



Connection

International Fibrodysplasia Ossificans Progressiva Association, Inc. (IFOPA)

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A Latin American Experience

By Dr. Patricia Delai

The dream of a Latin American meeting started three years ago when I attended the symposium in Philadelphia. Dreams like this rarely come true, but thanks to many wonderful American families who raised the funds for it, this dream became a reality.

Since the last symposium, I've been writing to families in Latin America, the U.S. and to Dr. Frederick Kaplan. All these friends are a part of my life and a part of my days. I open my computer every day and they are all there. I learned to understand, love and respect them during the past three years.

My description of the meeting will be like a diary, so I won't forget anything.

Friday, October 17

All of my "computer friends" were about to come out from my computer and become real. The meeting was about to start. Forty-seven families from many Latin American countries would soon arrive.

The first faces I saw were Dr. Kaplan and Amanda Cali, who is a mother of a child with FOP. Their beautiful smiles made me feel the magic of a dream becoming true.

We met at the airport and went to the hotel, where we worked together to set up everything for the clinics. Families would be arriving soon and we wanted them to feel at home.

The presidential suite was perfect. There were two small rooms that we were going to use as waiting rooms and as a place to take the blood samples, a big dining room where Dr. Kaplan would meet the families, and a bedroom where the person with FOP would be examined.

The first family to arrive at the hotel was a multigenerational family from Brazil whom we found only a week earlier. It was clear how much the situation was new and strange to them. A strange city and strange people.

On the same night, Dr. Kaplan saw this family at clin-

ics. It was a magical experience for everyone. The family met a doctor who was working to help them and discovered that "that doctor" was much more than just "another doctor" and that he was an approachable man with a wonderful heart.

Saturday, October 18

This was a day full of surprises and emotions. Families were arriving during the day from many Latin American countries. Each new family, each new face arriving at the hotel, was like an old friend with a new look. They were now real. I could talk to them and look into their eyes.

At first they were afraid to meet each other, afraid of the things they would see, the things they would learn. Things like "Will this be my future?" or "This was my past." were going through their minds. They did not know that FOP is different from person to person, that no one is the future or the past of anyone.

Slowly, it was possible to see them talking to each other, having a little fun.

As I heard so many times from Amanda Cali, "Their lives were about to change forever."

Night came and now everyone was already at the hotel.

I opened the meeting with some words and a message from Ricardo Pistoletti, a friend from Argentina, who was not able to come, but wanted to show his support and give some strength to the families.

The main message of that night was, "This meeting is yours, make it happen."

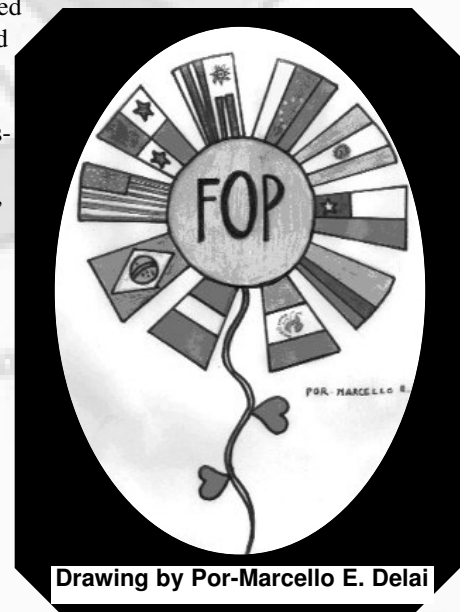
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Drawing by Por-Marcello E. Delai



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The International Fibrodysplasia Ossificans Progressiva Association (IFOPA) is a 501(c)(3) charitable organization that educates the general and medical publics about FOP, connects its members with newsletters and the web, and funds FOP research. The IFOPA was founded by Jeannie Peeper in 1988.

The *FOP Connection* is a quarterly publication of the IFOPA. 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. We do not, however, as an organization, 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! We hope that you will take a moment to let us know what you think of our newsletter, and what you would like to see in future issues. Please feel free to submit anything (articles, poems, artwork, suggestions, ideas) to FOPnews@aol.com. Thank you!

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Contributors: Robert Bonzelaar, Amanda Cali, Theresa Caruso, Amie Darnell, Dr. Patricia Delai, Por-Marcello E. Delai, Linda Daugherty, Ivan Garcia, Marilyn Hair, Melissa Helmick, Dr. Frederick Kaplan, Jeri Licht, Moira Liljestrom, Jeannie Peeper, Megan Pheif, Holly Pullano, Consuelo Ruiz, Jennifer Snow, Sarah Steele, and Gary Whyte

Meet Our New and Returning Board Members

Marilyn Hair, vice president,

has served on the IFOPA's Board of Directors for 10 years. Her positions have ranged from secretary to vice presi-



dent, and also, chairperson of the LIFE (Living Independently with Full Equality) Committee. Her daughter, Sarah Steele, 19, has FOP. Together, they attended all three FOP Symposia and appeared on several television programs about FOP, including 20/20 and Sally Jesse Raphael. Among other articles, Marilyn is the author of a five-part "Sarah Goes to College" column which appeared in the *Connection*. She holds a Master of Divinity from Yale Divinity School and is an ordained minister in the United Methodist Church. She and her husband, Rick Steele, celebrated their 25th anniversary last year. They have three children and live in Redmond, WA.

Holly

Pullano is a 23-year-old student from North Haven, CT. She studies journalism and sociology at Quinnipiac University in Hamden, CT. Her busy college schedule includes



serving as business manager and a reporter for her college newspaper, freelancing for several local papers and holding a part-time job at her father's construction firm. Holly was diagnosed with FOP at the age of 16, and over the years has been active on the IFOPA membership committee, involved in fundraising efforts and has written various articles for the *Connection*.

Jennifer

Snow has been a part of the IFOPA for ten years. Her 12-year-old daughter, Stephanie,



was diagnosed with FOP in March of 1994 at the age of three. Jennifer has supported the IFOPA through many fundraisers, two of which became annual events, now in their 10th years. She is the proud mother of two daughters, Ashley (8) and Stephanie (12), and lives on the central coast of California. She works with her husband and brother-in-law for their family business, Snow Construction, Inc. As busy as she is, she still finds time to actively participate in her children's activities, including Ashley's soccer team and Stephanie's involvement in 4-H, cheerleading and rabbit group. *

Thank you to Walt Whelan for his years of service as a board member. We appreciate all you've done to make the IFOPA a success!

