



Internationally, It's All About Awareness!

by Malcolm C. Munro
IFOPA Vice-Chairperson
Chairperson, International President's Council

Ground zero in the battle to control the malfunctioning FOP gene is the FOP Lab at the University of Pennsylvania School of Medicine. The IFOPA helps support the Lab by raising funds and creating greater FOP awareness worldwide.

A group of dedicated volunteers known as the International President's Council (IPC) is one of the IFOPA's most potent tools for creating "awareness" in countries outside the United States. Dr. Patricia Delai of Brazil founded the IPC in 2007 and recruited people within the international FOP community who were willing and able to represent the IFOPA in their region. The members of the IPC communicate with local FOP families and create FOP awareness in the medical community and general public. Most IPC members are parents who have a child with FOP, but one very active member has FOP -- his story follows.

Below, you'll find information about some of the truly amazing activities these creative and tireless volunteers have organized in different parts of the world.

Germany

"Everyone and his dog knows me here," jokes Roger zum Felde of Bad Fallingbostel, in the north of Germany.

This is a hard claim to refute! Through his many media and public appearances -- TV, radio, newspapers,



and service club presentations -- Roger has become, at the very least, a local celebrity. A charismatic character, he is front and center when it comes to creating FOP awareness in Germany.

Since his retirement from Bayer seven years ago at age 43, Roger has appeared in no less than 18 TV programs, on which he has informed the viewing public about FOP and how he has dealt with it. His interview with Domian, a popular TV talk show host in Germany, is a great example of Roger's visibility and comfort with the TV medium.

Domian, also known as the Nighthawk, met Roger when the two appeared together on another talk show. Impressed with how Roger communicated and was coping with his disability, Domian taped and televised a 10-minute interview with Roger at Roger's "favorite bar" and posted the result on YouTube. (Even if you don't understand German, it's still fun to see Roger in action. Visit YouTube and search for "Domian - Roger leidet an der Krankheit



**Roger zum Felde of
Germany.**



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Fibrodysplasia
Ossificans
Progressiva
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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 Eyal.Goldshmid@ifopa.org.

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Fibrodysplasia ossificans progressive” to view.)

As a somewhat different example of Roger’s high profile, he scored a special coup last year when he met Eva Louise Kohler, wife of Germany’s President Horst Kohler, and invited her to attend the annual German FOP meeting in July 2009.

Roger’s story is longer -- fundraisers, presentations to clubs such as the Rotary and Mercedes-Benz Auto, a Hamburg invitation to meet prominent German film director Soenke Wortmann -- but you get the picture! Roger is an accomplished veteran at informing the public about FOP.

United Kingdom

Julie Hopwood, mother of 24-year-old Rachel, who has FOP, is the IPC representative for the United Kingdom. Julie, her husband Stephen, daughter Rachel, son Ross, and their extended family could hardly be more heavily committed to generating FOP awareness. “Imaginative” would probably best describe their many efforts at awareness and fundraising.

For example, on one occasion they organized a “psychic night” fundraiser. For this novel evening, 10 tables containing eight guests were joined by a “medium” and, to use Julie’s words, “we’d wait and see what comes through!” Though Julie was uncertain about the whole concept at first, everyone enjoyed the event so much that a second night was held and the Hopwoods are planning yet another.

Other unique events organized by the Hopwoods include karaoke evenings, dinner parties entertained by her son Ross’s band, fashion shows, and “Jeans for Genes” (which asks primary schoolchildren to “earn” the right to wear



Julie Hopwood of the United Kingdom.

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jeans to school in exchange for a donation to FOP research). The family has also organized charity balls, during which professional entertainers (ventriloquists, singers, and comedians) volunteer their time. On a more personal level, friends of the Hopwoods even asked for donations in support of FOP research in lieu of wedding gifts!

For her part, Julie's daughter, Rachel, caught the attention of her entire community when, at age 16, she was featured in the TV show *Living for the Moment*, which consisted of four half-hour shows and a one-hour finale program -- all of which appeared on regional TV in northern England.

Additionally, local clubs have organized several fundraiser dinners in Rachel's honor that included raffles and auctions in support of FOP research. Rachel was chosen to carry the baton into her hometown of Rochdale on the night before the 2002 Commonwealth Games started in Manchester.

Over the years, Julie, Rachel, and the Hopwood family have raised tens of thousand of British pounds for FOP research! Through their efforts, FOP awareness in the UK and funding for research has been significantly advanced. They currently have an effort underway to establish a UK FOP website.

Brazil

Raquel, a beautiful 15 year old, was a mystery to the physicians at Santa Casa de Sao Paulo Hospital in Brazil, but few were as captivated by her as Dr. Patricia Delai.

Raquel was losing the ability to move her neck and arms, but no one had any idea why. Dr. Delai first learned of Raquel when she returned to medical school to study dermatology and internal medicine. Intrigued by Raquel's condition, Dr. Delai accepted her as a patient and, soon after accompanying Raquel on visits to many departments throughout the hospital, finally introduced her to a physician who identified Raquel's disorder as FOP.

This proved of limited value in 1999, because Dr. Delai was unable to find anything on the subject in her medical papers. Tiring of the process, Delai typed the name of the disease in English into Google, and "a whole new world appeared in front of my eyes -- I had found the IFOPA!" This began her intensive involvement with the FOP cause that continues to this day.

Dr. Delai is a very busy person. In addition to being a full-time dermatologist who sees 35-to-45 patients per day, she has several patients with FOP and until recently was the chairperson of the International President's Council. In fact, she was the founding organizer of the Council two years ago and began the process of working with IPC ambassadors at the IFOPA's 2007 International Symposium on FOP.

Like others who spread FOP awareness, Patricia

draws heavily on her experience and personal skills -- in her case, as a physician. With the diagnosis of Raquel, she increased her involvement with FOP by compiling lists of Brazilian hospitals and medical schools, and in many cases personally telephoned the medical schools to inform pediatricians, orthopedists, dermatologists, oncologists, geneticists and others about the condition. Reaching beyond the medical community, she contacted TV and radio stations, popular magazines and newspapers, and even celebrities. She sent them each a personal letter with a message about FOP, the same message that was sent by e-mail to doctors and hospitals all over Brazil. These activities led to TV and radio interviews, as well as articles in popular presses.

In a particularly clever move, Patricia prepared a poster showcasing FOP member Harry Eastlack's skeleton alongside the words, "FOP: You should know about it" (along with her website URL and e-mail address). She sent the poster to every office or workplace where a doctor or health care professional might be working. As Patricia said, "It caught people's attention!" Such intensive efforts paid off in her successful effort to aid in locating a multigenerational FOP family from Brazil, an important step in the eventual identification of the FOP gene in 2006. With the discovery of the gene, Patricia was able have the main television station in Brazil prepare a one-minute news item announcing the event. As Patricia says, "This kind of thing takes time and patience to achieve, but we did it!"

