



Connection

International Fibrodysplasia Ossificans Progressiva Association, Inc. (IFOPA)

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On June 8, 2008, the IFOPA celebrated its twentieth birthday. Founded in 1988 by Jeannie Peeper, the IFOPA began originally as a pen pal group. Peeper, who had not met anyone with FOP at the time, visited Dr. Michael Zasloff at the National Institutes of Health. Through him, she learned of 11 other persons with FOP. In wanting to know more about those 11 people, she wrote each of them letters and received prompt responses. That circle of communication eventually formed the foundation of the organization.

In the years that followed, the organization has grown by leaps and bounds. The IFOPA has hosted a number of family meetings and symposia over the years, which have allowed FOP members to speak directly with FOP scientists, physicians and researchers, and membership currently extends to 52 countries worldwide.

While at its heart, the IFOPA's mission has always been to advance and support FOP research, education and advocacy, it also plays a strong part in supporting FOP families with the day-to-day challenges brought upon by FOP.

Here are what some people have said, via FOPonline, the IFOPA's E-mail news-group, to commemorate this milestone:

"I remember that day I found the IFOPA on a NORD (National Organization for Rare Disorders) write up. I called Jeannie that day and found myself breathing much better after realizing we were not the only ones out here with this disease... Our family has grown to what it is today because of the unselfish hours devoted to this organization and continued effort on everyone's part to keep it what it has become."

-- Carol Kurpiel
Mother of FOP member Ashley Kurpiel

"Meeting Jeannie, Sharon, Nancy (and Andy), and others, reassured me that others with FOP had led normal lives, attended college and got married. It was not completely unrealistic for me to dream."

-- Sarah Steele
Age 23, diagnosed at 4 months

IFOPA CELEBRATES

20

YEARS

"We are all so much stronger because we have a single voice against FOP that instills confidence, strength and endurance to power on day in and day out. Congratulations to all."

-- Margy Holzer
Age 40, diagnosed at 3 weeks

"I will forever be grateful to Jeannie, who gave me hope during the most uncertain and scary time of my life. Just hearing her voice and words of encouragement coming from a strong woman who had accomplished so much in her life gave me so much hope for my own future. So many

that came before me did not have Jeannie or the IFOPA to guide them through their early days, and I realize how blessed all of those who came 'after' are for having Jeannie and her vision to end the isolation so that no one would ever again have to live alone with FOP.

"Jeannie, I want to take this opportunity to thank you for everything that you have done on behalf of all of us with FOP. My words alone cannot express my deep gratitude and inspiration of all that you do. You are an incredible, beautiful, brave and strong-willed woman, and I am forever grateful for not only your vision of the IFOPA, but your determination to triumph over FOP and create a better world for us all. I truly believe that everything happens for a reason, and that God put you on this earth for a reason -- to be an angel on earth to all of us with FOP. Happy anniversary to us all!"

-- Holly Pullano
Age 26, diagnosed at 16

"I'm very thankful to you for your idea and determination to start and put together this incredible group, as well as the spirit of solidarity, assistance and compassion for everyone of us that prevail in our communication. Since the dark time when Manuel was diagnosed, the IFOPA and the research team on FOP are a light of hope and help that let me expect a better future for my son. Thank you Jeannie and all of you that are always there."

-- Moira Liljeström
Mother of FOP member Manuel Robert

"I am in awe over all the resources, stories, joys and tears we have all been able to share. The connection we have through the challenges we share has truly been a blessing to me."

-- Nancy Sando
Age 49, diagnosed at age 5



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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 FOPnews@bellsouth.net.

Editor: Eyal Goldshmid

Contributors: Amanda Cali, Julie Collins, Linda Daugherty, Eyal Goldshmid, Marie Hallbert, Debbie Hazlett, Wendy Henke, Frederick S. Kaplan, M.D., Ashley Kurpiel, Jeannie Peeper, Caroline Pinke, Nancy Sando, Eileen M. Shore, Ph.D., Gary Whyte, and Roger zum Felde.

Mother's Retreat for New Mom's With Children with FOP

Every mother needs to build a support structure for herself. Mothers of children with FOP need that and so much more in order to weather the lives we live. Well, here is an opportunity for YOU to refuel your soul and kick up your heels...

October 2 - 5, 2008
Held in the Colorado Rocky Mountains, USA

This retreat will be for mothers with newly diagnosed children (diagnosed within the last 4 years) and your child is 12 years old or younger. Our time together will be an opportunity to share with one another as we focus on solutions to coping and everyday living with FOP.

Come join me for soul-searching workshops and be prepared to have some fun!

Private donations have been received to provide your lodging and a portion of your meals. Participants will be responsible for:

- Your airfare
- \$75 (estimated) to cover the remaining cost of meals
- Transportation from the airport to lodging and return
- Spa treatment(s) and any extras -- like shopping!

There is limited funding available to help with travel and transportation for those in need. All retreats are subject to change and space is limited.

Call now to hold your spot. For more information call or E-mail me directly: Amanda Cali (973) 402-7875 or E-mail at Akanga41@aol.com.

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FOP-Symposium in Luleå June '08

By Marie Hallbert

I planned to arrange an FOP meeting in Sweden during the summer of 2008 because I wanted Hugo to meet Dr. Fred Kaplan once a year. To be honest, I also wanted to meet with Fred every year, since he means so much to Hugo and our family.

Anyway, last year at the Fourth International Symposium on FOP in Orlando, I met Dr. Kaplan's father, Harold, and in doing so I invited him to come with Fred on his next trip to Sweden. But in order for me to arrange a meeting like this I needed energy, or someone to kick me in the right direction (that's just the way I am), and this past winter Hugo had a problem with fluid in his hip and was not feeling well so I was began to think the meeting might not happen this year.

But then in January I got an E-mail from Elin Ljoen, one of our FOPers from Norway, and she asked me if there was going to be a meeting in Sweden this year, and surprisingly enough that remark provided me with the "kick in the right direction" I needed.

