloff, Monica Anderson (front and center), Hillary Weldon, and Dr. Fred Kaplan at the conference.

a brainstorming session that allowed guests to exchange ideas freely on where they thought FOP research would be heading in the coming years. Though there is still much work to be done, the dialogue was optimistic, and I left feeling that the information presented might lead the IFOPA in some new directions in the near future.

Friday held more presentations on rare bone diseases, as well as Dr. Kaplan's discourse on FOP. His presentation was concise and very easy for everyone to understand. His compassion towards his patients was evident.

At the close of the meeting, I had the chance to talk to some of my counterparts from other rare disease associations, and I found the information they shared with me to be very beneficial. What surprised me most was that the study of FOP is rather advanced compared to the research being performed for some of the other rare diseases represented at the conference. While there is still much to do, I found it encouraging to see what the IFOPA has been able to accomplish in its 20 years.

The network of researchers and supporters the IFOPA has built over the last two decades is truly inspirational. While other organizations have been trying to do the same for their own particular disease, and have met with some success, the work of people in the FOP community has really made great strides, especially in the way our association has become responsive and proactive in terms of research and support. I left the conference inspired, excited by what the future holds, and believing that we can climb to even greater heights in the years ahead.

- On the Next Page -

More about the 1st Advances in Rare Bone Diseases Conference



PHOTO: Brian Harwell (left) with Dr. Kaplan at the 1st Advances in Rare Bone Diseases conference in Washington, D.C.

Renewed Hope

1st Advances in Rare Bone Diseases

by Brian Harwell

I had the honor of representing the FOP patient community at the 1st Advances in Rare Bone Diseases Scientific Conference in October in Washington, D.C. and the days were filled with past memories, present advances and future hope.

Listening to the many doctors present their findings for their respective rare bone diseases made me realize how far Dr. Kaplan, Dr. Shore, Dr. Zasloff, and the rest of the FOP research community have come in 20 short years.

I remember meeting Dr. Zasloff at the National Institutes of Health in 1991, and there was very little known about FOP at the time. He didn't know what gene caused FOP, he didn't have any treatment, and he wasn't clear on exactly what triggered FOP to cause so much damage. I saw a striking similarity between Dr. Zasloff and Dr. Reith, when Dr. Reith presented his findings on Gorham's Disease. Dr. Reith knew very little about what caused the disease and even less on how to cure it, but I saw a young doctor that was on a mission to help the few afflicted with this condition.

Dr. Shore and Dr. Kaplan gave presentations at the conference. Dr. Shore unveiled the chimera mouse. The immediate goal after finding the gene that causes FOP was to genetically engineer a mouse to have FOP. The chimera mouse has the short big toe and the extra bone along the neck and spine. The realization that our brilliant doctors have been able to accomplish this feat is nothing short of a miracle!

In compliment to Dr. Shore's presentation, Dr. Kaplan's presentation included information about dorsomorphin derivatives, chemical compounds that show promise as a possible treatment for FOP. According to Dr. Kaplan, idealistically the compounds might offer a solution by inhibiting the overactive switch that causes FOP. Though these compounds are still a long way from being used as drugs to help those with FOP, the founda-



LEFT TO RIGHT: Dr. Shore, Brian Harwell, Dr. Kaplan and Dr. Zasloff at the 1st Advances in Rare Bone Diseases conference in Washington, D.C.

tion for their use seems to be in place, which I consider a major achievement.

Dr. Kaplan said the ultimate goal of the FOP Lab is to implement a treatment that will either stop a flare up or prevent one altogether. I thought we would eventually need help from a large pharmaceutical company such as Merck or Pfizer in order to produce a medication to treat FOP, a task that seemed impossible considering the small number of people affected by FOP. But according to Dr. Zasloff, we do not need a large pharmaceutical company because there are hundreds of chemical manufacturers able to produce high quality medication for a small number of patients.

The past 20 years have been filled with incredible advances in unlocking the mysteries of FOP. In my lifetime, I have gone from being misdiagnosed to being diagnosed without any knowledge of what exactly FOP is to experiencing the discovery of the gene to the development of an FOP animal model and now to the hope that a viable treatment may be found in my lifetime. I cannot thank Dr. Kaplan, Dr. Shore, Dr. Zasloff, and the rest of the FOP research community enough for what they have done; they all are gifts from God. I am sure the rest of the FOP community agrees with me when I say that if there is anything we can do to help, please let us know.