Time-out for OT

With OT Melissa Helmick



Melissa Helmick, a registered occupational therapist, is waiting to hear from you! Her new column, entitled "Time-out for OT," will be geared toward answering any questions you may have about your occupational therapy concerns, needs

or curiosities. Melissa's nephew, Ian Cali, who is now 13 years old, has FOP. She said she has shared many adventures with him and therefore holds a special place in her heart for the FOP community. She is also a mother of two young daughters.

Melissa began her career in pediatrics in 1978. She has spent many years working in schools, developmental centers and doing home visits. Although her experience is with children, she is prepared to answer occupational therapy questions for all FOP members.

Please feel free to direct any question you wish to Melissa. She can be reached by email at helmickf@aol.com. We will publish your question and her answer in the next Connection so that everyone can learn her tips. Below is a question posed to Melissa by an FOP mother, and Melissa's answer follows:

Hello:

My son Manuel, who is 7 years old, is finishing the first grade at school. He has problems writing in his exercise book because he gets tired. I don't know if the tiredness is in his hand, because his mobility is still not good, or if the problem is in the position he must adopt to write, with an effort in his arm and back, since all those parts of the body are committed in the activity of writing. Since we are planning some changes to make his life easier, I wanted to ask you, what special equipment do you suggest for writing such as a desk or special pencils? Any comment in relation to this, would be welcome.

Moira, Manuel's mom

Hello Moira,

I am so glad you asked that question. Many children with FOP get tired from writing activities. My first suggestion is to wrap his pencil with foam so it is thicker than a regular pencil. Also, thicker pencil or markers at the store may help. Sometimes markers move across the paper easier than pencils, but using foam should be tried first,

Introducing LIFE

By Marilyn Hair

The IFOPA is proud to announce the start of a program to help members increase independence and quality of life. LIFE (Living Independently with Full Equality) Committee Quality of Life Awards will provide funds to help members obtain equipment and services. A Life Award could help purchase a wheelchair, lift for transferring to bed or chair, computer, home remodeling, vehicle, or it could pay tuition. This is the first time the IFOPA has been able to offer financial support to individual members.

Quality of Life Awards are available for up to \$500 per member per year. If the request is for a wheelchair, an award can be for \$1,000 and the member will be eligible for another award after two years. Awards are available to members whose dues are current or who have requested a sponsorship. Members must also look for other sources of

funding, including public school, health insurance, Medicaid, Department of Vocational Rehabilitation, family and fundraising, as appropriate.

Funds for the Quality of Life Award will come from designated funds in the IFOPA LIFE Committee budget. Families who hold fundraisers are invited to direct part of their fundraising dollars to support this new program.

For the application procedure, contact Marilyn Hair, LIFE Committee Chair, at marhair@earthlink.net or at 14809 NE 66th St. Redmond, WA 98052. Applications will be reviewed by the LIFE Award Subcommittee, which consists of Monica Anderson as Chair and Jo Holzer and Shay Williams as members. The subcommittee will be approving the awards. For more information on donating fundraising dollars, contact the IFOPA office at together@ifopa.com or call 407-365-4194.

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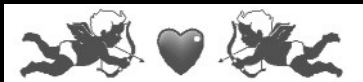
as each person is different. You made a valuable observation in suggesting that it may be Manuel's body position and not his hand that causes him to be tired. You might try to tilt his desk surface by using a book binder (three-ring binder). Book binders are books that have round clips in them that hold paper. Place the binder on his desk so the thick edge is away from him and the thin side is closest to him and place his paper on that. You may prevent the paper from slipping by using a paper clip, binder clip or tape. Sometimes tilting the work surface makes it easier for someone to see the paper and not get neck or eye strain. Another suggestion is to go to his school and try using pillows or foam on his desk seat so that he is more comfortable and at a better position to work at his desk. Manuel can tell you what is best.

If writing makes him tired, the teacher may want to encourage him to write in his exercise book, but not as much as the other children. He is still at a very young age for writing small letters between lines, so maybe larger lined paper would help. Let him practice at home making big letters on paper so he learns the movement better at a position that is comfortable for him.

Typing is a good change from writing if the school has a computer. If you try some of these suggestions and still have questions, please ask me again or email me directly. *

2004 Membership Dues

You recently received your 2004 Annual Fund and Dues Drive Appeal. Please remember to renew your 2004 membership dues. Your support is needed and always appreciated.



Happy Valentine's Day!

We are now one month from the First Latin American FOP Meeting and since the time I arrived in Brazil to attend this meeting, I have lived so many wonderful things. That is why I wrote everything, because these were unforgettable experiences, and to tell the truth, these experiences would never be possible without my friends Dr. Patricia Delai and Consuelo Ruiz.

When Dr. Patricia Delai invited me to come, I didn't believe it was true. I was saying to myself, "No one invites another person to go to another country like this!" and "Who will pay all this without knowing me?" With time, I had more contact with Dr. Patricia Delai and realized it was a reality. I didn't know what to answer. I became scared and nervous, but Patricia, with her dedication and patience, made me change my mind. I was always telling her that I was afraid

Looking Back at My Trip to Brazil

By Ivan Garcia

to attend the meeting and that many other people would be there. I said I didn't like to have so many people looking at me. I always thought people looked at me like I was a rare animal, and I never liked this. I didn't like to go out, to know people.

My family always insisted that I should go out, have new experiences. But, my favorite answer was "I don't want to".

I had doubts about coming to the meeting. My family and friends gave me strength to come, but the doubt was always inside me. Again, Patricia told me to be cool, that no one would look at me like a rare person, that I was a normal person and that this would be the opportunity to know more people with the same problem and to attend would be like being with family.

These words made me very curious and I decided to attend, but my main goal was to know Dr. Patricia Delai.

Less than two months before the meeting, we found out there were doubts about my transportation on the airplane. We didn't know if the airlines would help us with the trip. Then I met, first by e-mail and then by phone, Consuelo Ruiz, the meeting planner, who had the difficult task of making each one of us travel to Brazil in a safe and good way. We had a lot of contacts and I also wanted to meet her in person.

But, why meet these two women?

I wanted to know them, hold and kiss them, because I was forever thankful to them. I never thought that two people could give so much of themselves, their souls, bodies and hearts for a cause. This was my curiosity. It was impossible for me to understand how two women who didn't have an FOP person in their "blood" family could feel as if each one of us were part of their family.

