



Newsletter
2006

PRESIDENT'S MESSAGE 2006

Greetings to all of our Florida Cleft Palate Craniofacial Association members as we head into Fall 2006! There is plenty of good news to report regarding the 2006 operations of FCPA. First, we have contracted with a new office manager to centralize records and manage our website. Please welcome McGee Group's Mel Friedman aboard as an integral member of the team! As we prepare for our 2007 Winter Symposium, Mel continues to improve the website with the aim of setting up on-line registration for the 2008 symposium, one of our FCPA goals.

Our 2007 Winter Symposium will be held in beautiful Coral Gables. This is the first time in many years that it has been held in the Miami area and we look forward to an outstanding 2007 conference lead by our vice president, Mislen Bauer. Registration forms are available to print on-line along with conference information.



With the help of our accountants, we now have complete knowledge of our financial standing. Currently, we are in the process of raising membership dues slightly for the first time in many years, in an effort to meet our budgetary minimum. For the first time in FCPA history we have a Programmatic Budget that allows FCPA Executive to make clear financial decisions in each area of our operations. The budget, along with our increased dues, will take us out of the negative cash flow situation we are currently experiencing. By recommending both of these actions, the finance committee has taken a very positive step toward ensuring that FCPA remains an ongoing presence in Florida. In addition, we have initiated a grass roots effort to form a fund-raising branch of FCPA to support our website enhancements, scholarships and grants programs, as we no longer receive direct state support. Anyone interested in this effort should contact the current FCPA President.

An area that continues to need discussion is the relationship between FCPA and the Family Network at UF. Several members have voiced confusion over this relationship and wonder at the need for FCPA to increase dues and raise funds. The Family Network at UF has been funded by Children's Medical Services for the purpose of providing ongoing support to families living with craniofacial differences of all kinds. FCPA originally set up the family network, as a sub-contractor to UF, and has, since ceasing as sub-contractor, maintained a very close relationship with the Family Network at UF. The Family Network at UF actively supports and sponsors the Family Conference portion of our FCPA Winter Symposium, sponsors nursing participants and buys lunches for family participants. We are two separate entities, especially with regard to funding, though we have the common goals of improving the lives of cleft-affected families. FCPA currently receives no direct funds from the state, or from the Family Network at UF, in the way of grants or contracts.

I'd like to take this opportunity to thank the FCPA and its members for giving me the wonderful opportunity to serve as President in 2006. I would like to personally invite each of you to come and enjoy the Winter Symposium in Coral Gables. Finally, a special thanks to the Executive Committee for their hard work, dedication and support!

Wishing you a happy and successful 2007!

Bobby Brasher, ARNP
FCPA President

FCPA

Website:
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FAMILY PAGEBy Lyubov Yenatska and Margie Wells-Friedman

As usual Florida families of children with clefts or craniofacial anomalies benefit from two state camps. The following is a very brief summary of what can be experienced at each of our state camps, at no cost to our families, thanks to the Family Network at UF and DOH Children's' Medical Services with referrals of families by teams throughout FCPA's Florida teams. FCPA is proud to have our membership and families involved in these unique experiences.

NOVA CAMP:

The Nova camp "Everyone is a Star" (June 2-4, 2006) was prepared and organized this year by Seth Green and his parents Arthur and Shelley. This camp was especially memorable as it was to be the last time for the Green family involvement. From the moment the families arrived they were surrounded by love, care and fun. There were many exciting events happening, both day and night. Every child wanted to try and enjoy each activity including games, sport competitions, crafts, doll making, tie dyeing, a



talent show, a visit to the Dolphins football training grounds, dancing, and even hosting a "real" impromptu wedding, organized by the campers for Seth Green and his fiancée. This turned out to be a bit of a "dress rehearsal", as the two were officially married two weeks later.



Parents were very appreciative of all the guidance, support and advice they received during the

meeting from professionals, representing two craniofacial teams in the South Florida area. Most importantly though, the families expressed their gratitude for the great time they had at camp seeing their children as happy, active team members, winners, and performers on the stage, as "stars"! Thanks to the Florida Department of Health, Nova University and the University of Florida. A special big thanks goes out to the Green family. At Nova, camp is really a place where everyone is a "star"!!

BOGGY CREEK CRANIOFACIAL CAMP:

Boggy Creek Craniofacial Camp is held in May every year. The Department of Health, Camp Boggy Creek Administration and many generous contributors provide this great experience at no charge to the families who come. Boggy Creek, located in Central Florida, close to Eustis, is one of the best camping facilities in USA. It has been hosting groups of families of children who were born with cleft lip and/or palate and other craniofacial differences one weekend each year since the very beginning of the camp's existence in 1996. Parents can see all the detail about the camp at www.boggycreek.org and apply to participate next year directly to the Camp Boggy Creek. You may fill an application form on line, may request it by calling (352) 483-4200 ext 252 , or fax (352) 483-2959, or by writing to: Camp Boggy Creek, 30500 Brantley Branch Road, Eustis, FL 32736.





FAMILY PAGE(Continued)

2006 PARENT SURVEY REPLIES (All were positive so here is just a sampling:

“Our Craniofacial Camp Experience”

- We would beg to come every year but want too much for others to have the same experience. We had a great time. Loved it! Funtastic!