We may be fighting different battles against FOP but together I am sure we can win the war.



LEFT TO RIGHT: Toby King, Executive Director of the U.S. Bone and Joint Decade, Brian Harwell (center) and J. Edward Puzas, Ph.D., Donald & Mary Clark Professor of Orthopaedics at the University of Rochester School of Medicine and Dentistry at the 1st Advances in Rare Bone Diseases conference in Washington, D.C.

- On Page 13 -

More about Brian's Trip to Washington, D.C.

Meet the New Executive Director of the IFOPA

My name is James McKeever, and I became the new Executive Director on October 6, 2008. I am very excited to take this position, and my first few weeks on the job have enforced that feeling.

First, let me give you a bit on my background. I grew up in Trenton, NJ and have spent most of my career, since graduating Rutgers University, in the field of nonprofit management. For 12 years, I worked for the Boy Scouts of America, first on Long Island, NY and then in Syracuse, NY, central Pennsylvania and, finally, in New Jersey. At that time, to get promoted within the Boy Scout organization, one had to move around a lot.

Thanks to the great training I received from the professional staff at the Boy Scouts, I was able to move onto other organizations and contribute to their successes. Along the way, I held various positions, such as Program Director, Business Administrator and Executive Director.

One thing my career has taught me has been to obtain a clear understanding of what makes up a good association. I believe my strengths are my ability to organize and listen to people, and I feel I can use these skills to help guide the IFOPA in the direction the Members and Board of Directors desire. While FOP is new to me, the need to promote research, awareness, education and support of a rare disease is not. I want everyone to know that I am very open to suggestions and ideas. I look at my position as being one that serves the members of the IFOPA to the best of my ability.

On a personal level, most of my non-work activities revolve around my family. I am active with my church, enjoy the outdoors, traveling, reading, and writing for fun. At one time I even did some community theater and comedy club work. I have learned to strive and make things in life enjoyable.

My coming aboard has changed some of the dynamics of the International FOP Association. While our main office remains in Florida, I will be based in New

Jersey. This is because the Board of Directors believes it would be advantageous to have the new Executive Director stationed closer to the FOP Lab at Penn, as well as in a place where I could utilize the resources found in the corridor between New York and Washington, D.C. Thanks to the state of technology today, I have been able to setup a virtual office that allows me to maintain this location while letting me stay in contact with the staff in Florida at all times.

As time goes on, please feel free to get in touch with me regarding any questions you may have, or even just to say "Hi." I need to know what our community needs in order to best serve it. I've spent a great deal of time recently with Jeannie Peeper and admire how the IFOPA has grown from her efforts of running it out of her home to where it is today. I know the number one goal of the IFOPA is to help discover a cure for FOP, but I would also like to know your thoughts about other programs and hear any ideas you may have that might help us better serve and support our membership.

With that in mind, a survey has been established on our website to obtain your opinions on topics concerning the IFOPA. This survey may be viewed and completed anonymously by visiting the following URL:

<http://www.ifopa.org/membersurvey2.html>

I am very happy to be a part of our organization. Do not hesitate to contact me at anytime. I hope to get to know many of you in the months to come.

James McKeever
P.O. Box 342
Sewell, NJ 08080
ifopajm@yahoo.com
Phone: 856-404-2221
Fax: 856-494-1597



PHOTO: James McKeever, the IFOPA's new Executive Director.

From the President....

Linda Daugherty came to work for the IFOPA in July 2000 as a part-time bookkeeper and secretary. We quickly moved her to full-time status as we ramped up our preparations for the Third International Symposium on FOP in November 2000. As many of you already know, Linda's experience at that symposium forever changed her life.

Since then, she has been deeply committed to the FOP community. When I retired in 2005, Linda became the Executive Director of the IFOPA and in the process became someone all of us trusted immensely to oversee the day-to-day activities of the organization.

Linda has many wonderful skills and attributes and always gives it her all. She has many friends in the FOP community around the globe and her commitment to our cause can be seen in her work each and every day. She has a very special place in her heart for all of us.