I was feeling like a kid who wants to know his super heroes, but the difference was that I was not going to meet a super hero with his super powers. I was going to meet two wonderful women, made of flesh and bone, who were using affection, hope, comprehension and love for others as their weapons.

Today I will stop to think about the wonderful things I learned from the unforgettable First Latin American FOP Meeting.

This meeting made me see that there are wonderful people, a world to be discovered, and that there is nothing wrong on showing our feelings. I learned from this meeting that there are people that

give their hearts unconditionally, that our disease is not a reason to hide, and that we need to teach people and make them hear about it. If we do this, then tomorrow our disease won't be a mystery.



Dr. Patricia Delai and Ivan.

This meeting taught me that true friends exist.

It was a wonderful gift to meet people like Patricia, Consuelo, Amanda Cali (mother of a child with FOP), Dr. Frederick Kaplan, and all the people that work in the Blue Tree Towers Hotel in São Paulo. From the tables that the waiters kindly set up for me, I spent some time watching each one of those people, their faces, their love for each other, the hugs and their smiles when they came near us or were watching someone. Everything was incredible. It was incredible to believe in everything that was going on. It is hard to tell what happened during this meeting. It was possible to breathe air full of affection and friendship.

This event has changed the way I think and the way I see life. I am going home with new friends in my heart, new experiences, a new family, new targets and the big satisfaction that my wish became true because I knew and shared important moments of my life with Patricia and Consuelo. Now I know that we will always be united because true friends are forever.

I met many wonderful people, and I want to tell you about Celso (Consuelo's fiancé), who was always an inseparable friend with whom I shared so many happy moments. He will always be in my heart, like a father.

Cristina Ruiz, Helena, Marcelino, Fernando, Flavia, Kacciane, Claudette and many others are now in my heart too.

I am very happy to be part of the big work that was made by Patricia, Consuelo, Amanda, Dr. Kaplan and all those people that were related directly or indirectly with the FOP family. I want to do every possible effort to help the FOP family and the IFOPA. I wish that the ALAFOP (Latin American FOP Association) could become a reality. I will support, help and collaborate to have more meetings in the future and make people know about FOP so that in the future it won't be a mystery and people will have more opportunity than I have now.

I also want to mention the effort that many families put forth, donating money for this meeting. Without their support the First Latin American FOP Meeting would never have happened.

I want to thank the family of Dr. Patricia Delai too because they were an important part of this meeting. Her husband and children helped, supported and understood this great woman in her effort to go on with a dream.

On behalf of my mother, father, brother and my family I want to say that we will always be grateful. Coming to this meeting was a dream that became real.

You won't believe me, but I came to this meeting with only one wish, that was to know Patricia and Consuelo, and what happened? I now have a new life.

Is it impossible to believe? It is true. The First Latin American FOP Meeting changed my life.

I want to dedicate these words to my great friends Dr. Patricia Delai and Consuelo Ruiz. *

The planner behind the event

Consuelo Ruiz, event planner for the First Latin American FOP Meeting, held October 19-22, 2003, said that planning this event has changed her life forever. "For the first time in my life, I saw love in the air. People look for that in churches, temples and in Tibet. I found it in a business hotel."

Ruiz owns her own event planning company in Brazil called Consuelo Ruiz Eventos e Viagens de Incentivo. She worked for American Express Travel for five years as manager for groups and events before going off on her own two and a half years ago.

The First Latin American FOP Meeting was held in the Blue Tree Morumbi Hotel, with which Ruiz had already developed an established relationship. Through that relationship with the hotel, Ruiz was recommended to Dr. Patricia Delai, who was organizing the meeting. They started planning the meeting together about a year before it actually occurred, so Ruiz said she had plenty of time to learn about FOP, get to know the FOP community in the U.S., and become acquainted with the Latin American FOP community.

About six months before the event, Ruiz realized how involved planning this meeting would be. Some of her challenges were making sure all the people would have wheelchairs waiting for them at the airports, that the seats in the flights were adequate for each person's needs, for the planes and the hotel to

prepare to offer smooth and liquid food for people who needed it, that specific transportation accommodations be available for families once they were at the hotel and much, much more, along with the regular arrangements for big or special groups.



Consuelo Ruiz (left) and Dr. Patricia Delai (right)

Ruiz said her job was made easier by simply getting to know the Latin American FOP community. "After hearing about their stories and seeing their pictures, I got involved in their lives. But, when I met them at the event I was happy because I already loved them," she said.

Ruiz got so involved with the FOP community that she even opened her home to Ivan Garcia, an FOP member from Colombia, and his mother for the duration of the meeting. Ruiz said she was extremely impressed by both the strength of Ivan and his mother. "Ivan is a very special guy. He is so smart and funny. His mother is strong, nice and wonderful in every way. Together they have been fighting against FOP, and besides all the problems it can bring, they are winning their battles," she said.

Ruiz said she feels like she is a part of the FOP family and thinks the feeling may have been contagious. "The Latin American FOP community's lives have changed, but so have the managers of the hotel, the bellboys, the drivers, the valets and my staff. I know this because each one of them told me," she said. *

Facts about the First Latin American Meeting

Provided By Dr. Patricia Delai

- **Who Attended?** Nine Latin American countries were represented (Brazil, Venezuela, Chile, Argentina, Colombia, Panama, Uruguay, Mexico and Peru).
- **When it was held?** October 19-22, 2003. Clinics began on the 18th and ended on the 24th.
- **Where was it held?** São Paulo, Brazil at the Blue Tree Towers Morumbi Hotel.
- **What was accomplished?** It gave Latin American people a chance to learn more about FOP, so that they can discuss it with their

doctors. They all received a Portuguese guidebook and met Dr. Frederick Kaplan. Most families had never seen another person with FOP and they now know that they are not alone.

- **Why was it important?** 49 people with FOP were found in 3 years in Latin America. There has to be even more out there. More multigenerational families could be found by spreading the word about FOP research. It was also important because important blood samples were obtained, which will help the

FOP research team.

- **How many FOP members attended?** 43 people with FOP
- **How many people attended?** About 100 people total
- **What are the plans for the future Latin American FOP Association?** The Latin American association will start as a group only, until a country is found that would be best to host it in. There are representatives in each country who are responsible for expressing their will of having a Latin American FOP group. *

Background picture is the Blue Tree Towers Morumbi Hotel in São Paulo



WELCOME,



LATIN AMERICA!