Patricia keeps four FOP presentations on her computer at all times, making sure she is always ready to show them at any time to any kind of public audience. One presentation is for patients; a second is a more basic presentation for people who know little about genetics or diseases; a third is for a more knowledgeable audience; and a fourth is specifically tailored for an audience of doctors. As a result, she finds herself invited to talk about FOP not only to medical audiences but also to community associations and groups.

As if the above weren't enough, Patricia is also President of the Brazilian FOP Association and the Latin American medical advisor on FOP. Using her professional expertise, she has translated medical documents into



**Dr. Patricia Delai
of Brazil.**

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Portuguese, a valuable service for both the local medical community and FOP families. In particular, she provided the first translation of *The Medical Management of Fibrodysplasia Ossificans Progressiva: Current Treatment Considerations* into another language -- in her case, Portuguese. Since Brazil is a very large country that speaks a language other than English and has unique social and economic challenges, the IFOPA is particularly fortunate to have a physician such as Patricia available to serve the cause as ably as she does. Patricia's attitude toward spreading the word about FOP is best stated in her own words: "I see every opportunity to talk about FOP as a new seed in the garden."

Sweden

For many people, making even a short speech or presentation is frightening. For Marie Hallbert of Sweden, it's like breathing air -- or at least she makes it look that easy! Mom to 10-year-old FOP member Hugo and full-time caregiver when he is not at school, Marie lectures to doctors, nurses, students, teachers, school children and anyone else who will listen.

She got her first chance at lecturing when she was invited by a care center in Gothenburg to talk about FOP. She took the whole thing seriously, calling her presentation, "A Part of Our Life -- 10 years in Two Hours." Her lecture was riveting, and the event led to many other speaking opportunities. For her presentations, she also creates pamphlets on FOP that she distributes to those attending.

Marie tells an interesting story of how "one thing can lead to another." Some years ago, she spoke to a friend about her wish to contact FOP families and create an FOP network for Sweden. Her friend, a senior manager in a local hotel, offered to sponsor a hotel weekend for whomever Marie could attract. At the time, Marie knew only about four people in Sweden with FOP and proposed extending the network to include Denmark, Norway, and Finland, which expanded her group to nine families. Her friend quickly agreed, and they got organized. Marie invited Drs. Fred Kaplan and Eileen Shore, co-directors of the Center for Research in FOP and Related Disorders at the University of Pennsylvania School of Medicine, to attend alongside as many physicians in the region as she could contact. She and her friend passed this evolving story along to the press for further publicity! The symposium was so well received, her family doctor later told her it was "the best doctor symposium I have ever attended!"

With a critical mass of families drawn together, Marie pressed ahead to create FOP Sweden, complete with a website and a bank account to accept donations. Marie

organized two additional symposia in Stockholm in 2006 and 2008. She credits her own attendance at similar meetings across Europe in her years as owner/operator of a hair dressing salon as giving her an immediate understanding of how to organize a symposium. In addition to helping find a cure for FOP, Marie says that one of her personal goals is to make sure that any child born with FOP in Scandinavia or Finland is diagnosed at birth. We can see from Marie's dedication and activity level that she will achieve her goal. As Marie says, "One thing leads to another."



Marie Hallbert of Sweden.

Australia

If you were training a group of runners in Brisbane, Australia, who would you call on to motivate them at 5:30 a.m.? Why, Oliver Collins, of course!

Julie Collins, IPC representative for Australia, counts this event as only one of many triumphs for the talented speaker that is her 15-year-old son, "Ollie," who has FOP. The Pat Carroll Running Group, a professional training company for runners and fitness buffs, needed someone to help runners "break through their pain barrier" and chose to put on a fundraiser for Ollie. As a young man who lives with pain and knows how to overcome it, who better to call upon?



Oliver (left) and Julie Collins of Australia.

As a mom with a Masters Degree in Special Education and physical impairment adviser to primary and secondary schools, Julie has particular insight regarding her son's challenges and the importance of encouraging his evident leadership skills. The considerable daily support Ollie receives from his mom, dad, and two sisters enables him to commit actively to public speaking at conferences and charity fundraisers. As a family, they form an exceptionally potent "FOP awareness" team, spreading the FOP word to Queensland and beyond.

Participating in school debates as he does would be natural enough for someone comfortable with public speaking, but Ollie is also a member of a "future problem-solving" team, sings in a choir, and serves on the Youth Advisory Committee for the construction of a new Queensland Children's Hospital. In connection with his role on the Youth Advisory Committee, Ollie addressed a conference in Sydney on adolescent health. As a talented teenage speaker, Ollie is often called on to address teenage audiences. For example, a Queensland volunteer organization known as Teenage Adventure Camps, which caters to teenagers with life-threatening illnesses, called on Ollie to present to an audience of over 500 people at their fundraiser. Last year, Ollie and his mom spoke to about 200 people at a Department of Education workshop for special educators. In many of these events, Ollie is often discussing issues other than FOP but always explains to such audiences that because of his FOP he has the opportunity to discuss and promote a range of other health-related initiatives.

Julie Collins understands that the key to Ollie's success in generating FOP awareness is the teamwork her entire family provides. By supporting Ollie's talent, the Collins family directly shares in creating a much higher profile for FOP in Australia. Julie recounts her heavy heart upon learning of Ollie's diagnosis so many years ago, but looking back, she notes "there have been far more ups than downs since then." And no doubt, many more "ups" to come!

The Netherlands

Irene Snijder is a single mom from Amsterdam whose 18-year-old daughter, Tess, was diagnosed with FOP at age 10. Before her diagnosis, Tess was a very active child who rode horses, played tennis, and even learned to play the violin at age three! But an accident at a friend's place caused her FOP condition to reveal itself and change her life.

Perhaps this explains why Irene believes in the personal touch and takes special care to inform her friends and families about FOP in the Netherlands. Irene maintains a history of each FOP member in the country, uses e-mail to stay in regular contact, and records changes in their medications and condition over time. If any of her FOP



**Irene Snijder of The Netherlands (right)
with her daughter, Tess.**

friends are hospitalized, Irene visits them in the hospital, and if necessary will take care of their personal tasks and chores, such as laundry and minor housekeeping. If Irene hasn't heard from an FOP family for a while, she telephones them, letting them know she is there to help them if need be. She also stays in contact with a couple who tragically lost a child who had FOP.

Clearly, Irene's own personal story as mom of a child with FOP motivates her concern about the evolving lives of others and her desire to help them whenever she can.