So in June 2008, we held an FOP-Symposium in Luleå, which is located in a very northern part of Sweden, where the sun shines almost 24 hours a day during the summer season. One of our FOPers lives up there, Ann-Sofi. She is 27 years old and has a locked jaw and dental problems, and in setting the meeting up there I thought ... *maybe* ... we might be able to fix her problems while also bringing several FOPers together. So I invited Dr. Nussbaum and Dr. Grunwald to the Symposium, and they came. Unfortunately, we were not

able to handle Ann-Sofi's problem at the time, but we did get lots of attention from the local newspaper and we also were interviewed by the local TV station, TV4 (as was Ann-Sofi after we'd left). We hope that Dr. Nussbaum and Dr. Grunwald will be able to come back to Sweden and



The gang enjoys a meal at the home of Marie's parents in Eskilstuna, Sweden.

get the opportunity to educate a team in Sweden on FOP/dental anesthesia and at the same time help Ann-Sofi.

During the Symposium, I kept a diary of the events as they happened. Here are some entries from that journal:

Day One

The Symposium started on the last Friday in June, but my journey with Dr. Kaplan started more than one week before that. Fred and his dad, Harold, came to Eskilstuna, Sweden, our home town, for two days and we had dinner with them at Hugo's grandparent's home. (Hugo's grandparents also happen to be my parents.) After the dinner, my father

showed Fred and Harold his newest toy -- a Segway scooter, which, if you think about it, looks a lot like a stick with two wheels. So we had some fun in the garden, riding it, before I drove Fred and Harold back to their hotel around 9 p.m. I didn't want to keep them out too late because they needed to sleep. The next day was going to be a *looong* day -- since we would be celebrating the Swedish midsummer.

Day Two

This day is a major holiday in Sweden. Fred, Harold, Hugo's grandparents Anette and Pehr, Hugo, Kazper, Pelle (Hugo's father), myself, and our neighbors Jim, Tesson and their children Saga-Li and Fige were all in attendance. We started with a traditional "midsummer" lunch of herrings, potatoes and "snaps" (snap peas). After lunch, we sang some songs together and then took a 30-minute walk to a nearby celebration spot, where we joined several children and their parents in singing traditional songs and dancing around a midsummer may pole decorated with flowers.

As always during the midsummer holiday, it started to rain, so we went back home, where we drank coffee and ate strawberries with ice cream, which made everyone happy. Thankfully, the rain didn't last long, and once the sun was shining again, we went back outside and finished our evening with a barbecue and lots of talking and laughing -- it was a great time. And at this time, I couldn't find any bad things about Hugo having FOP. I could only thank him because if it weren't for him we wouldn't have been able to have this much fun or have the opportunity to get to know these new friends, doctors and families we would meet a few days later in Luleå.

CONTINUED ON
NEXT PAGE >>

Day Three

I stayed at home with my family while Hugo's grandparents took Fred and Harold to Stockholm. On the way, they stopped for lunch in Mariefred and visited Gripsholm Castle. When Fred arrived in Stockholm he sent me an E-mail and said that he had visited "our town." It took me two days before I understood what he meant.

Day Four

I took the train to Stockholm. I had aids working at home with Hugo (Pelle was working), so I was able to go sightseeing for three days in Stockholm with Fred, Harold and my parents. We went to the City Hall of Stockholm -- one of the most beautiful and well-known buildings in the world - - as well as the most exclusive ballroom in Stockholm, which is frequently used for the annual Nobel Prize Awards Banquet. We also had a late dinner in Fjaderholmarna, which is out on the archipelago and required us to take a boat to get there.

Day Five

We had lunch on a steamboat on the way to Drottningholm Castle, which is where the Swedish royal family lives, and as we waited for the boat to arrive we saw another boat pass us, named "Mariefred." When I saw it, I immediately understood what Fred had meant by "our town" a few days earlier. For dinner, we chose to eat at an Italian restaurant, because we felt that we had eaten so much Swedish food already.

Day Six

On our last day in Stockholm, Fred and Harold visited the Vasa Museum, which contains the worlds only surviving 17th century ship and is one of the foremost tourist sights in the world. After that, the three of us had a very nice dinner together with Dr. Burton Nussbaum, Dr. Zvi Grunwald and his wife Hava, and my parents.

Days Seven and Eight

On Wednesday, Pelle, Hugo and myself flew to Luleå. Hugo's brother Kazper stayed at home with his grandparents -- I've felt that I've had to force him to attend every FOP meeting for the past seven years, so this time he didn't have to come with us.



Marie and Dr. Kaplan stop before a familiarly named boat while waiting for the ferry to Drottningholm Castle.

A strange thing happened in Luleå: Fred, Harold, Zvi, Hava and Burt rented a car with a guide and took a *looong* trip way up north, past the arctic circle. When they came back to the hotel they had an amazing story to tell us:

The guide had asked them what they were doing in this part of Sweden, so they told him about the FOP-Symposium.

To this, the guide said, "I have heard about that!"

Of course, they were in disbelief and said to him, "No, it's too rare, it must be something else you are thinking about!"

The guide said, "Tell me more." "Muscles turn to bone and you get stiff, and also the jaw can get locked."

"My cousin has that condition," said the guide.

"Oh no! It must be something else!"

Then Fred asked him if he had known his cousin since he was a child.

The guide said, "Yes!"

Fred asked, "What do his great toes look like?"

He said, "They are bent like this!" And he maneuvered his thumbs to look exactly like the way a person with classic FOP has his or her toes bent.

Then the guide said that his cousin is around 40 years old and lives in Stockholm. Naturally, I asked the guide to E-mail me with more information, but I haven't heard back from him yet.