Above: Silvia Helena from Brazil posed with hotel staff when she received her new wheelchair. Top Center: Group shot of everyone who attended the meeting. Right: FOP family from Chile.



Above: Adalson, from Brazil, received a reacher as a gift. Center: Consuelo Ruiz dances with fellow Brazil meeting attendees.



Top Left: Dr. Patricia Delai and Maria Claudia from Peru. Above: Gisela from Panama just got married to John (behind her), both posed with Patricia and Dr. Kaplan. Left and Below: Group shots taken during the special dinner. Bottom: Amanda Cali with a multigenerational family from Brazil.



Above: Dr. Kaplan reading a scrapbook from the Latin American FOP community.



NOTABLE QUOTES:

"I learned a lot of new things. I learned that you don't need much to have a lot of wonderful things. I learned that people can't look at others differently just because they have a difference in their bodies. We are all equal."

Cecilia Sofia Musso Wever
Argentina, 19 years old

"Not even in my more impossible dreams could I imagine what my eyes were seeing. People of all regions of Brazil, Argentina, Uruguay, Chile, Colombia, Venezuela and many other countries of Latin America were there. Children, youths and adults of all ages with their relatives, together to discuss and share about a problem common to all of us: FOP. I believe that a miracle is beginning to happen right before my eyes, and I see it for the entire world."

Jose Miguel Zolano
Brazil, 47 years old

"That meeting touched me in such a deep way. The human warmth and the spirit, the energy put together in that place for all of us with dedication and love goes beyond words I could express. You needed to be there to feel it and live it."

Gisela Happel
Panama, 34 years old

"To me, the FOP meeting was one of the most important things that happened in my life and my family's lives. Until one year and a half ago, I didn't know anything about this disease. I had many doubts about the future. Now I am more calm and more secure because I know what to do during an FOP flare-up. Now I know that I am not alone in this battle."

Marilea Bessa
Brazil, mother of FOP child, Mauricio, 9 years old

"I have a 45-year-old brother with FOP and he has a daughter with FOP as well. I had the pleasure to be with my niece during the First Latin American FOP Meeting. At this meeting, I met many people with FOP and learned how they live and how they face their disease knowing that it doesn't have a cure yet. I want to say that I and everyone else at the meeting not only learned more about FOP, but also more about the person we know who has FOP. Now, we know that our family grew."

Marly Rubio,
sister of Roberto Ribeiro Barbosa Junior, 45 years old, and aunt of Roberlene Barbosa, 18 years old

IFOPA On Fundraising

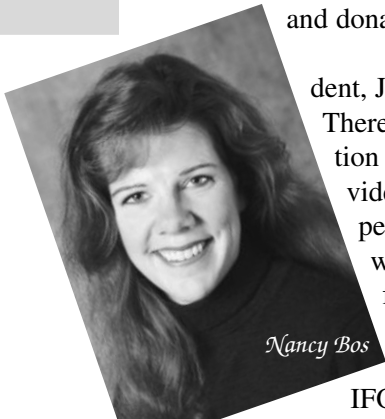
Recital held for Sarah Steele

By Marilyn Hair

Mezzo-Soprano Nancy Bos, Sarah Steele's voice teacher, offered her debut recital as a benefit for the IFOPA. Sarah Steele is a 19-year-old with FOP. The concert was held October 24th at Lake Washington United Methodist Church in Kirkland, WA. Sarah's mom, Marilyn Hair, made a brief presentation about FOP, and Sarah sang Andrew Lloyd Webber's *Any Dream Will Do*.

Nancy Bos performed a beautiful repertoire of classical and contemporary music in German, French and English, accompanied by Jan Navarro on the piano. A moving encore, Rogers and Hammerstein's *You'll Never Walk Alone*, was dedicated to Sarah and her family. The printed program included the lyrics to the music, biographies of Nancy, Jan and Sarah, and an IFOPA brochure and donation envelope.

Following the concert, Nancy's student, Judi Adcock, hosted a dessert buffet. There was a display of pictures and information about FOP and FOP research, and FOP videos were shown. Sarah's handcrafted pencil holders were offered for sale, as well. This was the first Steele family fundraiser. "It was a powerful experience to share the FOP story with the community and have people support the IFOPA," Marilyn said. *



Nancy Bos



Sarah's sister, Mollie Steele, standing in front of the display about FOP.

Another Successful Swimathon

The Third Annual Swimathon was held by the Bonzelaar family for 11-year-old Kyle Bonzelaar on August 13,



2003 in Jenison, MI. Robert Bonzelaar, Kyle's father, said it was quite a success. The Bonzelaar family would like to extend their gratitude to the Sunnybrook Country Club for having the event and to all the Sunnybrook Country Club members for their donations.

Special thanks goes to Ms. Kristen Degraaf and the pool staff for their help, and to Alanna Gerber, a friend of the Bonzelaar family, for obtaining the most pledges. *

\$A Research Proposal\$

Your help is needed now more than ever! As you know, we count on YOU, our generous contributors, to help us attain our research goals since the IFOPA receives no state or federal funding. This year marks a new height in research funding for the IFOPA as we try to meet the needs created by several recent events.

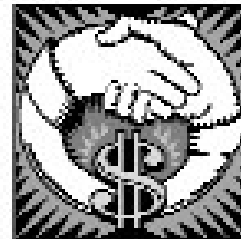
The National Institute of Health grant to the FOP Research Lab has expired and has not been renewed at this time. In addition, this year the IFOPA will start paying an overhead fee to the university, something we never had to do before thanks to the terms of the original grant set up

by Dr. Frederick Kaplan. Now that the current five-year IFOPA research grant has expired, the university wants the terms of the new grant to include some payment of overhead costs and the issue is currently being carefully negotiated. The 2004

IFOPA research budget is estimated at \$550,000, and an additional expense for overhead would raise our financial commitment even higher. Your support

is vitally needed at this time in order for us to meet our goals. Every dollar counts!!!!!!!

Please visit the *Ways to Help* section of our website at www.ifopa.org or contact us at together@ifopa.org for easy fundraising ideas. *



Hayden's Hope

By Megan Pheif

November 8th was almost a year to the day from when John and I first flew out with our son Hayden to Philadelphia to meet with Drs. Frederick Kaplan and David Glaser to learn about FOP. Hayden had been diagnosed with FOP in September of 2002. After our visit to Philadelphia, we knew that we didn't just want to sit around and wait for a cure. We wanted to take action and help raise funds for research. We started planning for a silent/live auction fundraiser in the town that I grew up in, Sausalito. Saturday, November 8, 2003 was the First Annual Hayden's Hope Benefit for FOP Research. It was the culmination of nine long months of hard work by our families and friends. The atmosphere was full of energy and excitement that even the torrential downpour could not dampen.