Irene is President of FOP Netherlands, a foundation she established in 2004 with the help of friends. FOP Netherlands is holding an FOP Symposium in November 2009. The event will enable Dutch FOP patients to meet with Dr. Fred Kaplan, who will be attending.

Irene also serves The Netherlands' FOP community as a translator. Since English is the language in which most of the major medical journals are published, FOP families who do not normally speak English do not often receive news about research or encouraging FOP findings in a timely manner. Using her language skills, Irene is ready to translate such materials into Dutch. As a particularly challenging example, Irene translated an article about the AVCR1 receptor into Dutch from the journal *Nature Genetics*, even though, as she confessed, "Even the translated version is hard to understand!"

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Moira Lilljestrom of Argentina (center) with sons Julian (left) and Manuel. Manuel has FOP.

Argentina

Moira Lilljestrom lives in Buenos Aires with her husband and two sons, the youngest of whom is 12-year-old Manuel, who has FOP. Moira is an architect and professor at the University of Buenos Aires. She holds a Master's Degree in Urban and Regional Planning. She also works as a researcher, and since Manuel's diagnosis she has focused on urban accessibility for disabled people.

Her current research project gathers data throughout Argentina on the major problems faced by people with rare diseases, including FOP. To spread word about her rare diseases research project and about FOP, Moira has published articles in national newspapers, as well as in the newsletters for the European Organization for Rare Diseases and the Taiwan Foundation for Rare Disorders, respectively. One of her articles in Argentina's main national newspaper focused on locating multigenerational FOP families to assist in the effort to identify the FOP gene. This article was picked up by a news agency and syndicated to many smaller newspapers throughout the country.

Moira and her husband have been particularly active in creating awareness in the medical community. Their first opportunity in this regard involved presenting to a group of about 70 doctors during a workshop on skeletal dysplasia at the main children's hospital in Buenos Aires. This was followed later by a second presentation to Buenos Aires pediatricians. Moira also wrote an article that was published in a pediatric association newsletter distributed to approximately 15,000 members in Argentina and other Latin American countries.

Moira has presented information about FOP at international conferences in Lyon, France and Rio de Janeiro, Brazil, the second of which included a large audience with an international medical congress. Moira and her husband also organized a meeting for Argentine FOP families, to which she invited a lawyer to speak about their rights. Moira and her husband are presently organizing the Second Latino American FOP Meeting, to be held the second week of November 2009.

As with other IPC representatives, the above does not fully describe the range of FOP awareness and support activities undertaken by Moira and her husband. Suffice it to say that Moira fully exploits her understanding of how the academic community operates in her efforts to create greater awareness of FOP.

Canada

Carrie Connell is the education and program coordinator for a regional children's rehabilitation center in London, Canada. She administers the logistics of workshops and other administrative support for recreational programs for kids with disabilities -- a purely coincidental fact, considering her daughter, Brooke, was diagnosed with FOP at age 6 in March 2007.

Soon after Brooke's diagnosis, Carrie began contacting Canadian researchers and the Canadian Institutes of Health Research to learn Canada's role in FOP research in light of the gene discovery. Carrie was disappointed to discover that no one in Canada was currently performing or had performed any research on FOP. Furthermore, she discovered that Canada was unrepresented on the International FOP Clinical Consortium. Undaunted, she soon partnered with the IFOPA to pioneer the establishment of a Canadian FOP organization to draw together Canadian FOP families.



Carrie Connell of Canada.

Carrie next organized the first Canadian symposium on FOP. This highly successful event was held in May 2009 in London, Canada, at the Thames Valley Children's Centre where Carrie works. The symposium was attended by FOP families, physicians, scientists, and Drs. Kaplan, Shore, Nussbaum and Grunwald, all of the University of Pennsylvania, and Dr. Jane Aubin, Scientific Director of the Canadian Institute of Health Research's Musculoskeletal Health and Arthritis Research Group. About 80 people

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attended the main presentations with the main body breaking down into groups for workshops and family medical clinics. Carrie garnered the support of a local pediatric orthopedic surgeon with the London Health Sciences Centre, who helped plan the event and spread the word through Canada via his network. The symposium concluded with the formal founding of the Canadian FOP Network (CFOPN) and the election of a board of directors.

Meanwhile, Carrie's family and friends grew active on the fundraising front. Carrie's husband, Cam, and his good friend, Derek O'Leary (both of whom work at London International Airport), held a "Chili Fundraiser" for the airport staff, many of whom were asking how they could help. Not only did Derek and Cam almost double their expected fundraising totals from the event, but so many of their friends had brought chili that their pots covered a very long table! When the event wound up, their friends at the airport were already asking when Cam and Derek would do it all again. Planning is underway for a repeat event; to add further fun, they may stage a chili tasting competition as well!

One of Carrie's major goals, going forward, is to allow Canadians to participate in any drug trials as soon as an FOP treatment is available to be tested. CFOPN provides a framework within which participation in drug trials may be facilitated. She is also concentrating on ensuring Canadian drug laws provide timely support for new FOP medicines whenever they become available and makes herself and CFOPN available to lobby for this cause. Lastly, Carrie and FOP mom/attorney Karen Munro are applying to the Canada Revenue Agency to have CFOPN registered as a Canadian charity, thereby allowing the organization to issue tax-deductible receipts for donations.

In less than two years, and with support from her husband Cam and children Brooke and Hunter, Carrie Connell has created a Canadian FOP organization, organized a symposium, generated significant awareness of FOP in the Canadian medical community, and drawn together FOP families from across Canada. With the symposium an accomplished fact, Carrie is pushing ahead with the other initiatives indicated above. Carrie says, "It would be wonderful if we could establish a team of FOP experts in Canada who could work closely with the US experts to offer better informed care to our Canadian families."

Only a Sampling...

The preceding stories are only a sampling of the accomplishments of the International President's Council, but they do very well in illustrating the group's diversity of talent and initiatives. This dedicated team has made outstanding contributions towards creating greater FOP awareness in their home countries and communities. For a fascinating tour of FOP websites from around the world, visit the links below. For more FOP-related sites, check out the IFOPA website at www.ifopa.org, click on the "Living with FOP" tab, then on "Helpful Links." If you would like more detail about any aspects of this article, please e-mail its author, Malcolm Munro, at malcolm.munro@shaw.ca.

FOP Argentina

www.fundacionfop.org.ar

FOP Spain

www.aefop.org

CFOPN Canada

www.cfopn.org

FOP Sweden

www.fopsverige.se

FOP Germany

www.fop-ev.de

FOP Action (United Kingdom)

www.fopaction.co.uk

FOP Italy

www.fopitalia.it

IFOPA France (on Facebook)

www.facebook.com and search "IFOPA France"

FOP Latin America

www.geocities.com/alafof/principal.htm

FIBRODISPASIA OSIFICANTE PROGRESIVA

(on Facebook, in Spanish)

www.facebook.com and search

"FIBRODISPASIA OSIFICANTE PROGRESIVA"

FOP Netherlands

www.fopstichting.nl

Canadian FOP Network (on Facebook)

www.facebook.com and search "Canadian FOP Network"

FOP Poland

fop.prv.pl

Meet Robert Pignolo, M.D., Ph.D.