Day Nine

On Friday afternoon, we met with the press and then set two doctor appointments for the families. This year we decided to give each family 40 minutes with Dr. Kaplan and all the other doctors that attended the meeting. These meetings tend to be the most important thing for families, because they offer them the opportunity to get answers to all their personal questions and also allow the doctors to meet with patients of different ages, each of which has a different

story to tell and has different questions to ask. The experience, I feel, is much better than having the doctors see only one patient with FOP at a time. This way, everyone really learns a lot over the event's two days. Also, this time Hugo's doctor, Anders Wallin, took recommendations directly from Dr Kaplan and promised to distribute those notes to every patient's doctor.

On Friday evening, we met at the hotel bar to mingle and get to know each other in a more relaxed manner. Everyone had name tags on, each showing his or her first name, the person's relationship to FOP, and the city and country where they currently live. Mine read: "Marie, Hugo's mum, Eskilstuna, Sweden." Hugo's doctor's read: "Anders Wallin, Hugo's doctor, Eskilstuna, Sweden." Having these

name tags made things much easier for everyone to communicate. More than 35 people attended, including three doctors, six families from Sweden, one family from Denmark, one from Norway, and Dr. Kaplan, Dr. Shore, Dr. Grunwald and Dr. Nussbaum from Philadelphia.

Days Ten and Eleven

Saturday morning, we started with a lecture from Dr. Fred Kaplan and Dr. Eileen Shore, who talked about FOP and their research. The rest of the day, we held more doctor appointments and had a Scandinavian FOP Association meeting, during which we discussed what we can do to help each other, what we have been doing the last year to promote our cause, and what we would like to see happen in the future.

Later on, after dinner, we went to a park. One of the parents of the attendees builds remote controlled airplanes and wanted to show us his latest creation. This same parent first showed us his planes four years ago and now his presentations have become a tradition of ours.

And of course the sun shined that Saturday night, allowing us to spend a few more hours together and letting us end our Symposium outside, where we admired the beauty around us and took pictures of the midnight sun that went down around 11:30 p.m. And some of us stayed outside, talking until long after midnight.

RIGHT: Dr. Kaplan rides a Segway scooter in the backyard of Marie Hallbert's parents' house in Eskilstuna, Sweden.



European Day of Rare Disease

Invitation from the German President Horst Koehler and his wife Eva-Luise

By Roger zum Felde

On February 29, 2008, I was invited to be a guest in Berlin where our President and his wife were presenting a prize of 50,000 Euros to somebody who has helped people with rare diseases.

In 2006, Germany started a foundation for people with rare diseases. This year, the 50,000-Euro award was given to Volkmar Gieselmann from the University Bochum and Biochem and Hans-Joachim Galla from Universität Münster. Both are working on a project involving the blood-brain barrier.

Jens Luebben, who was with me at the Symposium 2000 in Philadelphia, drove me to Berlin and checked us into a hotel near the location where the event was taking place. I picked this hotel because the best chef I know is the head of its kitchen, and in my opinion his kitchen is the best in Berlin. That evening, we had a fabulous five-course dinner with Dr. Petra Seeman,

who was at the last Symposium, and her life-companion, Lutz.

After only four hours of sleep (*yes, the night was that long*), we drove around the



Roger zum Felde (left) and Dr. Croft of the German Office of Rare Disease.

corner to the headquarters of the telecom. Germany's First Lady is the protector of ACHSE, the organization for rare disease in Germany. FOP is also organized there and I was invited as a guest.

After the *Laudatio* from Miss Koehler, there was a podium discussion with Dr. Croft (Office of Rare Disease), Dr. Reimann (ACHSE) and Dr. Harms (University Muenster) about research on rare disease. Following that, the First Lady presented the 50,000-Euro prize to Mr. Gieselmann and Dr. Galla.

During the lunch break, I had the opportunity to talk to Miss Koehler and presented her a flyer on FOP, as well as invite her to a charity dinner and to the annual German FOP meeting, which took place from August 1, 2008 to August 3, 2008.

After our lunch, Dr. Croft held an interesting lecture titled "Research Perspectives for Rare Disease in America as a Global Beginning."

Before the event ended, I talked to Dr. Croft and we exchanged cards. Shortly after, Jens and I heard from the CEO of an organization who fulfilled "heart wishes" for handicapped people. Apparently, they remembered seeing me on a TV show called "TalkShow" about five years back.

Anyway, thanks to them, we left Berlin with the promise of a new Dell computer system, courtesy of these friendly people. Jens and I had celebratory drink about that. Our trip to Berlin was a full success.

Oliver Collins Visits Italy, Meets the Pope

By Julie Collins

For Easter 2008, Oliver Collins and his family headed overseas from Brisbane, Australia on a “Make-A-Wish” trip to Italy. Ollie had wanted to taste authentic Italian pasta and pizza ever since doing a “Blokes That Cook” course at school in 2007.

Thanks to the efforts of his wonderful doctor, Jim McGill, and the “Make-A-Wish” organization, he got to try the real thing and more.

The trip started off in fine style for Ollie and his family and friends with a surprise party at his local *gelati* café, where Ollie was presented with his travel tickets and itinerary. Then it was *up up and away*, and thanks to Ollie’s school principal, the family got to fly business class for the first leg of the trip -- pure luxury!

One of the highlights of the trip was having a Papal audience, kindly arranged by friends from Ollie’s school. The tour also involved a fast-train journey to Venice and



riding on a gondola, traveling to Pompeii and exploring the ruins of Rome, the Coliseum, Trevi fountain, the Vatican and lots of cafes and *gelati* bars.

We stayed in a 17th century apartment, which was very quaint and charming. Ollie got a warm reception from most of the waiters and taxi drivers he met, especially after he attempted to speak some basic Italian with them.

It was all over in 10 days, a whirlwind trip of great memories to share as a family, thanks to a wonderful organization.

Meeting the Dalai Lama

By Ashley Kurpiel

Thanks to my good friend Diane Weiss, I got to meet the Dalai Lama in October of 2007. It happened quickly: Diane called me, asked me to get dressed and meet her at the Ritz in Atlanta and meet the Dalai Lama.

Once I got there, Diane was not sure if I would have any one-on-one time with him but said would get to see him from where I was going to be sitting -- just two feet away.