For personal reasons, Linda has chosen to abdicate her position as Executive Director, but she will stay with IFOPA in a different capacity. Her new role will be as Director of Operations and will be focusing on strengthening the ways the IFOPA supports its members and families.

Thank you for dedication.

-- Jeannie Peeper

A World Without Steps

Handicap Accessible Living in Washington, D.C.

by Brian Harwell

During my recent trip to Washington, D.C., I realized how easy it can be to get around when the world is handicap accessible.

I currently live in Cincinnati, OH. Like any large city, Cincinnati has many townships, villages and neighborhoods. Unfortunately, handicap accessibility was not in the minds of city planners or building engineers when they were putting the city together. The public transportation in Cincinnati is unreliable at best, and many of the establishments that my friends and I like to visit are not suited for people with disabilities. One area in particular has steps going into every establishment without any wheelchair ramp or elevator.

Washington, D.C. and the surrounding areas were a stark contrast. From the moment I left Cincinnati, every place I visited had a wheelchair ramp or an elevator.

The first day I took the metro to the Smithsonian Institute. The metro has a street elevator at every station and elevators to get down to the trains. The trains are level with the boarding platform so a wheelchair or scooter can board with ease. The doors are manually operated by the driver, so if you board at the front of the train the driver will see you and give you plenty of time to get situated.

On my way back to the hotel, I saw that the street elevator was out of service at the Bethesda station; street elevator outages are unfortunately common. However, the station manager

approached me and instructed me to take the metro to the Medical Center to catch a shuttle. When I arrived at the Medical Center, the station manager was expecting me and informed me that she had called for a shuttle. After a short wait, a bus arrived, but it did not have a wheelchair lift. The driver pulled up to the curb, the front of the bus lowered to the ground, and a ramp came out; I boarded the bus with ease.

In addition to the metro and busses being completely handicap accessible, every restaurant I went to was either at street level, had a ramp or had a wheelchair lift. Even the gas station next to the hotel had a wheelchair ramp! There wasn't any place I found that I couldn't go without my scooter.

On the last day, I took a taxi to the airport. I was planning on disassembling my scooter and sitting uncomfortably for the 40-minute trip, but when the taxi arrived the driver opened the back of the van and pulled out a wheelchair ramp; I rode comfortably on my scooter to the airport.

They say ignorance is bliss, but that couldn't be further from the truth. I can't help but think about how my life would be easier and more independent if I lived in a city that is better equipped to accommodate the handicapped. At the moment, I rely on others for transportation and am home bound much of the time, due to high transportation costs. I have to go to work, and I have to go to the grocery store, and that doesn't leave much left for nights out with friends.

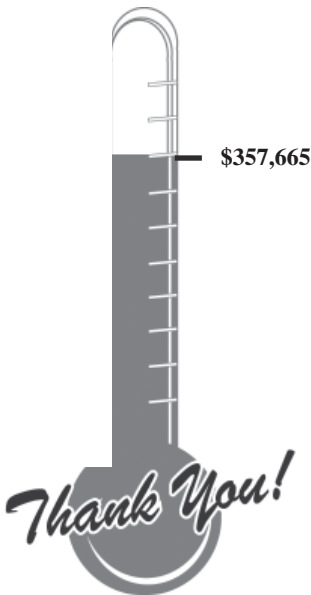
If I lived in Washington, D.C., I could hop on the metro and visit any of the surrounding areas with confidence, knowing that once I got there I wouldn't have any steps to get in my way.

2008 Fundraising Thermometer

This is our 2008 Fundraiser Thermometer. It reflects funds raised for the IFOPA from events and programs that our members sponsor. This does not reflect funds from donations or dues. In the 3rd quarter (July 1, 2008 – September 30, 2008), our fundraisers raised \$41,996. The IFOPA would like to extend a special thank you to the many individuals who supported and were involved in our recent fundraising events. We appreciate the following recent fundraisers for contributing to the current amount raised:

- amazon.com
- Bean Bag Toss Fundraiser in Honor of Dilyn Martin
- Coins for a Cure
- Delaware Riptide Aquatics Swim Team T-Shirt Sales Fundraiser in Honor of Justin Henke
- District Office of the Santa Maria Joint Union High School District Fundraiser in Honor of Stephanie Snow
- DuPont Letter Drive in Honor of Jasmin Floyd