The New Ian Cali Clinical & Research Scholar at the Center for FOP and Related Disorders

In June 2009, Robert Pignolo, M.D., Ph.D., was named the Ian Cali Clinical and Research Scholar at the Center for Research in FOP and Related Disorders at the University of Pennsylvania School of Medicine (Penn). In this position, Dr. Pignolo will pursue projects in FOP research, participate in collaborative grant proposals, develop FOP clinical guidelines and guidelines for clinical trials, and have defined clinical exposure to FOP members. These duties are in addition to his existing responsibilities at the University.

Currently, Dr. Pignolo is an Assistant Professor in the Department of Medicine, Division of Geriatric Medicine, at Penn. He received a B.A. in Biochemistry and a Ph.D. in Molecular Biology from Penn. He completed his M.D. and residency in internal medicine at the Medical College of Pennsylvania and completed a fellowship in geriatric medicine at Penn, where he received the prestigious John A. Hartford Foundation Research Award. He joined the Penn faculty in 2003, and has received many prestigious awards including the Robert Austrian Award for Outstanding Bench Research and the Advances in Mineral Metabolism (AIMM) Young Investigator Award.

Dr. Pignolo is a clinician-scientist whose areas of expertise include metabolic bone disease, gerontology, geriatric medicine, genetic and non-hereditary heterotopic ossification, and cell and molecular biology. His research efforts focus primarily on osteoblast differentiation in conditions that reflect either impaired or inappropriate osteogenesis, age-related bone loss, and disorders of extra-skeletal ossification -- conditions linked by the common thread of dysregulated osteoblast differentiation.

Over the years, he has authored more than 60 articles and has been a key contributor to the the *Annual Report of the FOP Collaborative Project* and *The Medical Management of Fibrodysplasia Ossificans Progressiva: Current Treatment Considerations*. In addition, he has mentored undergraduate, medical, and graduate students as well as post-doctoral

fellows. Dr. Pignolo also assumes numerous teaching responsibilities in clinical and basic science research at the University.

He has been the Director of the Ralston-Penn Clinic for Osteoporosis and Related Bone Disorders since 2003 and has been actively involved in FOP research since 2004. His FOP research alone includes

many major contributions, such as identifying the role of circulating osteogenic cells in ectopic bone formation in FOP and investigating the role of hypoxia as a mediator of early signal promotion through the FOP receptor. He oversees the current focus on hypoxic injury in FOP lesion formation and will assist in the FOP Laboratory studies on the collaborative NIH project in FOP.

Of Dr. Pignolo's appointment to be the Ian Cali Clinical and Research Scholar at the Center for FOP and Related Disorders, Dr. Kaplan said, "Bob is ideally suited for this position because he brings an impressive combination of research experience in bone biology, pursuit of clinical excellence in caring for patients with bone disorders, as well as high prospects for continued and significant contributions to the field of FOP research. He is a valued colleague and collaborator at all levels."

Sara Olsen, the IFOPA's Chairman of the Board, said, "Dr. Pignolo has been a familiar figure to the IFOPA for years now, especially in his work as co-author of the Annual Reports. He has definitely made an impact on our community and we thank him for that. Through this role, we look forward to working with him in greater depth and benefiting from his knowledge."



For Your Information

For IFOPA and FOP members, Dr. Pignolo should be considered an alternate physician to contact if Dr. Kaplan is unavailable. For any questions that need immediate attention, you can reach him by pager at (215) 308-9643 or via e-mail at pignolo@mail.med.upenn.edu. He is also available by "text paging," which allows you to send him a text message through the online service USA Mobility.

To "text page" Dr. Pignolo, visit www.usamobility.com, choose the "Send a Message" link, enter his pager number, write a short message and your contact information, and submit.

Alternately, during the business hours of 9 a.m. and 5 p.m. EST, Monday through Friday, Dr. Pignolo can be reached via the FOP Lab's main office number at (215) 349-8726.

FOP Mothers' Retreat

Seven Mothers Experience a 'Wonderful' Event

by Karen Munro

The June 26 – 29, 2009 FOP Mothers' Retreat was a fantastic event! The retreat was hosted in New Jersey by FOP mom Amanda Cali, mother of 19-year-old Ian. Seven mothers joined Amanda for the retreat, as follows:

- Karen Munro (me!) from Canada, mother of Miranda, age 4
- Linnett Ruiz from the U.S.A., mother of Lindsay, age 16
- Barbara Rossano from the U.S.A., mother of Laura, age 20
- Marie Hallbert from Sweden, mother of Hugo, age 11
- Moira Liljestrom from Argentina, mother of Manuel, age 12
- Heidi Padilla from the U.S.A., mother of Nathaniel, age 5
- Wendy Henke from the U.S.A., mother of Justin, age 9



The FOP mothers visit the FOP Lab.

From Friday through Sunday, we relaxed on the beach, shopped, took pictures, did yoga, cooked and shared our lives in parenting workshops led by Amanda. All these experiences were terrific for getting to know each other, and for discussing how we live with FOP. We shared many tears, but also lots of laughter and fun.

One of many noteworthy moments was an outing with Hillary Weldon, mother of 16-year-old Whitney, who lives nearby. We enjoyed drinks and a wonderful dinner with Hillary, and it was great to get to know her, too.

Monday was a highlight of the retreat. On our last day together, we drove to Philadelphia for a tour of the FOP Lab at the University of Pennsylvania. Dr. Eileen Shore and Dr. Fred Kaplan showed us around the Lab. This was another emotional experience. We all expressed our immense and awestruck gratitude to the people who work so hard for a treatment to help our kids.

Here are some comments from the mothers who attended the retreat:

"I came away with the lasting and reassuring impression that though life with FOP can be challenging, it's beautiful, enriching and full of promise nonetheless."

-- Wendy

"It was a wonderful weekend for so many reasons. I really enjoyed meeting the other mothers and being able to get away for a weekend to just be me."

-- Heidi

"We had such a wonderful time -- full of tears, smiled and laughter -- what a way to begin the summer, looking at the sun that lies ahead."

-- Linnett

"The mothers' retreat was really great. We had time to meet each other, talk about our families, share experiences, laugh, have fun and also cry. What was remarkable for me was that it allowed me to open my mind to other points of view and ways to face the every day living. Being a FOP mother, no matter the country or culture we belong to, we all have the same feelings about FOP and our kids. The visit to the Lab, meeting all those people that every day are working so hard to find the cure for FOP, was very exciting."

