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IFOPA
International Fibrodysplasia Ossificans Progressiva Association

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FOP makes Washington plea

by Eyal Goldshmid
photos courtesy of Todd Kaplan and Linda Daugherty

Taking on the Capitol: The IFOPA/USBJD reception was held in the Lyndon B. Johnson Room in the Capitol building.

July 13, 2005 marked FOP's first monumental foray into national politics. IFOPA organizers and members held a "Friendraiser" reception (as opposed to a fundraiser) with national politicians in Washington, DC as a means to increase FOP awareness and research funds. Eight FOP patients and their families attended the event, including Monica Anderson, Ian Cali, Steve Eichner, Sophia Forshtay, Daniel Licht, Holly Pullano, Kim Shields and Whitney Weldon.

The event, hosted by Senator Frank Lautenberg (D-NJ) and Senator Rick Santorum (R-PA), marked a culmination of recent efforts by various IFOPA members and families who shared the vision to have FOP represented on Capitol Hill.

"The experience was humbling, impressive, and exciting all at once," said Jeri Licht, mother of Daniel. "Everyone in the FOP community owes a huge debt of gratitude to each and every person who worked so hard to make this reception such a grand success."

The day was marked with many special guest appearances, including co-hosts Senators Lautenberg and Santorum. Other senators that stopped in during the reception included Jon Corzine (D-NJ), Lincoln Chafee (R-RI), Craig Thomas (R-WY) and John McCain (R-AZ). Each of the senators wore a green FOP awareness bracelet, spoke of their support for FOP and posed for a picture with the FOP patients.

In addition, both U.S. Marshal George Walsh and author Carol Higgins Clark were in attendance. Clark inspired the audience with a wonderful speech about moving forward from this event and not giving up in our fight for a cure and treatment.

Senator Hillary Clinton (D-NY) also made an appearance to receive a brief about FOP and a green

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More photos from the event:

Political power: FOP patients share the spotlight with Sen. Rick Santorum (R-Penn.), left.

bracelet. And if that weren't enough, the Weldon family also met two additional senators, Senator Olympia Snow (R-ME) and Senator Lindsey Graham (R-SC), during their dinner following the reception.

"I appreciate the opportunity to host this bi-partisan briefing to raise awareness for this rare disease," said Senator Santorum. "FOP is a terribly debilitating disease which unfortunately has no known treatment or cure. I was pleased to learn more about the various research that is being done to advance the options for children and adults suffering from FOP, particularly that of Dr. David Glaser at the FOP Lab at the University of Pennsylvania. His research holds the potential for curing other bone maladies such as arthritis, osteoporosis, bone spurs and spinal cord injuries."

Another highlight of the reception was a speech given by Holly Pullano, an adult with FOP and a member of the IFOPA Board of Directors.
"She was a glorious representative of people coping with the difficulties of FOP as she asked for financial support from the government with passion, dignity, and just the right amount of FOP details," Licht said.
According to IFOPA Chairman Amanda Cali, the "friendraiser" was the result of Gary Whyte's tireless work on behalf of FOP that led to the reception in Washington.

"Gary Whyte's work supplied the foreplay to what we're doing on the national level, getting mayors, assemblymen and senators signing proclamations on behalf of FOP in New Jersey and New York," Cali said. "Then Hillary Weldon and her daughter Whitney were asked to represent the disease and tell the Senators and Congressman about FOP. That's where I came in."

In order to make the reception a reality, Cali joined forces with Whyte, the Weldon family, University of Pennsylvania FOP researcher Dr. David Glaser, IFOPA Executive Director Linda Daugherty and officials from the United States Bone and Joint Decade. Together the group forged forward with the plan to get FOP to Washington.

One of the first steps in this process was the decision of the IFOPA to hire George Sifakis of Axela Government Relations LLC to represent the IFOPA in Washington DC. Sifakis and the group immediately began discussing how the team could secure federal funding outside of the National Institute of Health for FOP research.

Holly Pullano, an adult with FOP and a member of the IFOPA Board, addresses the crowd.

Other actions included the advocacy of additional funding and

USBJD and IFOPA representatives, doctors, U.S. Marshal George Walsh, Sen. Rick Santorum and George Sifakis gather for a group photograph.

Senator John McCain with IFOPA members and George Sifakis at the reception.

Carol Higgins Clark with Sen. Rick Santorum show off their green FOP bracelets.

overall awareness of FOP, as well as a letter campaign that has so far resulted in more than one thousand mailings and emails. In addition, Cali hoped Sifakis would help to get federal commitment to assign funds to the FOP lab at the University of Pennsylvania through the appropriations bill.

"We have had great success communicating the details about FOP to members and staff on Capitol Hill, which we feel is extremely important in our quest for more federal funding for FOP research," Sifakis said. "We are hopeful that through our efforts, Congress will consider appropriating additional funding to FOP research. We see our efforts in raising awareness on Capitol Hill as having a major impact on the funding of FOP research and to raising overall awareness of FOP."

"When Amanda Cali gathered all the other FOP moms around her with our green bracelets raised in hope, it was another major emotional moment that made an impact similar to Holly's speech," Licht said. "Our family left with the hope that the future funding of FOP research will include some Federal support and feeling honored to have been a part of this remarkable event."

Dr. David Glaser was equally hopeful that the efforts pay off in order to benefit those with FOP.

FOP moms show their team spirit with Sen. Richard Santorum (R-Penn.) and Sen. Craig Thomas (R-Wyoming).

"We would like the money to fund the research effort," Glaser said. "My hope is that the money will go to offset the money we get from private foundations and families. The government doesn't fund events, only lab fees, so the money we receive has to go to labs and such. But if we can get money, it will give some relief to the families supporting much of the research. It will leave more money to be used by those same foundations and individuals for events the government will not fund, including IFOPA operations and family events and help in fund other items, such as education and awareness programs, supporting research in other programs and get-togethers and symposiums."

Just as optimistic was FOP patient, Monica Anderson.

"I was so excited about being a part of this special day, and I was so happy to be involved," she said. "I was so surprised that so many senators came to hear about our cause. It makes me feel that something positive will come from all of this, and I am praying that a bill will be written to give us federal funding for our foundation."

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Hillary Weldon with Senator Frank Lautenberg.

Whitney Weldon, Sen. Lincoln Chafee and Ian Cali sporting their FOP bracelets.

(L to R) Gary Whyte, George Sifakis, Dr. Peter Armstrong, Sen. Jon Corzine, Amanda Cali, Dr. David Glaser, Dr. David Spiegel, Carol Higgins Clark, Dr. Eileen Shore, U.S. Marshal George Walsh, and Hillary Weldon.

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