- Find-A-Cure Fundraiser in Honor of Kyle McWilliams
- Governor Livingston High School NJ Penny Wars Fundraiser in Honor of Holly Pullano
- Havre De Grace Yacht Club Inc. Fundraiser in Honor of Nathaniel Padilla
- IFOPA Awareness Merchandise
- iGive
- Martin Family Garage Sale in Honor of Dilyn Martin
- Sovereign Grant Alliance, Inc. - Bring Home a Cure Fundraiser in Honor of Nick Mahler
- The Legislative Idol Sponsored by NYC OTB in Honor of Theresa Caruso
- Lutheran Church of Our Savior VBS Fundraiser in Honor of Stephanie Snow
- VG's Food Community Based Fundraiser in Honor of Justin Henke
- Wadd, Rizzo, Jayne, & Nelli Families Annual Garage Sales in Honor of Mathew Wadd
- Your Purse Connection Fundraiser in Honor of Joshua Scoble



Northern Exposure

4th of July Fundraiser in Kotzebue, AK

by Jade Hill

Kotzebue, AK is a small, rural community about 26 miles above the Arctic Circle. It has approximately 3,000 residents and is not connected by any roads or infrastructure to any other community or place in Alaska. Kotzebue can feel remote until you see the community come together at events such as its 4th of July celebration, held annually of course.

This year, the celebration in little ol' Kotzebue was held at a new fairground location and offered many new games and fun activities, like carnival games. Along with the great new atmosphere, Kotzebue hit record high temperatures of over 80 degrees Fahrenheit!

Our daughter Dilyn was diagnosed at age one with FOP. After her diagnoses, it was with our every intention to help the cause and find a cure for FOP. We feel that every little bit helps, so we purchased a booth at the 4th of July fairgrounds to raise money for FOP and hoped to raise awareness about rare diseases and FOP as well.

With a few spare pieces of wood and some nails, Derek (Dilyn's dad) made two bean bag boxes. We purchased some bean bags and our fundraiser was created. People from our community competed against one another, trying to toss as many bags in the hole as they could; they won prizes for doing well. We also had a donation can and sold FOP bracelets. It was a great time.

Our community came together to help find a cure for FOP. Our community may be very small, but we continue to get the greatest support from our neighbors. They constantly watch over our Dilyn and are now aware of our FOP community and the work we are doing to find that cure. Dilyn is two and a half now and has shown us all of the life beyond disease and disability that every person should know. We will continue to do little events in Kotzebue, AK (and hopefully statewide) that raise awareness and money to find that cure.



PHOTO: Dilyn (left), age 2, with her friend Ally, age 5.

A Hole in One

“Find-a-Cure” Benefit In Honor of Kyle McWilliams

by Ryan McWilliams

On September 20, 2008, the “Find-a-Cure” Benefit in Honor of Kyle McWilliams for FOP research was held in Victor, IA. The day started out at 10:00 a.m. with an 18-team four-person best shot at the Brooklyn Victor Country Club. The weather was very nice, with temperatures in the low 70s and not a cloud in the sky. Golfers of different experience levels enjoyed themselves. A couple of teams had so much fun that they placed fireworks behind others teams to distract them. Kyle was able to putt and chip while his Grandpa McWilliams drove the ball off the tee for him. Kyle had two putts and one chip used.

Two other FOP families were able to partake in the golf event. Jim, Nancy, Chris and Cody Bell of Cedar Rapids were able to golf on two separate teams. Jim and Cody played with Mitch and Mike Miller of Cedar Rapids, who are friends of ours. They were able to win the golf event with a score of 14 under par. Nancy and Chris played with Mary Miller and Rob Rolfes of Cedar Rapids, who are also good friends of ours and devoted IFOPA supporters. They also did well. Chris enjoyed golfing.

Scott, Dee, Jarrad, Jeremy, Madison and Lucas Whitmore were able to travel down from Illinois and arrived at the golf event around 1:30 p.m. Lucas had fun running the gas pedal of his golf cart at full throttle while going down a hill. He also got to putt on Hole 15 for a player that was kind enough to give up his shot. Lucas also used the practice green for about an hour.