-- Moira

"I am a constant student to a life with FOP, and being with the other FOP moms makes my life sweeter, more empowered and reassuring that we are in this together."

-- Amanda

Many well-deserved kudos go to Amanda Cali for organizing this wonderful retreat. Also, heartfelt thanks to Heidi, Wendy, Linnett, Barbara, Moira and Marie for being such terrific companions and wise mothers.

IFOPA Website Gets Makeover

Online Home Offers Members Many New Features

by Eyal Goldshmid

The IFOPA has recently re-designed its website with a sleeker look and a more capable means of handling the community's online needs.

While much of the same information found on the old site is available here, it is now organized in a cleaner fashion and is easier to navigate and read. We have also added several new features, like streaming videos, an easy-to-search "Catalog of FOP Resources" (formerly known as "Overcoming Obstacles,"), an online membership directory, and more.

Also, this new website will soon be expanded to include some of the web's latest technology, such as social media and blogging, to name a few.

Membership Directory Now Online

The IFOPA's newly designed website marks the first time the IFOPA membership directory has been made available online to its membership. This has been done to eliminate the cost of publishing new directories every two years and to supply members with a directory that houses more up-to-date information. (Note: Printouts of the IFOPA Membership Directory are available upon request.)

Because of this, membership information (i.e. New Members, Member Changes) usually published in the *FOP Connection* will no longer be listed in full; instead only basic information will be provided. To view complete listings for these members, please visit the online directory or contact the IFOPA office.

The online membership directory has been divided into two distinct parts: One contains complete contact information for FOP members only; and one contains complete contact information for all active members of the IFOPA. Only the IFOPA's current members can access the directory -- the general public cannot view this information. Access to the directory can be obtained through personalized IFOPA website logins, which were emailed to all members in early June 2009.

Please let us know if you do not have your login information or would prefer not to be listed in the directory (an option available to all members).



Screenshot of the IFOPA's new home page.

New IFOPA Videos Online

In May 2009, the IFOPA completed production on a new promotional video, titled "Our Mission of Hope." A 17-minute version and six-minute version of the video are available for viewing at www.ifopa.org, under the "News and Events" tab, or on the IFOPA's YouTube Channel (www.youtube.com/FOPNews).

The videos include information on FOP and the organization that can be used to educate people on FOP or help spread awareness. It features interviews with Drs. Frederick Kaplan and Eileen Shore, Ph.D. of the University of Pennsylvania School of Medicine, as well as several members of the IFOPA community.

"FOP Facts and Insights" is a 16-part video series containing an abundance of information and advice for FOP members, parents and caregivers. The videos include interviews with Drs. Frederick Kaplan Eileen Shore, as well as IFOPA member Lori Henrotay, who spearheaded production of the series. (Thanks very much to Lori for putting this series together – she's done a great job and created a valuable resource for membership around the world.)

The videos can be viewed on the IFOPA website (under the "Living with FOP" section) or at the IFOPA's YouTube Channel.

If you have any questions or comments about the IFOPA's new website, please contact Eyal Goldshmid, Marketing and Communications Manager, via email at Eyal.Goldshmid@ifopa.org.

IFOPA Staff Gets New E-mail Addresses

Along with the re-design of our website, the IFOPA staff now has new email addresses. Here they are for your reference. Please adjust your address books accordingly.

Linda Daugherty
Executive Director
Linda.Daugherty@ifopa.org

Karen Revels
Associate Executive Director
Karen.Revels@ifopa.org

Eyal Goldshmid
Marketing and Communications Manager
Eyal.Goldshmid@ifopa.org

Becky Kaplan
Bookkeeper
Becky.Kaplan@ifopa.org

Erin Turner
Administrative Assistant
Erin.Turner@ifopa.org

General IFOPA Inquiries
Together@ifopa.org

All IFOPA office contact information is also available on our website, under the "About the IFOPA" tab. Note: The IFOPA's main office phone number remains unchanged -- (407) 365-4194.

Meet Karen Neely Revels

The IFOPA's New Associate Executive Director

Dear IFOPA members,

Hello! I am so thrilled to join the IFOPA family. I feel so blessed to have my path lead me to the IFOPA. After attending the Teen and Young Adult Meeting in August 2009, and having the opportunity to meet many of you there, I am certain that this is the right place for me. What an incredible group of teens, young adults and terrific family members I was able to spend time with. I look forward to working closely with you, the office staff and the Board.

A bit about my family: I am happily married to Jeff Revels, Artistic Director of the Orlando Repertory Theatre. We have an eight-year-old daughter, Kate, who loves the stage, and a four-year-old son, Carson, who loves anything his sister loves. I was born and raised in Orlando, FL and I graduated from the University of Central Florida with a degree in Public Administration/Nonprofit Management.

I have spent the past 12 years working for nonprofits and must say I love it. I spent eight and half years with the American Cancer Society (ACS) in several roles, most recently as Area Executive Director for Central Florida and Brevard County. (Brevard County is the home to Kennedy Space Center.) While I was with the ACS, I was responsible for the growth of "Relay for Life" (the organization's largest fundraiser) in the state of Florida, as well as managing programs and services for those diagnosed with cancer. I was able to meet many inspirational people and make a difference in the fight against cancer, but as with everything in life, there comes a time for change.

After making the difficult decision to leave ACS, I went to work for the Jewish Community Center (JCC)

in Orlando, where I was the Director of Development and helped the JCC raise much needed funding for their various programs and services. I spent three years at the JCC, then I faced a medical crisis in my family and felt the need to return to the medical/health-related nonprofit sector. That experience led me to the IFOPA.

My medical crisis involved my daughter being misdiagnosed with Ewing's Sarcoma (a rare bone cancer) at age seven. After enduring six harrowing weeks of bone scans, trips to the oncologist, tests, MRIs, etc., we underwent a bone biopsy on her lower leg, which thankfully did not reveal any cancer cells. The experience was life-changing and not only changed our family but guided me to search for a place where I could use my experiences and skills to help move a mission I believed in forward.

I hope that I can do that for you. I welcome your thoughts, wisdom and friendship as we move down this road filled with turns and speed bumps. I look forward to meeting and talking to each of you in the near future.

Fondly,
Karen Revels
Associate Executive Director



Focus on Fundraising

A 'Stroke' of Good Fortune for FOP

by Wendy Henke

Our kids' swim team, the Delaware Riptide, held an hour-long swim-a-thon for my son, Justin, who has FOP, on July 24, 2009. The coaches approached us a month before the event about the idea, and we 'dove' at the opportunity.