After the Dalai Lama gave his speech, we were told that he was not going to eat dinner with us, as lunch is usually his last meal of the day. Instead, he planned to go to his personal quarters and retire to bed early.

However, as he left the podium, he told his secret service men to hold on. He made his way to my table, gave me a hug, said a prayer for me, then asked when my operation would be.

Given the little time we had, we quickly told him the arm came off when I was three and that I had a rare bone disease.

That was when I took my FOP green bracelet off



my wrist and gave it to him and told him what it represented -- and he put it on!

He put his head down onto my head, hugged me and said, “Thank You.” Then he left the ballroom without saying a word to any of the other 300 guests.

After he left, Diane told me that out of the five different occasions she’s met the Dalai Lama, she has NEVER seen him embrace anyone like he’d done with me. At our dinner table was the Dalai’s interpreter (who has been by his side for more than 22 years) and the president of Emory University.

The Dalai Lama is a very sweet, spiritual, and in-touch man. That night is a night I will never forget!

American Academy of Orthopaedic Surgeons 2008 Research Capitol Hill Days

By Amanda Cali

My son Ian and I, Dr. Frederick Kaplan and Hillary Weldon (mother of FOPer Whitney Weldon), were invited by the American Academy of Orthopaedic Surgeons (AAOS) to participate in their annual "Capitol Hill Days" in January of this year. Ian was asked to visit Capitol Hill as one of 32 patients representing rare and common musculoskeletal conditions. The purpose of this annual event is for patients and their doctors to educate senators and congressman about the importance of supporting NIH-funded research for musculoskeletal diseases, and for legislators to meet with their constituents who have these conditions and hear their personal stories. This opportunity came to us through the tireless work that Hillary Weldon has done in Washington to bring awareness and attention to FOP. She has seized each opportunity to spread awareness about FOP to lawmakers, and it was a pleasure to be there with her and to be introduced first-hand to the many individuals that she and Whitney have met in the previous three years that they have been participating in the AAOS Capitol Hill Days event.

During our visit to Capitol Hill, on a very cold wintry day, we met with

the senior legislative aids of nine senators and congressmen from Pennsylvania and New Jersey and snuck a quick visit to the offices of Senator Barack Obama (Illinois) and Senator Lisa Murkowski (Alaska) to drop-off information on FOP. One of our favorite visits was with the new senator from PA, Senator Robert Casey. His interest and concern for FOP was genuine and he spent a lot of



Left to right: Mrs. Amanda Cali, Ian Cali, Senator Robert Casey, Dr. Fredrick Kaplan and Mrs. Hillary Weldon.

time with Ian and Dr. Kaplan learning as much as he could. Senator Casey's health aide and legislative counsel even spoke about making a road trip to see the FOP lab later this year. We extended a warm invitation in hopes that they will come.

The AAOS provided training for us to be informed representatives and armed us with many statistics about bone conditions to help us make our case for the need for funding medical research on musculoskeletal conditions. It was disappointing when *each* senator and congressman's offices informed us

that there had not been any increase in funding for the entire NIH budget for the last seven years. Due to inflation and the increase in expenses each of those seven years, this lack of even a minimal increase has lead to a decline in available funding and a lack of quality researchers being hired for many diseases. Although each legislator vowed to fight for more funding for musculoskeletal research, we were told that the legislation would be vetoed by the President and returned to a Congress that did not have the votes to override a Presidential veto. We were stunned when an aide to a senior republican senator told us that there wasn't much hope of an increase

at least until a new President (of either party) took office in January 2009. We emphasized that FOP showed no political affiliations, or for that matter any racial, ethnic, gender or geographic preferences in who was affected. We realized how fortunate we have all been to have received one of the few NIH grants to support the extraordinary work that Dr. Kaplan and his team do to help find a treatment for FOP. The hope

for an increase in funding in 2009 was expressed by everyone.

We encourage each FOP family to take the time to meet with your senators and congressmen both on the state and federal levels and let them know your story. We would be happy to supply anyone with the materials and information provided to us by the AAOS.

Just E-mail Amanda at Akanga41@aol.com, and let me know what you need.

FOP and Pregnancy

A Note from Dr. Ruth Westheimer...

May 23, 2008

Dear Jeannie, Nancy, Eileen, and Fred:

Thank you for bringing your personal perspectives on FOP to my attention. I greatly applaud the work that you and the international FOP community are doing to address the sensitive and critical issues of intimacy and responsibility that are so vitally important to all individuals. While FOP may be one of the most disabling conditions known to mankind, the physical handicaps that result should not stand in the way of sexual satisfaction and personal fulfillment -- issues to which I have dedicated my life.

Your comments are inspirational and enlightening, and address an urgent and unmet educational need not only for those with FOP but also for many others with physical disabilities. Your statements and perspectives are heartfelt and informative, and provide a beacon of hope and enlightenment to many. Again, I congratulate you and the FOP community for addressing this extremely important matter.

With my best wishes.

Sincerely yours,



Dr. Ruth K. Westheimer

FOP and Pregnancy

Women with FOP span the globe, living in different cultures, having different religious beliefs and moral standards, but one of the things that we share in common is the effects of FOP when it comes to pregnancy. Dr. Kaplan, Nancy Sando and I are passionate about the topic of women with FOP and pregnancy, and we wanted to take this opportunity to share with you our personal views, as well as Dr. Kaplan and Dr. Shore's viewpoint on the medical implications of pregnancy. I urge you to read the three following articles carefully to fully understand the *life changing consequences of pregnancy* for a woman with FOP. Ultimately, it is your decision.

As Nancy and I look back on the generation of FOP women that we have known before us, sex was not discussed because people with disabilities were very isolated. As our

network grew and research developed, our generation had a little more information given to us, we were informed that we could never conceive and then learned we could conceive but with great risks to us and our child. We realize that we now have a new generation of young adults and teens that are sexually active, but what sets you apart from generations before you is that *you* are the "**Generation of Knowledge.**" You know more about FOP and are more connected at a younger age than we were growing up. So, it is very important that you embrace this knowledge to make the best informed choices about your life.