At 4:30 p.m. the barbecue and silent auction kicked off at the Victor American Legion. The silent auction had over 100 items up for bid, which shows the support of the small community that we live in. Nearly 400 people came through the food line and had a good meal of barbecue pork, corn, salad and a cookie. The evening came to a close with the results of the silent auction and the handing out of prizes for the team and individual winners.

All the McWilliams -- Curt, Margie, Ryan, Nick, Michelle and Kyle -- would like to thank everyone who supported the “Find-a-Cure” benefit in any way and hope that the money raised will help “move mountains.”

Scare Aware FOP

Scoble Family Spreads FOP Awareness with Halloween Fun



On October 18, 2008, we had our annual Halloween parade in Emmaus, PA, and we did our part by putting together an FOP awareness float for the event. The theme for our float was "Help!! Scare Away FOP!" It was a blast! Not only did we have almost 50 people walking with us in support of FOP, and honoring Joshua Scoble, but we also won first Place -- and \$150 -- for our float in our town's contest!

Along the parade route, the children managed to hand out over 10,000 pieces of candy (all donated), and the adults handed out informational slips containing information about FOP, as well as upcoming fundraising events, including our next Bingo For a Cure, which will take place on March 29, 2009 (www.bingoforacure.com). In all, the adults handed out almost 6,000 slips of paper.

We were very fortunate to have everything involved in the event donated to us, from the truck and trailer to the decorations -- even the paper slips we handed out! I totally encourage anyone to do something like this in the future. Not only was it fun, but we also managed to educate a large group of people in just one outing! We will certainly be doing this again!

Chrissy Flexer

Aunt to Joshua Scoble

Diagnosed at 3 months, now 2 1/2 years old

Prizes and Publicity

Spencer Man Memorial Benefit Drawing Introduces Many to IFOPA

by Linda Daugherty

I want to take this opportunity to thank everyone who participated in the 2008 Spencer Man Memorial Benefit Drawing. This was a wonderful opportunity to introduce many new people to the IFOPA and let them learn about FOP.

I also would like to thank Mike Man for his participation. Every dollar donated to the IFOPA from the drawing was matched (doubled), up to a total of \$4,000, by the Spencer Barnett Man Foundation.

Congratulations to the following winners:

- **Toshiba 32" 720P LCD HDTV** -- *Pamela Montez*
- **\$400 Visa Gift Card** -- *Laura Haberberger*
- **Nintendo Wii, 5 games, controller and nunchuck** -- *Alice Wilson*
- **Ladies' Dooney & Bourke Handbag** -- *Laura Haberberger*
- **Ladies' Swiss Quartz Platinum Watch** -- *Dorothy Brooks*
- **Flip Video Mino Camcorder, carrying case, \$10 gift card** -- *Nancy Ruth*

All individuals that took tickets on consignment were eligible for the "Special Opportunity Drawing." For every "Spencer Man Memorial Drawing" ticket stub they returned along with a donation, they received a ticket for the "Special Opportunity Drawing." The winner of the **\$200 Visa Gift Card** is *Monica Anderson*.

Thank you again to all that participated -- YOU made this an extremely successful fundraiser!



PHOTO: Dyneene Howes of Howes Insurance Agency picks the winners.

Distinguished Contributors & Fundraisers

Thank you to the individuals and businesses listed on these next few pages for their generous contributions to the IFOPA, which will help us fund FOP research. Contributions from **July 1, 2008 – September 30, 2008** are listed. Contributions received after **September 30, 2008** will be acknowledged in the next edition of the *FOP Connection*.



Platinum

*Donations of
\$10,000 or more*

Contributors

FOP e.V.
(The German FOP Organization)

Fundraisers

Find-A-Cure Fundraiser
In Honor of Kyle McWilliams



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Bean Bag Toss Fundraiser

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Governor Livingston High School NJ

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In Honor of Theresa Caruso

Martin Family Garage Sale

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Bronze

*Donations of
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Delaware Riptide Aquatics Swim Team T-Shirt Sales Fundraiser

In Honor of Justin Henke

Your Purse Connection Fundraiser

In Honor of Joshua Scoble

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Sue Hodson
Russell & Beverly Huff
Opal Johnson
John McDermott
Ed McDermott
Loretta Pesha
Wilbur & Nora Reichert
Judith Roberts
Santa Barbara County 4-H Camp