Off the starting blocks, I quickly gathered sponsors to cover the long-sleeve T-shirts, and then asked local businesses to donate gifts as incentives for swimmers to win. I also offered businesses the opportunity to provide promotional materials for us to display at the event.

For every \$10 a swimmer raised for FOP, he or she earned one raffle ticket, plus two 'bone'-us raffle tickets for every \$100 raised, to be entered into a big raffle drawing of prizes.

It was a win-win-win situation, since it was for a good cause. The prizes were great, too, and the businesses received good publicity in return.

We had more than 60 businesses participate in some shape or form, with prizes totaling in excess of \$3000 in value. Prizes ranged from an iPod Touch and a golf

and dining package to bowling games and gift certificates to our local bagel shop, to name a few.

Care and concern for Justin, coupled with great fun prizes, resulted in a BIG SPLASH OF CASH for the IFOPA -- a great finish considering our expenses were low in comparison.

We're still 'floating' from the unexpected 'just-add-water' recipe of success for a fundraiser. The coaches and the team are all looking forward to next year.



Justin Henke at the "CURE FOP Swim-A-Thon."

Show your support with every purchase you make!

Apply for the
International FOP Association, Inc.
credit card

Donate to our cause with your everyday purchases!

- \$ Earn \$25 for our organization after your first purchase with your card.
- % 1% of every purchase you make is donated to our organization.
- Personalized images increase awareness with every swipe.

Apply today!

www.CardLabConnect.com/internationalfopassociation



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Apply for a Credit Card, Raise Funds for the IFOPA, Find a Cure!

Here's a unique and practical way to support the IFOPA! Apply for the IFOPA credit card, courtesy of Capital One Credit Cards' "Card Connect" program. One percent of every purchase you make will be donated to the IFOPA. Plus, Capital One will donate \$25 to the IFOPA after you make your first purchase with your new card.

The IFOPA has designed three original cards to choose from, each bearing the organization's logo. View them at:

[https://www.cardlabconnect.com/
InternationalFOPAssociation](https://www.cardlabconnect.com/InternationalFOPAssociation)

Choose your favorite or create a card of your own using the site's easy-to-follow design tools.

For more information, or to apply for this credit card, please visit the URL above or contact the IFOPA office.

Focus on Fundraising

GET YOUR TICKETS!

4th Annual Spencer Man Memorial Benefit Drawing November 6, 2009

LIMITED TICKETS AVAILABLE! ENTER NOW!

Two round trip tickets on AirTran Airways. A sleek iPod Touch. An elegant Dooney and Burke handbag.

These are just a few of the wonderful prizes you can win by entering the 4th Annual Spencer Man Memorial Benefit Drawing.

The event has become an IFOPA tradition -- and one of the organization's most successful yearly fundraisers. This time around, we've held nothing back, offering a selection of prizes that caters to just about every taste -- from travellers to music fans to fashion-lovers, and more. Plus, all proceeds benefit the IFOPA and its mission of instilling HOPE through Research, Education and Support while searching for a CURE for FOP.


Please join us in promoting this event to your family, friends, co-workers and neighbors. The Spencer Barnett Man Foundation will match (double) every dollar donated to the IFOPA from the drawing (up to \$4,000). This means a \$25.00 contribution will become a donation of \$50.00!

All drawing selections will take place at the IFOPA headquarters and will be conducted by a staff member of a neighboring business on November 6, 2009 at 4 p.m. All winners will be notified by phone. In a break from tradition, this year's winners will choose their prizes based on the order they are selected until all prizes are distributed.

Prizes this year include:

- **Two Round Trip Tickets Compliments of AirTran Airways** -- (Tickets are valid to/from any U.S.-based/domestic AirTran Airways destination. All travel must be completed by May 31, 2011. \$1000 value.)
- **Ladies Brighton Wallet and \$200** -- (\$200 is presented in American Express gift cards. \$275 value.)
- **Flip Ultra HD Video** -- (White and chrome camcorder, 8GB of memory, records 120 minutes of video. \$199 value.)
- **iPod Touch 16 GB with Universal Docking Station** -- (\$250 value.)
- **Ladies Dooney & Bourke Handbag** -- (\$350 value.)

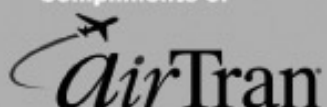
Tickets for the drawing will be available through midnight of November 5, 2009 and can be purchased through the IFOPA website at www.ifopa.org, by contacting the IFOPA office by phone at (407) 365-4194 or by e-mail at together@ifopa.org. Tickets are a suggested contribution of \$5 for one (1) ticket or seven (7) tickets for \$25.



benefit drawing

SPENCER MAN MEMORIAL BENEFIT DRAWING

Prizes include:

- **Two Round Trip Tickets Compliments of**

- **iPod Touch w/ Universal Docking Station**
- **Flip Video Camera**
- **Dooney and Bourke Handbag**
- **\$200 & Ladies Brighton Wallet**

All prizes donated

The winners will choose their prize in the order they were drawn until all prizes are chosen.

5 lucky winners!

Proceeds from the Spencer Man Memorial Benefit Drawing will support research, programs and services provided by International Fibrodysplasia Ossificans Progressiva Association (IFOPA).

\$5 suggested minimum donation or 7 for \$25

Focus on Fundraising

Hundreds Participate in “Golf for a Cure” Fundraiser

By Kim Hayes

“Let’s get this party started!” That’s what Shane Terry announced to the 100 golfers who joined him on July 25, 2009 at the Highland Meadows Country Club. They were there for the “Golf for a Cure in Honor of Shane Terry” fundraiser, which included support not only from golfers but also from various hole sponsors and local businesses.

For the game itself, it was a beautiful day with plenty of sunshine and 80-degree temperatures. At 9:00 a.m., the players, in their golf carts, headed out onto the course and awaited the start of the round -- a siren signaling the beginning of the event’s shot-gun tee off.

For our game, we had three unique divisions of play: One with all women, one with men, and one with co-ed teams. We gave prizes to the two teams in each division with the best scores. Prizes were also given to the player with the longest drive, the one who reached “closest to the pin” on his or her tee-off, to two teams that scored the highest among all divisions, and to the one co-ed team that consisted of one male golfer with lots of experience and three female golfers with no experience -- Richard, the male player on the team, received the “Good Sport Award” for his “hard work.”



Shane Terry (center) is joined by his mother, Kim Hayes (left), and his step-father, Pete (right), at the “Golf for a Cure” fundraiser.



Shane Terry (left) with his cousin Katie at the “Golf for a Cure” fundraiser.

Meanwhile, Shane and I were busy riding around the course, greeting the teams and taking lots of pictures. Shane, by the end of the day, got great at driving the golf cart -- he was very busy delivering beverages and refills to the teams on the course, since it grew very hot and muggy as the day went on.