Nancy and I both have experienced being in love and having a committed relationship, so we clearly understand the issues that you as young men and women face. I think that it is so important for a young person to have confidence in who you are, know what your goals are in life and have a mission on how to accomplish those goals. Don't rely on someone else to give you self worth. You must believe that you are truly a beautiful person and love the person that you are.

I would encourage you to consider the following information and ideas that follow in these articles in order to make the best informed choices about your life.

Think about the following questions and answers, which place the situation in more practical matters, before taking the next steps:

Q: *Why would I want to get pregnant knowing the risks I am taking on my own life as well as the baby?*

A: Life is a very precious gift. We face many obstacles, living with FOP, and pregnancy is one of them. By choosing to become pregnant, we jeopardize both our health and that of our baby.

Q: *Why would I knowingly want to try to have a child that could have FOP?*

A: Our goal is to one day find a cure for FOP, not to knowingly create new generations of children with FOP.

Q: *Why would I want to have a child that I will have limited ability to care and provide for?*

A: Providing yourself with a proper caregiver for your own life as an adult is already cumbersome and time-consuming. Developing a plan that ensures the proper care of your child in addition to that is overwhelmingly complex.

As a young adult, your partner will probably not fully understand the lifelong commitment that he will be making to have a child. The progression of FOP will be a learning experience for both of you to adapt to. Having children is always a challenge; having a child with FOP brings its own additional challenges.

There are so many emotional reasons women want children; one, being pressure to think that the only way to keep your partner is to get pregnant; another is that it would be fun; and yet another reason is to have a little child love you. Children are a lifelong responsibility that require many selfless moments of care. I encourage you to develop a relationship with your partner based on love -- a love that is unconditional. Your relationship

will take time to grow and your partner becomes an extension of who you are because you should already be grounded in who you are.

I encourage you to empower yourself:

- Some women abstain from sex until marriage as taught by their religious beliefs.
- If you are sexually active, ALWAYS use a birth control contraceptive. Please consult your doctor for medical advice.
- Remember that there are many ways to satisfy your yearning to nurture without having your own child. Be involved with your nieces and nephews' lives, and actively help your friend's with their children. There are also many nonprofit organizations for children that need loving, caring people to volunteer to help children in need and mentor programs for

children are also available.

- Adoption is also a wonderful opportunity to provide a loving home to children in need of loving parents.

I hope that you will always make informed decisions for yourself and those around you that you love. I honor the differences and the choices we each make. Life can be a challenge when you have FOP and life can be grand and exciting as well. All of us have the opportunity to find a balance between those things in life that we can control and those we can not. Life is a dance of those balances.

*Sincerely,
Jeannie Peeper
Woman with FOP
Age 49, diagnosed at age 4*

Maternity and Motherhood

In 1986, I had the opportunity to go to the NIH to meet with Dr. Zasloff and the research team there. I was intrigued by everything I learned and observed during my week-long stay. One of Dr. Zasloff's colleagues approached me with a topic I really hadn't thought about: Pregnancy and FOP. I was in my mid-twenties at the time and was made aware during this chat that pregnancy could be very risky for myself and a baby (*see the medical article by Dr. Kaplan and Dr. Shore on the next page for more information on this*). I put this information on the back burner for possible future reference.

Then in 1988, I met and married Andy Sando. We were both challenged by having FOP and as a young couple we knew early on that having our own children would be physically impossible, yet we dreamed of making a difference in the "next generation." We had even contemplated adoption at one point, but as we questioned ourselves with a myriad of "what if's," we soon realized that we needed to discover an alternative. What filled the void of having and caring for our own children was getting involved with children of our families and friends. Our nieces and nephews became "ours" during their overnight visits. This may sound trite to anyone with the innate desire to have a baby of their own, but given the sacrifice and the commitment to a 24/7 situation, I feel it was and continues to be a fair and very rewarding compromise. Andy and I were married for fourteen years, until his untimely death at age 44.

In dealing with FOP now for more than 40 years, I have made many sacrifices because of the disease, as I'm sure most you have done as well. At this stage of my life, I am comfortable with the fact that I didn't have to sacrifice my health, the baby's life -- even my own life -- if I'd had a baby in my younger years. In my personal opinion, the risk of complication was much too great.

The commitment to a new life, not only during pregnancy, must be addressed as well. Does the couple (preferably a married couple) have a firm foundation in their relationship to withstand another dependent? Dependency has many meanings, emotionally, physically and financially. These elements must be balanced and periodically adjusted if the family is to remain strong. As FOP has its own timetable in its progression, one has to be realistic that the mother of the new baby will undoubtedly need some assistance in caring for the infant. Who will offer that? The father? Grandparents? Caregivers? How will the new Mom emotionally handle others caring for her baby? Seems like an easy question, but there are many situations that I can think of that could cause a great deal of stress for the new Mom. Maternity and motherhood are topics that need attention in our unique FOP family. I hope that what I have shared will help anyone pondering beginning a family to "look outside the box" to alternative parenting.

*Regards,
Nancy Sando
Age 49, diagnosed at age 5
Petoskey, Michigan*

NEXT PAGE >>

DR. KAPLAN AND DR. SHORE
OFFER THEIR PERSPECTIVE ON
FOP AND PREGANCY.

A Serious Life Decision: Stop and Think!

By Frederick S. Kaplan, M.D. and
Eileen M. Shore, Ph.D.

The decision to have a child is one of the most important and serious life decisions a couple can make. Because FOP is an inherited disease, anyone (man or woman) with FOP will have similar concerns about passing the FOP mutation to his/her child. If a parent has FOP, the risk that the child will have FOP is 50 percent. A woman with FOP has additional concerns that must be carefully considered. In addition to the usual risks of pregnancy that any woman might encounter, pregnancy in a patient with FOP is perilous and poses substantial life-threatening risks to both the mother and child.