Wahoo!
Dean & Barbara Ubben
Patricia Vasquez
Gary & Jodi Waples
Dana Yudovin
Judith Zielonka
Donald & Judith Zielonka

In Honor of Amie Specht
Timothy & Melisa Baize

In Honor of Sarah Steele
Microsoft Matching Gifts
Mike & Jan Navarro
Anita Nicoll
Roxanne Poole
Rick Steele & Marilyn Hair

In Honor of Matthew Wadd
GE Foundation
North Main Street United
Methodist Church
David & Gloria Wadd
Ken Winston

In Honor of Whitney Weldon
Anita O'Neal
Carl Pedersen & Lynn Wirth

In Honor of Vincent Whelan
Ann Andersen
George Contrades
Mark Freitas
Lisa & Michael Gragnani
Nancy & Chuck Hindenburg
Robert & Cherie Lonjers
Robert & Joan Vanderhorst

In Honor of Lucas Whitmore
Calvin & Phyllis Whitmore

In Honor of Dana Williams
Frances & Ray Holdren

In Honor of Luciana Wulkan
Yisel Estrada

In Memory of Jordan Bartholomew
Rita Bartholomew
Mary Bartholomew

In Memory of Heidi Hostetler
Larry & Mary Jones

In Memory of Robert Marrone
Loretta Donato

In Memory of Barbara Neeb
Anthony & Bonita Hermes

In Memory of Nancy Prellwitz
Shirley & Harry Prellwitz

In Memory of Cheryl Thompson
Larry & Rita Thompson

In Memory of Mary Kay Weber
Mr. Robin Rice

Others:

Ms. Barbara Beck
Richard & Jane Bennett
Matthew G. Borski
Monica A. Carter
Mark C. Dill
Rose Toboni Haar
Ms. Valerie Herce
International Longshoremen's Assoc.
Katherine Lane
Ms. Sandi Lee
Lawrence Maguire
Krista Maki
Michael J. McCue
Margaret A. Moniz
Kevin M. Mowry
John & Eleanor Pierce
Ruth Ann Repici
United Way of Grayson County, Inc.
Kathleen Valero
Richard & Paula Zyne

IFOPA Announcements

We Need Volunteers to Help Update Our Website Content

In early 2009, the IFOPA will launch a re-designed version of its website, which aims to provide information on FOP in a more user-friendly manner while also offering several new interactive features to better serve the membership.

One of our goals for the site is to update and ensure the accuracy and usefulness of its existing content. Because of the large quantity of information found on the current site, we are asking the FOP community for assistance in the matter. If you are interested in helping, please contact Eyal Goldshmid at fopnews@bellsouth.net.

Seeking More “Faces of FOP”

In addition to our website re-design, the IFOPA would also like to update and upgrade its “Faces of FOP” online photo gallery. Rather than merely display photos, as we currently do, we would like to incorporate a slideshow of FOP member pictures set to music. No names will be used, just pictures.

At least 50 pictures need to be submitted in order to develop the slideshow successfully and have it properly implemented on our new website. So, please help by sending us a picture of yourself! We must receive all pictures no later than January 15, 2009.

To submit, feel free to include your photo in the return envelope for your Membership Annual Fund and Voting Ballot, or you can mail your picture to the IFOPA office at the following address: Faces of FOP, c/o International FOP Association, P.O. Box 196217, Winter Springs, FL 32719-6217.

In addition, you can also email your photo to the following email address: fopnews@bellsouth.net.

If you are sending digital photos, please make sure they are at least 500 pixels in width and greater than 72 dpi in resolution. Digital photos should be in the following file formats: JPG, TIFF or BMP.

FOPonline Has New Moderator

Theresa Caruso has been named the new moderator for FOPonline. In this role, she will ensure all members follow the guidelines set down for this email newsgroup. If you have any questions for her, she can be contacted at hamsancity@aol.com.

For more information on FOPonline, or to enroll, please visit: <http://www.ifopa.org/foponlineoverview.html>

2008 Annual Fund Campaign

Look for the IFOPA's 2008 Annual Fund Campaign letter in your mailbox. In it, you will be able to renew your IFOPA membership for the coming year and make a donation to our organization.

International FOP Association

P.O. Box 196217
Winter Springs, FL 32719-6217

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