After play, everyone met at the course’s clubhouse, where they were entertained by DJ Matt and served a wonderful dinner consisting of Italian chicken, macaroni salad, baked beans, bread and butter.

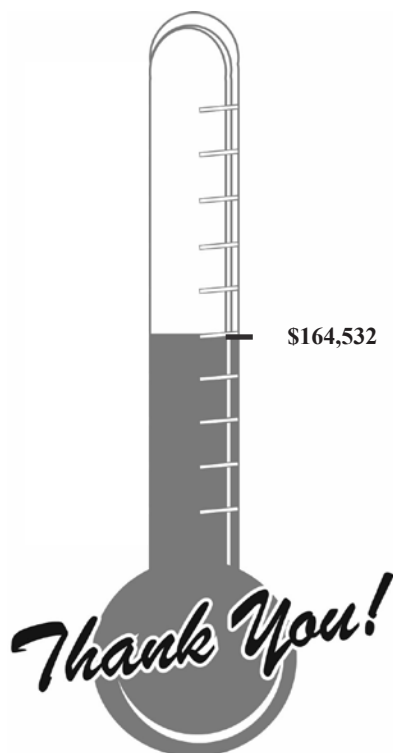
Once dinner was over, we announced all the winners for the event’s enormous auction. We had items donated for all ages, so everyone got to participate. DJ Matt played until 7:00 p.m. Everyone said what a fun time they had, what a great tournament it was, and that they were looking forward to next years tournament.

We have booked next year’s tournament for July 24, 2010 and are looking forward to making it bigger and better for the second annual Golf for a Cure in Honor of Shane Terry to help find a cure for FOP.

View pictures from the golf tournament at
www.shaneterryfop.com

2009 Fundraising Thermometer

This is our 2009 Fundraiser Thermometer. It reflects funds raised for the IFOPA from events and programs that our members organized and planned. This does not reflect funds from donations or dues. From January 1, 2009 - June 30, 2009, your fundraisers raised \$164,532. The IFOPA would like to extend a special thank you to the many individuals who supported and were involved in these fundraising events. These are the fundraisers that have collectively raised \$164,532:



Reminder:
The IFOPA office
can assist you in
planning your
fundraiser.

- 3rd Annual FOP Garage Sale & Fundraiser in Honor of Dilyn Martin
- 8th Annual Comedy Show in Honor of Whitney Weldon
- amazon.com
- Applebee's Fundraiser in Honor of Shane Terry
- Arctic Blast 2009 in Honor of Shane Terry
- Bingo for a Cure in Honor of Joshua Scoble
- Coins for a Cure
- Coupon Book & Candy Bar Fundraiser in Honor of Nathaniel Padilla
- Crop for a Cure in Honor of Shane Terry
- FirstGiving
- Friendly's Fun Night in Honor of Justin Henke
- Funding Factory
- IFOPA Awareness Merchandise
- iGive
- Jeans Day at Seabrook Intermediate School in Honor of Cody Dennings
- Kane Yama Japanese Steak & Sushi Restaurant Fundraiser in Honor of Ashley Kurpiel
- Knickerbocker Elementary School - Spare Change Drive in Honor of Shane Terry
- Kotzebue Schools Spring Carnival in Honor of Dilyn Martin
- Oz Pizza Night in Honor of Ashley Kurpiel
- Roemex Burns Supper
- St Clare School Fundraiser in Honor of Timothy Hazlett
- University of Miami Talent Show
- Unmasking The Mystery of FOP in Honor of Cody Dennings
- Walk in the Woods to Cure FOP in Honor of Whitney Weldon
- Webkinz Bingo to Benefit FOP in Honor of Wayne Gopshes
- Woodside Elementary School Fundraiser in Honor of Wayne Gopshes

Upcoming IFOPA Fundraisers

Hope Hayden's Hope Benefit for FOP in Honor of Hayden Pheif
September 19, 2009 at 7 p.m.
Fundraiser gala, dinner and auction held at the 142 Throckmorton Theatre in Mill Valley, CA. Visit www.haydenshope.com for more information.

Cure FOP 5K Dash and Cash
September 27, 2009 at 2 p.m.
Fun run and walk to be held at Glasgow Park in Newark, DE. For more information, contact Wendy Henke at wendyhenke@yahoo.com.

Race for the Cure
October 11, 2009
In honor of Kyle McWilliams and to raise FOP awareness, Kyle's brother, Ryan, and Ryan's girlfriend, Danielle, will run the 2009 Chicago Marathon. Visit www.ifopa.org for more information or to donate.

Distinguished Contributors and Fundraisers

Thanks 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 April 1, 2009 – June 30, 2009 are listed. Contributions received after June 30, 2009 will be acknowledged in the next edition of the *FOP Connection*.



DIAMOND

*Donations of
\$25,000 or more*

Fundraisers

Bingo For A Cure

In Honor of Joshua Scoble



PLATINUM

*Donations of
\$10,000 or more*

Fundraisers

Richard Simcox & The Roemex Burns Supper



GOLD

*Donations of
\$5,000 or more*

CONTRIBUTORS

Ms. Severine Letartre



SILVER

*Donations of
\$1,000 or more*

CONTRIBUTORS

In Honor of Ian Cali

John & Amanda Cali

In Honor of Kyle McWilliams

Archer Daniels Midland Company

In Honor of Hayden Pheif

Egan & Gitte Cieply

In Honor of Stephanie Snow

Shirley Kloss

In Honor of Whitney Weldon

American Stevedoring, Inc.

William E. Simon Foundation

In Memory of Anthony Gapastione

Doug & Angela Gapastione

Fundraisers

3rd Annual FOP Garage Sale & Fundraiser

Kotzebue Schools Spring Carnival

In Honor of Dilyn Martin

Coupon Book & Candy Bar Fundraiser

In Honor of Nathaniel Padilla

Knickerbocker Elementary School Spare Change Drive

In Honor of Shane Terry



BRONZE

*Donations of
\$500 or more*

CONTRIBUTORS

In Honor of Cassie Eckart

Main Street Shell Service

In Honor of Jasmin Floyd

Lucille & Randal Doege

In Honor of Sophia Forshtay

Kiwanis Club of Hot Springs Village
Foundation

Park Ridge Rotary Charity

Foundation, Inc.

In Honor of Sara Gillooly

Pat & Lisa Gillooly

In Honor of Justin Henke

Kevin & Wendy Henke

In Honor of Hayden Pheif

David & Kristin Gannon

In Honor of Stephanie Snow

Main Street Shell Service

In Honor of Whitney Weldon

APS Trucking Corp.