Specific risks to the mother include, but are not limited to:

- 1. Risk of FOP flare-ups during pregnancy.** To protect the fetus, the use of palliative medications, that are often used to treat flare-ups may have to be limited.
- 2. Risk of breathing difficulties during the latter part of pregnancy.** FOP causes severe limitation of expansion of the chest wall due to a developmental problem in the joints that connect the ribs to the spine. As a result of FOP, these joints do not form properly and severely limit expansion of the chest with breathing. Breathing problems can also arise due to bone formation in the chest muscles. As the baby grows in the womb, it presses upward on the diaphragm, the major breathing muscle that separates the chest cavity from the abdominal cavity. This upward pressure on the diaphragm further limits the space for the FOP mother's constricted lungs to expand resulting in increased difficulty breathing. Breathing may be rendered even more difficult if the mother has already formed heterotopic bone in the abdominal wall that restricts

outward growth of the fetus. As a result, the growing baby will further press upwards on the mother's diaphragm, restricting breathing even further.

- 3. Risk of childbirth complications.** Caesarian section is necessary for a mother with FOP due to the pelvic deformity, joint fusions and decreased plasticity of the birth canal that will not safely permit a normal vaginal delivery. It would not be safe or even possible to have normal childbirth due to the physical limitations and mobility restrictions of FOP.
- 4. Risk of the general anesthesia for Caesarian delivery.** Caesarian delivery is a surgical procedure that requires anesthesia. Due to FOP, local or regional anesthetics are technically unfeasible and dangerous and cannot be used. General anesthesia is required. In addition to the dramatic increased risks to the mother, general anesthetics pose substantial risks to the fetus/newborn baby (see below).
- 5. Risk of phlebitis and pulmonary embolism.** These potentially life-threatening complications can arise due to the severe immobility of FOP. The added constraints of pregnancy, such as extended bed rest mandated by a high-risk pregnancy along with the lower limb edema that invariably occurs in the last trimester of pregnancy further increase the risk of these life-threatening complications.

Specific risks to the child include, but are not limited to:

- 1. Risk that the child may have FOP.** If a parent has FOP, the chance that the child will have FOP is 50 percent.
- 2. Risk of prematurity.** The mother may not be able to carry to full-term due to breathing difficulties. As a result, there is a severe risk of premature delivery. Numerous lifelong consequences are often associated with premature birth.

- 3. Risk of severe fetal distress.** The risk of severe fetal distress, a condition in which the fetus is at risk of dying or suffering severe brain injury, is primarily due to hypoxia (diminished oxygen to the fetus). This complication may result from maternal breathing difficulties or other unrecognized problems later in pregnancy (see above).
- 4. Risk of cerebral palsy.** There is a high risk of cerebral palsy due to oxygen deprivation to the fetus, especially if fetal distress occurs during the latter part of pregnancy or during delivery.
- 5. Risk of complications from general anesthesia.** There is a high risk of complications to the newborn resulting from general anesthesia during Caesarian section (see above). General anesthesia is required, as the more preferable local or regional anesthesia is technically impossible when the mother has FOP.

Additional complications to consider are: Who will care for the mother during the complications and added stress of pregnancy? Who will care for the child if the mother's mobility restriction from FOP prevents her from caring for the child? What is the role of the father, siblings, and grandparents in the care of the newborn child?

Although it is possible for a woman with FOP to carry a child to term, and at least four known instances have been reported in the medical literature, there are substantial life-threatening risks to both the mother and child. Pregnancy in FOP should never be undertaken without serious consideration and family planning. Unwanted pregnancies should be assiduously avoided. Independent genetic counseling is available, if desired.

Should a pregnancy occur, guidance and care at a high-risk pregnancy center are imperative. At least two lives are at stake: that of the mother and that of the child. In addition, the lives of many others will be impacted by a pregnancy in a mother with FOP -- specifically, those of other family members who, by necessity, are involved in the consequences of any such occurrence.

In summary, pregnancy in FOP poses major life-threatening risks to the mother and child as well as life-altering consequences to the entire family that must be carefully considered and balanced.

Pregnancy in FOP is a serious life decision. Stop and think!

Focus on Fundraising

Hitting Our Stride

By Wendy Henke

In its second year, Stride to Cure FOP took a giant leap forward, growing to a continent-wide endeavor, as friends and families of FOP members in Alaska, British Columbia, Washington, California, Michigan, Florida, the Carolinas, Pennsylvania, Maryland and Delaware literally took steps to raise awareness and funds for FOP and the IFOPA.

FOP members Justin Henke, Nathaniel Padilla, Jordyn Bugarin, Wayne Gopshes, Nancy Sando, Miranda Munro, Robin Rice, Dylin Martin, and Daniel Licht all participated in some fashion. The event, which was held on Justin Henke's eighth birthday, encouraged participants to gather pledges and stride for the cause of FOP, wherever they happened to be on May 10.

Sporting "Stride to Cure FOP" shirts, generously provided by more than

a dozen business sponsors, some folks walked along trails at local parks, others walked along boardwalks at the beach, while others walked at the mall or at their children's sporting events.

In Delaware, a good number of us, including staff from the FOP Lab, met at the brand new Glasgow Park. The weather was damp at first, but the skies gradually cleared. Some people arrived early and others later in the day, depending on their busy Saturday schedules. A friend captured the real beauty of the day on video, which you can view on the IFOPA website.

We aimed at having 405 striders participate, one for each FOP member in the IFOPA, and the level of participation surpassed our expectations. What bonded us together, indeed, were the FOP members whose names we proudly and lovingly donned on our shirts. Friends to this day still tell me they often think and pray about the person for whom they walked on May 10. In fact, sitting (probably stuck for



Left to right: Jordyn, Nathaniel and Justin at the Stride to Cure FOP walk in Delaware.

good) on top of my jewelry box, is my own "Striding in honor of Jimmy, Rome, GA" sticker. It continually reminds me of all the precious gems we have in the IFOPA community.