My younger sister, Sara, coincided the launching of Hayden's website, www.haydenshope.com, for the same day as the fundraiser. David Rossi of Smithwood Drive, generously donated his time, talent and creativity towards making Sara's idea of Hayden's website a reality.

The weekend started on Friday. My twin sister's father-in-law, Dr. Harvey Kaplan, arranged for Dr. Kaplan to speak at grand rounds at the Lucille Packard Children's Hospital, which is a part of Stanford Medical Center. It was a wonderful way to educate more of the medical community about FOP. At the same time, one of my best friends Michele Barnum, coordinated with the local NBC station to have them film Dr. Kaplan's presentation and interview him afterwards. The resulting segment was shown on local news a few days later.

The Sausalito Women's Club generously donated their clubhouse for the event. Local businesses donated or partially sponsored everything from the invitation design and printing, the beer and wine, the catering, all the way down to the tent that kept us dry from the pouring rain. It was very touching to see so many people come out and volunteer their services and time for Hayden and our cause.

With a jazz trio playing in the background, everyone munched on hors d'oeuvres and sipped cocktails, while bid-



ding on silent auction items. We had about 175 people attend and

were excited to have others from the FOP community join us. Matt Horrick, who has FOP, came down from Petaluma with his dad, Brian, and step mom, Nina. Joining them were Dr. Joe Kitterman and his wife Karen. We were also lucky to enjoy the company of Kelly Alexy who is the nurse that happened to be in the radiology room when the doctors were discussing Hayden's condition prior to his diagnosis. Because her sister was a teacher of a child with FOP, Kelly knew of the disease and asked the telling question, "Are his big toes deformed?" And the rest is history, as they say.

The evening really got animated when the live auction started. The most exciting bidding was for the US Postal Service Bike Jersey signed by Lance Armstrong and the Architectural/Engineering/Construction package which was donated by my dad, Don Olsen of Don Olsen Architects, my husband, John, of Pheif Engineering and Brian Horrick of Haack & Horrick Construction. The three of them actually had the distinction of raising the most money on a live auction item!

The night seemed to last forever and when the last people waved good-bye; we had raised enough money to fund two postdoctoral fellowships at the FOP Collaborative Research Laboratory. We look forward to next year's fundraiser with anticipation and optimism of being more successful than this year. *



Megan and Hayden (far left), Megan, John and Hayden Pheif (top), and Dr. Kaplan, Megan, John and Hayden (below) at the First Annual Hayden's Hope Benefit.



"There's something in a simple hug that always warms the heart; it welcomes us back home and makes it easier to part."

- Jill Wolf

TIDBITS

- Joni and Friends Family Retreats are currently open for registration. The retreats are held in the summer months in Pennsylvania, North Carolina, Texas, California, Indiana, Ohio, Georgia, Texas and other states

that are soon to be announced.

Family Retreats are five-day programs that refresh and strengthen families affected by disability. For more information, call 818-707-5664 or go to www.joniandfriends.org. These camps promote Christian values.

Sarah Goes To College

Sarah Sets Out, On Her Own

By Marilyn Hair and Sarah Steele

*This is the fifth and final column in the
Sarah Goes to College series.*

Sarah speaks:

The day before I moved to college, my mom asked if I was nervous. "No," I told her, "I'm excited. Some people say that college was the best years of their life." In late September, I moved to Seattle Pacific University (SPU), a 3000-student Christian college in down town Seattle, Washington.

I am taking 12 credits in fall quarter. Spanish and Freshman Seminar are each five credits. Intermediate Spanish is a lot of review since I took Spanish for five years in public school. Freshman Seminar requires writing a short paper every week. Learning to write at a college level is a challenge! These classes meet one after another from 8am to 10:50 am Monday, Wednesday and Friday. Freshman Seminar was scheduled to meet in a building that has stairs at the entrance and is far away from where my Spanish class meets, so the Disabled Student Services (DSS) office moved my Freshman Seminar to a room down the hall from my Spanish classroom. My third class is Women's Choir. It is a two-credit class, which meets Tuesday and Thursday in the afternoon. Fall quarter has gone well and I plan to take 15 credits during the winter quarter.

I live in a five-story dormitory called Emerson Hall. The dorm is three years old and has many nice features like a laundry room, gym, elevator, underground parking, suites with bathrooms, and a kitchen and

lounge on each floor. There are four floors for women students and one for men.

The Residence Life program organizes social opportunities for students who live on campus. Each dormitory floor has a Peer Advisor and a Student Ministries Coordinator. My floor-mates eat dinner together in the dining hall every Thursday. We have a floor discussion group that meets once a week, where we share our life stories. We drew names for "secret sisters." In the evenings, I join several girls to watch TV in the lounge. Everyone makes an effort to include me as much as possible.

The university has done a lot to make living on campus possible for me. They remodeled my dorm room, which has a roll-in shower and a drive-in closet. There is space for my wheelchair and equipment, and two single beds for my attendant and me. My room is on the first floor for easy access and emergency exit. It has a height-adjustable desk, and I drive my wheelchair underneath it to work at my computer. The Department of Vocational Rehabilitation (DVR) purchased my computer, a Gateway with a CD/DVD drive, plus computer adaptations that help me study. These adaptations include a cordless mini-keyboard, mini-trackball mouse, and Kurzweil 3000, which is reading, writing and learning software that lets me read textbook pages on the monitor, highlight text, and extract notes. The



Sarah outside of Emerson Hall.

computer can read the text to me with Kurzweil, even in Spanish. I also have a combination scanner/printer and handheld iPAC computer that downloads to the desktop.

I open my room door by swiping my ID card across the keyless entry pad. The barcode unlocks the door and it swings open. There's a switch on the wall, which I push with my wheelchair to open the door from inside the room. My attendants each have an ID card they use to unlock the outside door of the dorm and my room door when they come to work. There is an underground parking place reserved for my attendant.

I have an attendant with me all the time. My daytime attendant, Linda, is paid by DVR. She works 43 hours per week. Two attendants, Nabila and Kelly, work alternate nights Monday through Thursday; they are paid by the Community Options Program Entry System (COPES), a state program that provides personal care. I have one volunteer attendant who comes on Tuesday mornings.