International Longshoremen's Assoc
Local 1291

In Honor of Lincoln Wheelock

Mark & Robin Gambaiana

Scottsdale Center For Dentistry, LLC

In Memory of Anthony Gapastione

Calportland

Others:

Dr. Roberto Bufo

Refrigeration Design Inc.

Fundraisers

Webkinz Bingo to Benefit FOP

In Honor of Wayne Gopshes

**“Once you
choose hope,
anything’s
possible.”**

*-- Christopher
Reeve*

Contributions to the IFOPA: April 1, 2009 – June 30, 2009

In Honor of Emma Albee

Thomas McEnaney
Joyce Spurling
Timothy & Jean Taylor

In Honor of Jordyn Bugarin

Sharon & Edward Houseknecht
Titan America

In Honor of Ian Cali

Center for International
Training, Inc.
Leslie Feldman
Bernard & Virginia Gardner

In Honor of Chad Campbell

Beverly Litt

In Honor of Erin Danzer

Lisa & Jerrold Danzer

In Honor of Patrick Doerr

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**In Honor of Catherine
Drechsler**

GE Foundation

In Honor of Cassie Eckart

Betty Boyce

In Honor of Sophia Forshtay

Ralph Hackenbracht
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John & Jacqueline Pearson

In Honor of Wayne Gopshes

Foundation Coal Corporation
PAC
Carolyn & Franklin Scherr

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Matthew & Susan Clarke
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Dean & Jeanne Hatton
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**In Honor of Dr. Frederick
Kaplan**

Sylvia Bock
Betty Boyce
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In Honor of Ellecia Klein

JPMorgan Chase Foundation

In Honor of Ashley Kurpiel

Wayne & Linda Brule
WellPoint Associate Giving
Campaign

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Laurita
Frank & Elizabeth Laurita

In Honor of Daniel Licht

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**In Honor of Cameron
McGuire**

Gretchen & Grady Taute

In Honor of Kyle

McWilliams
Delmar & Mabel McWilliams

In Honor of Hayden Pheif

Howie & Annie Booth
Warren & Caroline Dowd
Donald & Joan Pheif

In Honor of Lindsay Ruiz

Merck Partnership for Giving

In Honor of Joshua Scoble

Mrs. Abraham Lichtenstein

In Honor of Stephanie Snow

Betty Boyce

In Honor of Gabriele Sotgiu

Irene Sotgiu

In Honor of Sarah Steele

Microsoft Matching Gifts
Mike & Jan Navarro

In Honor of Jordyn Valona

Douglas & Sharon Coleman

In Honor of Matthew Wadd

GE Foundation

**In Honor of Whitney
Weldon**

Peggy & Howard Menaker
Carl Pedersen & Lynn Wirth

**In Honor of Lincoln
Wheelock**

Bethany Conover
Roger Johnson
Todd & Cathy Nilson
Denise Smith
Heidi Templeton
Marilyn Wheelock

In Honor of Vincent Whelan

John Lorick, III
Kenneth & Zoe Scott

**In Honor of Lucas
Whitmore**

Calvin & Phyllis Whitmore

**In Memory of Anthony
Gapastione**

Genevieve Brown
Aurelio & Cecelia Calderon
Jimmy Cayson
Stephen & Mary Dall
Robert Fatigate
Ralph & Ronald Fatigate
Jerome Friedland, M.D.
Charles & Cherie Harris
Jerome and Marcia Harvey
Dave & Karen Hawkins
Anthony Kabala
Annette Knight
Michael & Sharon Lalande
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Rosalie Philips
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John & Lori Raskin
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John & Lucille Sangalli
Loretta Scott
Bob Taylor
Mike & Lynda Turner
Becky & Jack Warren
WellPoint Associate Giving
Campaign
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Rita & Herb Zartler

In Memory of Carl Hischka

Mr. & Mrs. Carl W. Hischka
Carol Thompson

In Memory of Barbara Neeb

Anthony & Bonita Hermes
Cindy Neeb

In Memory of Peter Purs
Mr. & Mrs. Charlie Purs**In Memory of Tina Smith**

Barbara Gahring
Benita Kaffenberger
Jeff & Michelle King
Alma Marko
Mark & Jennifer Marko
Gary & Kim Osburn
Meredith & Carylton Osburn
Yvonne Poppe
Jim & Shirleen Ramsey
Rosedale Mobile Home Park,
LLC
Wanda Spangler
Doris Young

Others:

Luz Cardenas
Carroll County General Health
Department
Monica A. Carter
CustomInk.com
Jeff Deese
Mark C. Dill
Ms. Eleni Economidou
Patricia Elmy
Dave Geissberger
Eddie Hampton
Mr. Brian Harwell
Katina Kapellas
Murray Kennedy
Jacqueline Weston Kloster
Katherine Lane
Ms. Elizabeth LaRue
Krista Maki
Michael J. McCue
Patrick McSweeney
Kevin M. Mowry
Nestle
Mrs. Hakima Nordström
Frederique Poirier
Carol Raleigh
Sanofi Aventis
Alan Sklar
Toys R Us
United Way of New York City
United Way of the Greater
Lehigh Valley, Inc.

Note: Contributions do
not include payment of
membership dues.

International FOP Association

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Announcements

Services of Note: GiveTech and DCRF

The IFOPA would like its membership to become aware of the following two organizations, which we feel may provide valuable resources to you.

GiveTech offers computer tools designed specifically for those with severe physical disabilities, allowing for increased self-reliance and a vastly enhanced computing and internet experience. The organization's goal is to provide such technological tools to those in need. While GiveTech does not give away computers, it does give away input devices that allow people with quadriplegia to use computers. For more information, or to apply, visit www.givetechnology.org.

Disabled Children's Relief Fund (DCRF) is a non-profit 501(c)(3) organization providing disabled children assistance to obtain wheelchairs, orthopedic braces, walkers, lifts, hearing aids, eyeglasses, medical equipment, physical therapy, and surgery. Blind, deaf, amputees, and children with cerebral palsy, muscular dystrophy, spastic quadriplegia, encephalitis, rheumatoid arthritis, spina bifida, Down's syndrome, and other disabilities are eligible to receive assistance. DCRF focuses special attention on helping children throughout the U.S. that do not have adequate health insurance, especially the physically challenged. For more information, visit www.dcrf.com.

Board of Directors Update

The IFOPA would like to thank Heather Wiley Starankovic for her service on the Board of Directors. Heather joined the IFOPA Board in 2007 and chaired the Fund Development Committee, where she helped organize several fundraisers and fundraising surveys.

"We would like to thank Heather for the new perspective she brought to the IFOPA Board, and for pushing us to think creatively about fundraising, grants and donor development," said Sara Olsen, the IFOPA's Chairman of the Board. "We wish her all the best in her endeavors at Penn and as a new mom, and we look forward to keeping her involved in the IFOPA family."