What a rock (diamond, of course!) the IFOPA office is, too. Its support was invaluable in helping us to coordinate so many feet -- and to accomplish such a feat! We look forward to next year. Perhaps the event will grow to become a worldwide "Stride to Cure FOP" event? Contact the IFOPA office if you're interested in participating next year.

To view photos from the many Stride to Cure FOP events held around the U.S. and Canada, visit http://www.ifopa.org/fundraise_photos.html.

Hazlett Family Holds 'Truly Memorable Evening'

By Debbie Hazlett

On the evening of April 19, 2008, we hosted a dinner party fundraiser for FOP research in honor of our son Tim and Carli Henrotay, who both have FOP.

This was a truly memorable evening, as 30 of our dear friends and neighbors joined us at our home for cocktails and dinner. It was great to be able to fundraise for FOP research and enjoy the company of our dear friends. We were also blessed with donations from several local businesses, which helped reduce our expenses and raise our profit.

We are very appreciative to the donors for their generosity and also to the friends that helped greet, serve, cook and clean up. We are so blessed to have friends and neighbors that care about Tim and Carli and are willing to give their time and resources to help in this cause. Having a fundraiser always touches our hearts with the goodness and love of others.

We want to thank the following individuals, many of whom are seen in this photo (right), for participating in this fundraiser: Susanne Kearns; Linda Son and her dad Hugh; Mike and Teresa Schaltenbrand; Melinda and Kevin Dall; George and Ellen Hall; David

and Jennifer Eghigian; Mike and Kristin Murphy; Lisa and Craig Reno; Cheryl and Charlie Palus; Mary Anne and Nick Williams; Jeff and Suzie Scrivner; Randy Tate; Linda Lang; Mary and Lou Howell; Mike and Linda Bereyso; Rose Nersesian; Tim Hollenbach of Hart Food and Drug; Dan Schwendenman of Belleville Fanner's Market; and Carli and Lori Henrotay.



Focus on Fundraising

A Winner for the IFOPA

New York Legislative Idol Takes Center Stage

By Gary Whyte

Anyone who has ever watched "American Idol" knows how much excitement the show brings to its contestants, judges, audience and viewers.

Now think about that same concept, only this time the contestants are New York State Assemblymen and Senators -- and they are not touting their talents for individual fame and fortune but instead raising money for the IFOPA in honor of FOP member Theresa Caruso.

Theresa used to live in New York City and worked as a school teacher there but has since moved to Nevada. Theresa's uncle, Dan Wray, decided to honor her New York roots by working with Kristina Kwacz, legislative aid to Assemblyman William Parment, to put together this year's "Legislative Idol" to benefit the IFOPA.

On May 27, 2008, the New York State Legislature held its annual Legislative Idol at Jillian's in Albany, NY, with the proceeds from the event going to the IFOPA. The room was packed with spectators as

contestants sang their songs with back-up music supplied by musicians from the Dan Wray Band and the Budget Blues Boys. The venue was hosted by Senator Joe Robach, who captivated the audience with little tidbits about each performer.

The panel of three judges consisted of: Wayne Jackson, Assembly Sergeant at Arms; Marilee King, ZAP Legislative Courier Services; and Paul Rapp, entertainment attorney and columnist for *Metroland*, an Albany newspaper. As with any venue, there are a number of components that make the show come together, with the final component being the performers.

New York Legislator George Latimer, hailing from Westchester, stepped onto the stage first and sang that old-time country favorite, "A Boy Named Sue." After him, Darryl Towns of Brooklyn, belted out "I Only Wanna Be With You." He was followed by Jim Conte of Huntington Station, who crooned "Sweet Melissa," then Dan Burling of Warsaw, who performed the oldie "Eve of Destruction," Joe Saladino of Massapequa, who sang that old-time favorite "Stormy Monday," William Parment of North Harmony (taking the political route) singing "Billy and the State Thruway" and finally William Scarborough of Jamaica, who brought the house down with his rendition of "One in a Million."

I was asked to represent the IFOPA at the event, and with the help of my godson, Brian Retersdorf, we manned the front desk, collected donations and handed out literature



Gary Whyte, representing the IFOPA, at New York Legislative Idol.

about FOP and the IFOPA. I was also given the opportunity to say a few words about FOP, Theresa Caruso and the IFOPA, and I thanked everyone for attending and making this year's receipts go towards helping the IFOPA and their mission.

Based on audience applause and the thoughts of the three judges, this year's 2008 Legislative Idol Award went to Assemblyman William Parment for his performance of "Billy and the State Thruway." In the true spirit of bi-partisanship, Republicans and Democrats alike put their differences aside and collectively they took center stage to benefit the IFOPA. We thank them for that.

On a personal note, I totally enjoyed the performances, meeting new people, listening to good music, spreading the word about FOP and having the opportunity to help. For me it was also a wheel-turning moment for my mind, as I'm still contemplating how to get our Legislature to agree to have the first annual "Legislative Idol" in New Jersey. Stay tuned for future announcements and thank you New York!



Finalists Darryl Towns (left) and William Scarborough (right) congratulate 2008 Legislative Idol Winner William Parment (center).

Focus on Fundraising

Figure Skate for FOP

By Caroline Pinke

For the past eleven years, figure skating has been a major part of my life. For the past four years, I have been inspired by Whitney Weldon's courageous struggle with FOP. I learned about her condition when she became a freshman at The Pingry School, the high school from which I recently graduated; more recently, I became aware that Ian Cali, a resident of Mountain Lakes, NJ, my hometown, also has FOP. So about six months ago, I decided to channel my passion for figure skating toward this cause in honor of Whitney and Ian.

On May 31, 2008 at the William G. Mennen Sports Arena in Morristown, NJ, I held a figure skating exhibition called "Figure Skate for FOP." For the event, I employed extensive planning and advertisement and recruited 14 fellow high-level figure skaters, ages 10 to 20, to perform in the show with me. The goal of "Figure Skate for FOP" was threefold: to spread awareness of FOP; to raise money for The Weldon FOP Research Fund; and hopefully to inspire others to continue contributing to the cause any way they can.