I met Linda the day before classes started. The first week I felt uncomfortable with her because she laughed all the time and I felt like she was laughing at me. Maybe she was nervous. Finally we had a private talk and she told me not to worry about hurting her feelings, but to let her know what I wanted and what bothered me. She wanted us to have a good working relationship. Once I was honest, I have gotten used to working with Linda and our relationship has improved.

My overnight attendant Nabila works for a home health care agency and has been taking care of me since last spring. Kelly was one of my aides in high school. She is an Independent Provider and I am her only client. Kelly has a different job during the day and the hours she works for me depend on her work schedule at her day job. Once a week, she has to leave at 6:30 am, so I have to get up at 5:30 am and be dressed at 6:30 am when Linda arrives. I have to remember to go to bed early the night before or I fall asleep in class! Some evenings, Kelly comes at 7:30 pm, two hours after Linda leaves. My dad is a professor at SPU, and he stays with me until Kelly arrives. We eat dinner together.

I am happy to say there has not been a single time when my attendant has not shown up for work. A few times, an attendant has told me ahead of time that she can't come, and I have been able to rearrange the other attendants' hours or find a classmate or my dad to help me. Dad meets me at 5 pm on Fridays and I come home for the weekends. Sometimes I come to campus over the weekend with my dad or mom.

There are some physical accommodations and procedures for students who have disabilities at Seattle Pacific University. There are automatic buttons to open doors, as well as elevators in most of the campus buildings. The Mailing Services Department collects the mail from my student mailbox and I pick it up at the desk. When I couldn't find food I could eat for lunch, I met with the food service director. I suggested some soft,

protein-rich foods I enjoy, and they added tuna fish and egg salad to the lunch buffet. Also, I can register early for classes each quarter. This gives the DSS office time to scan my books and change room assignments, as it did fall quarter. Early registration allows me to get into the classes I want before they are filled.

There were bound to be some unexpected challenges in my move to college. The first week, I wrote a paper on my iPac handheld computer, and when I tried to download it onto my computer, the computer didn't recognize it, so I couldn't print it. I called DVR for technical support, but the paper had to be retyped so I could turn it in on time. Thanks, Dad!

Another challenge is getting enough sleep. I enjoy watching TV with my floor-mates until 11 pm, and I go to bed at midnight. The problem is that I have an 8 am class, and I was falling asleep in class. I've been taking a nap on weekend afternoons and going to bed earlier on the night before my 8 am class.

Once, my wheelchair broke down. I used my uncomfortable old manual chair while my mom took my Permobil power wheelchair in for repair. It took 10 days, three service calls, and an overnight delivery of parts, not to mention patience and perseverance from everyone, before the wheelchair was fixed. I was able to stay at college and didn't even miss any classes.

I love college. I'm learning and making friends. I'm also gaining important life skills like working with attendants, supervising my personal care, keeping track of my belongings, and managing my schedule. Living away from home is great. I'm having the time of my life.

Marilyn speaks:

"We are at the edge of the

waterfall, about to go over. Last night, Sarah's dad dreamt about falling over the brink. I dreamt that Sarah was attacked and nobody advocated for her when I wasn't there." This was my journal entry the morning my daughter, Sarah, attended her first college class at Seattle Pacific University.

The day Sarah moved into the dorm, I accompanied her to the US Bank to buy quarters to use in the washing machine. I was transported back to last February when Sarah opened her checking account. We chose US Bank because it had this branch location on the campus. The efforts of eight months ago made this transaction easy. Opening her bank account was one of dozens of preparations Sarah made to get ready for college.

Sarah spent the nights at home that weekend. She returned to campus Sunday evening to attend her residence hall meeting, and stayed overnight with her long-time respite worker, Somer. The next morning, Somer wrote this email: "I just got home from staying with Sarah, and we had a really good night. I think she was nervous because she was up at 3 am, and again at 4 am and 5 am. All the meetings went well. Sarah was quite the social butterfly going around introducing herself to people and talking it up with everyone. I stayed in the background and let her do her thing. We didn't get into bed until almost midnight. It was hard this morning

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leaving her as she went off. I almost started crying because I am so proud of her. I still don't believe she is old enough to be in college. You and Rick should be so proud."

Sarah's dad, Rick Steele, is a professor in the School of Theology at Seattle Pacific University. When he introduced himself to his students on the first day of class, Rick told them he is the parent of a freshman. A student raised her hand and asked, "Are you Sarah Steele's father? Sarah is on my floor. At the meeting last night, she volunteered you to be in the Emerson Hall Film Festival!" When Rick related this exchange, he added dryly, "Imagine my joy." But, he was smiling.

Sarah called me after the first day of classes. As I hung up, I said, "Talk to you soon." Sarah responded, "Well....maybe."

Making it possible for Sarah to move to college is the most gratifying thing I have ever done for her. Seeing her custom-remodeled dorm room, watching university staff welcome her, working with a team of providers (Social Security, Medicaid, Independent Living Center, and Department of Vocational Rehabilitation) is immensely fulfilling. But, it is a huge transition. Our parental roles have shifted. Rick is more involved in Sarah's daily routine. He drives the wheelchair van so he is available if Sarah needs transportation, and he stays on campus until Sarah's overnight attendant arrives. Sarah calls Rick when she needs help with her computer or wheelchair, or has questions about university procedures. Our schedule at home is differ-

ent, too. Weekdays are quieter and evenings are more leisurely, but the weekends are busier than ever. Sarah is tired when she comes home on Friday nights. She brings dirty laundry, a grocery list, and homework. I spend the weekend helping her get ready for the next week.

As Sarah said, there have been some challenges. I notified Social Security when Sarah moved to campus and SSI did a re-evaluation of Sarah's eligibility. SSI ruled that room and board costs more than a person who depends solely on SSI income can afford. Paradoxically, Sarah's monthly SSI check has been reduced by \$200. This is a penalty she will have to pay in order to live in the dorm.

Another challenge was the venue of the fall choir concert in the sanctuary of the campus church, Seattle First Free Methodist. The chancel has three short steps, an insurmountable obstacle for Sarah's power wheelchair. A university staff member built a ramp, and, on the night of the concert, I went with Sarah to try it out. It is a bulky contraption made from rough 2x4s, in sharp contrast to the polished oak woodwork in the sanctuary. I suggested that someone stand beside Sarah, to make sure the wheelchair didn't fall off the planks. After Sarah tested it, the ramp was dismantled and stored under the front pew until it was Sarah's choir's turn to perform.