“Evening Activities and Entertainment”

- Great effort and energy went into these. We thoroughly enjoyed them.
- The gym experience was the perfect icebreaker – Samantha’s little calm shell opened because Kelly and Rob took the time to help her through her fears before moving on with the crowd.



“Activity Areas”

- Quality and quantity. Awesome workshop. Fishing was the highlight.
- We had a great time doing the arts/crafts and woodshop. There was a great variety of things to do for the whole family. Everywhere my kids went we had to drag them away. The kids have a blast and not only do they take home memories but crafts too.

“Parent’s Night Out”

- This was awesome – it gave the parents a time to kickback and relax (which we don’t get a chance to do very often).





American Cleft Palate-Craniofacial Association Annual Meeting Vancouver, Canada April 3-8, 2006

As you can see, quite a few FCPA Members (several not captured photographically) managed the long flight to Vancouver this past spring for the annual ACPA professional meetings and festivities. The professional portion of the convention, city and surrounding countryside were magnificent.

Highlights of the convention included:

Pre-Conference: Speech, Growth, Occlusion and Appearance on the first two days focused on early speech and orthodontic intervention, timing and staging of surgeries. Our own Dr. Sam Berkowitz presented during this event. A cogent and controversial closing keynote address was made by Ron Strauss, DMD regarding the social values, moral, legal and ethical issues as well as healthcare policy issues related to how society and individuals deal with decisions regarding giving birth and treatment after birth. Dr. Strauss handled this delicate discussion with his usual finesse.

Pre-Conference: Nuts and Bolts for Nursing on the second day proved meaningful and beneficial to the nurses in attendance. Experienced ACPA members and our own Bobby Brasher, ARNP presented to attendees.

General Sessions: The last four days were devoted to general group sessions and individual profession sessions to update attendees on the latest and greatest innovations in cleft care or to give newcomers a foundation of information from which to begin their learning. Advances in tissue engineering, Furlow Double Z plasty, velopharyngeal gap size, mandibular distraction and countless other topics were presented and discussed. The information is entirely too vast to include in this format



Memories:

Memories were also made at social events such as the Gala at the Vancouver Aquarium with the Beluga Whale Show and room after room of exhibits and food. The event to support the Cleft Palate Foundation was a scenic Dinner Cruise around Vancouver and vicinity at sunset and beyond. If you ventured away from the convention to walk through Stanley Park, ride a gondola up Grouse Mountain, visit the local gardens,



galleries or museums or eat in the many gourmet restaurants then you were duly rewarded. This was an ACPA site that was memorable indeed.

Next Year:

If you have been encouraged by the above to attend next year's meeting it will be held at the Omni Interlocken Resort, Broomfield, Colorado. It promises to be a memorable experience as well. Go to www.acpa-cpf.org.

SCHOLARSHIPS AWARDED

The FCPA scholarships are awarded annually to 2 deserving Florida High School seniors with cleft or craniofacial conditions, who have been nominated by members of FCPA and admitted to an undergraduate college or university. The students with the highest commitment to community and those with the best scholarly effort are chosen by committee for this award.

One scholarship was awarded to Emily Silcox of Lake City. Emily studied AP and Honors college prep courses in high school and was ranked third in her class. Her extracurricular activities included volunteer work at Craniofacial Speech Camps, Leo Club community service and leadership as well as dance. Emily is attending the University of Florida and majoring in Communication Sciences and Disorders to become either a speech-language pathologist or a doctor of audiology. She wants to work mainly with craniofacial children, because of her life-long connection.



The second recipient of an FCPA scholarship was Iva Ballou of Jacksonville. Iva has also studied college prep courses in high school and been involved in a large number of and a wide variety of charitable causes. These include: Girl Scouts, Journey into Womanhood, Girls Inc., Religious Affiliations and Volunteer Jax. Congratulations Iva on your future plans to become a physical therapist.

To apply a student must be nominated by members of their cleft/craniofacial team. Applications for 2007 are available from FCPA at P.O. Box 4203, Deerfield Beach, FL 33442 or on the website at www.floridacleft.org.



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FCPA ANNUAL SYMPOSIUM 2007

Join us January 12-14, 2007 at the Colonnade Hotel in beautiful Coral Gables, Florida. The hotel is located at 180 Aragon Avenue, Coral Gables, FL 33134. You can visit their website at www.colonnadecoralgables.com directly at (305) 441-2600. The FCPA reduced rate is good for reservations made prior to December 31, 2006.

KEY NOTE SPEAKER: Dr. Michael H. Carstens, medical director of plastic surgery at Cardinal Glennon Children's Hospital and associate professor in the plastic surgery division of the St. Louis University School of Medicine. Topics include the Developmental Anatomy of Cleft Lip and Palate and the Clinical Approach of Bone Morphogenesis Protein in Plastic Surgery.

NEW MEMBER RECRUITMENT

Recruit new members by:

1. Calling your team members and encouraging them. Help them log on to www.floridacleft.org today.
2. Offer to share a room or drive together to reduce room and parking costs at FCPA's Winter Symposium.

SMALL GRANT PROGRAM!

Grants for new team projects or ideas are available for up to \$1500 and can be applied for yearly. Grant applications are available from FCPA at P.O. Box 4203 Deerfield Beach, FL 33442 OR on line at www.floridacleft.org. You can also obtain applications at the annual meeting during the Winter Symposium.

CONTACT US!

You may contact FCPA by e-mail at info@floridacleft.org, or by writing to

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