I sold admission tickets for the show, homemade cookies, "Figure Skate for FOP" logo T-shirts, and DVDs of the show at the door. All proceeds benefited The Weldon FOP Research Fund; I wanted to generate as much revenue as possible in the hopes of accelerating the University of Pennsylvania's FOP researchers' noble effort to develop treatments and a cure for the disease.



Fifteen high-level skaters participated in the event.

After two hours of talented performers entertaining an incredibly enthusiastic audience, the skaters all came back onto the ice for a grand finale that brought the show to a perfect conclusion; the positive energy in the rink was palpable.

I would like to thank the USFSA for sanctioning the event, Linda Daugherty and the IFOPA for all of their help, the Weldon and Cali families for their support, the Brown family for its delicious baked goods donations, and the William G. Mennen Sports Arena for providing a venue in which the event could take place.

I would also like to thank all of the figure skaters, the amazing audience, those who were unable to attend but kindly donated to the cause or helped out in any way, and all of my friends and family for their unwavering encouragement throughout the stressful planning, organizing and advertising process.

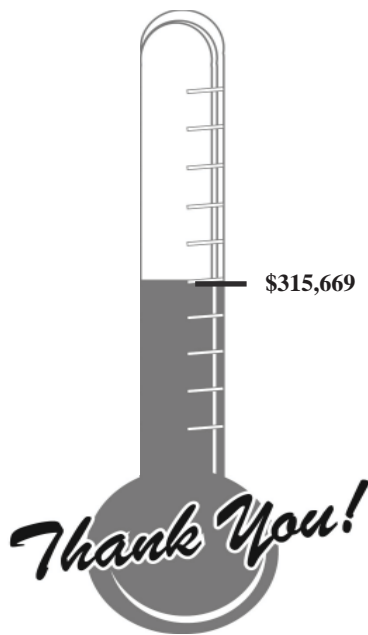
The success of "Figure Skate for FOP" far surpassed my expectations, and it certainly would not have been possible without each of you.

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 1st and 2nd quarters (January 1, 2008 – June 30, 2008), our fundraisers raised \$315,669. 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
- Coins for a Cure
- Bingo for a Cure hosted by Emmaus Fourth Alarmers in Honor of Joshua Scoble
- Figure Skate for FOP in Honor of Ian Cali & Whitney Weldon
- Friendly's Fun Night in Honor of Justine Henke
- Hazlett Dinner Party in Honor of Timothy Hazlett & Carli Henrotay
- Holyname School of Nursing Popcorn & Cupcake Fundraiser in Honor of Sophia Forshtay

- Ice Fishing in Honor of Kyle McWilliams
- IFOPA Awareness Merchandise
- iGive
- JustGive
- Marymount Manhattan College -Resident Hall Council Fundraiser in Honor of Daniel Licht
- Roemex Burns Supper in Memory of Cameron Barclay
- Roger zum Felde's Charity Dinner Fundraiser
- Sovereign Grant Alliance, Inc. - Bring Home a Cure Fundraiser in Honor of Nick Mahler
- St. Martin's In-The-Field Day School Bake Sale in Honor of Wayne Gopshes
- Stride to Cure FOP in Honor of Jordyn Bugarin, Miranda Friz, Wayne Gopshes, Justin Henke, Daniel Licht, Dilyn Martin, Nathaniel Padilla, & Nancy Sando
- W.I.S.E. Book Fair in Honor of Joshua Scoble
- Walk in the Woods to Cure FOP in Honor of Ian Cali & Whitney Weldon
- Whitney Weldon Golf Invitational in Honor of Whitney Weldon



Announcements

FOP Resource Center Giveaways

The Resource Center at the Fourth International Symposium on FOP featured many useful gadgets and tools. However, not all items or quantities were sold. Therefore, the IFOPA would like to offer FOP members the chance to win approximately 40 items. These items include personal care, dressing and grooming, cooking and eating items and much more. To view the items available, please visit:

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

To be included in the giveaway, FOP members must inform the IFOPA office of their interest in a particular item or items by calling (407) 365-4194 or E-mailing together@ifopa.org no later than September 30, 2008.

If only one person is interested in a particular item, then that person will receive the item. If more than one member is interested in a particular item, all names will be placed into a drawing for that item and the IFOPA will select a name randomly. The IFOPA will cover all shipping costs.

To request a printed copy -- to be received by mail -- of the giveaway items, or for more information, contact the IFOPA office via the information listed above.

Advocate Yourself or Your Child in the Medical World Binder

FOP mother Amanda Cali has developed an organization system (a "Medical World Binder") for medical documents that has proven invaluable in communicating information with the medical

community about a rare condition like FOP. Doctors who have seen the organized medical information have appreciated having this data readily available to them during appointments or hospitalization.

Medical issues are difficult enough with FOP. Having personalized medical information at your fingertips helps reduce stress and in some cases provides the opportunity for better care.

If you are interested in receiving this Medical Binder for your use, please contact the IFOPA office at together@ifopa.org or call (407) 365-4194.

Spencer Man Memorial Benefit Drawing

The Fourth Annual Spencer Man Memorial Benefit Drawing will take place in November 2008 and will feature some outstanding prizes. As an added incentive, Mike Man, father of Spencer Man and president of the Spencer Barnett Man Foundation of Oklahoma City, OK, will match the first \$4,000 raised by the event.

Look for more information soon in the mail or contact the IFOPA office via email at together@ifopa.org or by phone at (407) 365-4194. We hope you will join in and help make this year's drawing bigger than ever!

New *National Geographic* Book Spotlights FOP

A newly published book, *National Geographic Investigates: Medical Mysteries*, by Scott Auden, examines cases that have baffled the scientific community for years and features a chapter on FOP. The book is for high school students and is available in bookstores or at online retailers like Amazon.com.

International FOP Association

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