During the concert, the men's choir filed in procession down the center aisle and up the three steps to the chancel. After their performance, the singers recessed, except for four tenors in tuxedos. The young men

assembled the ramp and stood beside it while Sarah drove down the center aisle, up the ramp, and onto the chancel. I could scarcely keep myself from applauding. It was a metaphor for the graceful approach the University has taken to meeting Sarah's needs.

There is postscript to this story: The sanctuary was remodeled last summer, and the architect was in the audience at the concert. He volunteered to design a permanent ramp.

The next concert was a Music Department Christmas extravaganza held at Benaroya Hall, home of the Seattle Symphony. Sarah sang Mendelssohn and Gounod with 200 fellow students. To see her on the stage of one of the finest concert halls in the world, before an audience of thousands, was stunning. We couldn't have imagined this kind of achievement 18 years ago, when Sarah was diagnosed with FOP.

Is all this effort worth it? Not everyone would say it is. I talked to my doctor about our work to help Sarah live at college. He responded, "Wouldn't it be easier just to let Sarah live at home?" After the University DSS Coordinator took an inventory of Sarah's needs, she said, "Do you think Sarah could commute?"

Making it possible for Sarah to go to college and live on campus takes tremendous effort from a host of people, including Sarah. We think it is worth it. Sarah is gaining freedom, independence, and higher education. Being able to attend college will raise her expectations of what she can do in life. As her dad said, "This is the best thing that ever happened to Sarah, and she knows it!" *

MEDICAL NEWS

- An article was recently published in The Journal of Bone and Joint Surgery entitled "In Vivo Somatic Cell Gene Transfer of an Engineered Noggin Mutein Prevents BMP₄-Induced Heterotopic Ossification" by Dr. Frederick Kaplan, Dr. David

Glaser, Dr. Eileen Shore and other colleagues.

The article can be obtained through the IFOPA's research center in the IFOPA office, or go to www.ifopa.org, click on resource center, and contact us by email to obtain a copy of the article.


answer for kid's korner - noche-día (night-day), frío-caliente (cold-hot), alegre-triste (happy-sad), rápido-despacio (rapid-slow)


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Tackling Job Interviews





We recently came across a question posed on FOP online concerning job interviews. To address this issue, we put together a list of interview tips for job seekers. Some of these tips directly relate to our FOP members and how they should go about telling potential employers all about it. Mainly, these tips were compiled to benefit the entire FOP community in order to help them tackle their next job interview!


 **Be Enthusiastic and Confident:** Show your interest in the job you are seeking and in the business. Look for opportunities to bring meaningful anecdotes about yourself into the conversation. Make sure they relate to your skills and abilities.


 **Be Yourself:** Don't put on an act. Being yourself can help you relax during an interview and cut down on stress.


 **Be Prepared:** Bring a copy of your resume with you to the interview along with anything else you feel the interviewer would be interested in seeing, such as samples of work you had done for previous jobs or letters of recommendation. Also, be knowledgeable of the organization you are interviewing with. Research the company thoroughly before the interview and come prepared with questions about what they do.


 **Be Honest:** Tell the interviewer about your work skills, strengths and experience. If you haven't had a particular experience, say so, but indicate your willingness to learn.


 **Look your Best:** You will never have a second chance to make a good first impression. Looking your best will make you feel more confident and more relaxed.


 **Practice with "mock" interviews:** Ask a few people to practice doing an interview with you. This will help you get comfortable with a variety of ways of how to answer, or how not to answer, some of the common interview questions.

 **Disclosure about FOP:** You will need to decide if and when to disclose facts about FOP. There are no hard rules on doing it. Disclosing this information will be a strategic judgment call on your part. More importantly then when you do it, is how you do it. Make sure that you are presenting yourself as an enthusiastic and qualified candidate first and someone with FOP, second. Open discussions could make the interviewing and hiring process easier and more comfortable for both the interviewer and the interviewee. Discriminatory behavior is often guided by misconceptions and unfounded fears.

 **Requesting Accommodations:** If you need accommodations, even just to interview, work with the employer/interviewer. Make it as simple as possible for them. You want to be someone who could be accommodated easily and effectively.

 **Relieving Tension:** You can do a lot to relieve the interviewer's tension. Be friendly and personable. You can still be professional by being relaxed. Humor is often a great way to break the ice.

 **Resolving Concerns:** Keep one goal in mind on an interview - give the interviewer the confidence that you have the ability to do the job well. Take it upon yourself to guess what the interviewer's concerns might be in relation to the particular job's tasks and tell them how you would carry out the duties.

 **What they CAN'T ask you:** An interviewer cannot ask you any specific personal questions, such as your marital status, if you have children or even disability-specific questions, etc. It is up to you to disclose that information. They may, however, ask you non-specific questions, such as if their hours of operation cause any inconvenience for you or how you would go about performing a certain job-related function. *



Inspiring Words About FOP

My little secret to keep my spirits up is to look at FOP in a way most people I know don't understand. You see, FOP is a gift to me. It was given to me for a special reason and I'm supposed to take this gift and embrace it.

My gift has given me the strength to overcome any obstacles I may encounter. It has given me a heart to love people for who they are and to not judge them before actually knowing them. It has given me a reason to want to speak my words and let the world know what great people there are with this special gift. In the end, FOP will help me more than hurt me. It can't hurt me much more, and I'm only 19, so I still have, hopefully, another 50 years to have good come from this gift. Don't let the gift turn into coal. Take it and show the world that it is yours.

By Amie Darnell,
19 years old,
diagnosed at age 4

Monday, October 20

The real meeting began. Faces were now different. It was possible to see more smiles and less of those scared eyes.

I opened this morning with a very basic presentation about FOP.

I guess you may be wondering how so many people from so many different countries were able to understand a presentation. Well, here we had the help of angels. Not only angels from the sky, but earth angels, the wonderful translators who did a wonderful job. For the first time at an FOP meeting, simultaneous translation was used and it worked very well. People could hear and understand what was being said in their own language.

After my presentation, Dr. Kaplan spoke to the families. He introduced the people who work in the FOP lab and told us about the research. Now, much more than just knowing what FOP was, families were discovering that there were people who care and work everyday to help them.

Families now understood more, learning more. Scared eyes were turning into wise eyes.

In the afternoon the clinical appointments continued. It is important to tell you that blood samples were being taken with the help of a nurse whom none of us will ever forget, Monica. Her kindness and love were enormous. She made every possible effort to get the blood samples without hurting the patients, and you could see her serious work trying to get veins that sometimes insisted on disappearing. Monica had the help of Augusta, a hostess who was in charge of preparing the blood samples to be sent to Philadelphia. Without these two women and the love they put in everything they did, blood samples would never arrive in the U.S.

Monday afternoon was also a great time for the families. Parents, adults and teenagers with FOP formed groups to discuss common issues. There were tears, emotions and laughter. Years of isolation were now ending and people could finally share their feelings.

At night we had an informal dinner. An official photo was taken in the middle of a lot of colored balloons. More and more smiles appeared. It was hard to find a scared eye.

A family was born.

Tuesday, October 21

Of course at this time, there were

a lot of questions to be given to Dr. Kaplan for a special workshop. The wiser you become, the more questions you have. On Tuesday morning, families had a meeting to prepare questions to be given to Dr. Kaplan and then answered in the afternoon.

After lunch, a big workshop about FOP and independence happened. Diana Carboni, mother of Maria Luiza, and Amanda Cali showed the families that life is possible, that although we don't have a cure for FOP yet, it is possible to live and be independent with FOP. Thanks to Jeri Licht, another mother of a child with FOP, who sent a lot of things for the meeting, families saw useful tools and had a lot of new ideas.

Wise faces, beautiful smiles and a new hope.

At the end of the afternoon, Dr. Kaplan answered questions, very intelligent questions that were answered with patience and love.

Night came. It was our special dinner night. I would call it "Special," with a big "S," because it really meant a lot to all of us.

The big dining room was decorated with 1,000 golden paper birds (cranes), an origami work called "tzurus," which is a Japanese word for cranes. There is a legend in Japan that says that when you fold 1,000 cranes and make a wish, this wish will come true. During the past year, I folded 1,000 cranes for FOP, and now they were all falling from the ceiling and decorating the tables.

I know you all want to know what my wish was. It was, of course, to find a cure or treatment for FOP.

Speeches, homage, tears, laughter, gifts. It was a room full of brothers and sisters who were all full of smiles. Scared eyes were now impossible to find.

Everyone who was there on that night said there was energy in the air that they had never felt before.

The people who were working at the hotel (the waiters, hostesses and maids) were working with smiles on their faces. I could see waiters cutting food for those who could not cut it themselves, making special arrangements to make everyone feel good and special. People who got paid for their work were not working for money anymore. They were working for love.

Well, I have to stop my description for a moment. You must be wondering

who did all this? Who worked on the meals, decorations, hired translators and bought the airline tickets? Of course there is a person behind it all. It was a person who was much more than a meeting planner, a real friend. This person, Consuelo Ruiz, was the one behind the scenes, the person who made this dream real. Without her work and her love, this dream would never have happened.

Consuelo is a name synonymous with sincerity, perfectionism, love, compassion, friendship and understanding. She is a friend who will remain in our hearts.

Wednesday, October 22

Wise people met again. This time, we talked about the creation of a Latin American FOP Association. Of course, it will take time to start it, but strength and will were present, and we are all sure that this family will get there.

Time to say goodbye. It was time for me to hide too, because I had tears in my eyes just watching them leave. Hugs, kisses and words of love.

People were returning home with a smile, a guidebook, a directory and an emergency card. Thanks to Diana Carboni, Moira Liljeström and Gisela Samudio for their help with translating, and to Sharon Kantanie who helped with preparing the guidebooks and directory. People who arrived days ago without knowing anything were now going home different.

Their lives were now in their hands.

Promises: "One day, my friend, I will meet you again."

One by one, they were leaving the hotel, going back to their homes, to their lives.

I would meet them again in a few days, this time in my computer.

The last ones to leave were Dr. Kaplan and Amanda Cali.

The lights were off. The show was over.

But it was only over here at the Blue Tree Towers Hotel in São Paulo, not inside our hearts and minds.

The sensation of the accomplished mission and the feeling that there was much more to be done lived in our hearts.

We have many more dreams to dream, many more missions to accomplish.

Now, we (the FOP community) are a larger group. I am sure that this is just the beginning... *

NJ and NY Recognize FOP

The New Jersey State General Assembly in Trenton passed a bill on December 15, 2003 that urges the Department of Health and Senior Services to encourage research and awareness within the New Jersey health care community for FOP and recognizes 2002-2011 as National Bone and Joint Decade (a proclamation that President George W. Bush issued in March of 2002). On May 19, 2003 a similar bill was passed in the New Jersey Senate.

New Jersey Assemblyman Joseph Cryan introduced AJR-46, which was passed in December, and New Jersey State Senator Thomas H. Kean, Jr. introduced SJR-43 in the Statehouse last May. AJR-46 was unanimously passed in the assembly with 80 votes, and SJR-43 was unanimously passed in the Senate with 37

votes.

Also, New York City Councilman Michael E. McMahon declared February 2004 as FOP Awareness Month in New York City. The borough of Staten Island recognized January 2003 as FOP Awareness Month throughout the borough, and sometime in the early part of 2004 there will be a Joint Resolution in the New York state capital in Albany by New York State Senator John Marchi and New York Assemblyman John Lavelle.

Gary Whyte, of New Jersey, who is FOP member Whitney Wheldon's friend, has taken on the campaign to significantly increase awareness of FOP and to promote the need for more research. He has made presentations on FOP in clubs, churches, temples, to community groups, mayors, US congressmen, US

senators, NJ state senators, NJ state assemblymen, New York Governor Pataki's office, to the Office of Health under New York City Mayor Michael Bloomberg and to numerous New York City councilmen and assemblymen. In addition, there have been three Congressional Record Statements given on the House floor in Washington, DC.

During the FOP Awareness Campaign in 2003, Whyte was able to secure a Proclamation or Resolution from 216 mayors across the state of New Jersey who declared their support for further research and awareness into FOP, as well as their endorsement for the National Bone and Joint Decade.

For more information on Whyte and on the Bone and Joint Decade, go to www.boneandjointdecade.org/usa and click on News. *

Learn some Spanish vocabulary as you try to connect these Spanish opposites!



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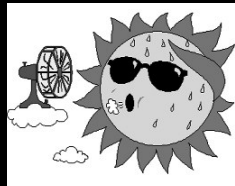
rápido



día



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despacio

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