



# NEWS letter



American Cleft Palate-Craniofacial Association

1504 East Franklin Street, Suite 102, Chapel Hill, NC 27514

CLEFT PALATE FOUNDATION

VOLUME 30, Number 4

Winter 2004

## Myrtle Beach, South Carolina to Host the 62nd Annual Meeting

By Carlos Salinas, DMD  
2005 Local Arrangements Chair

*The Atlantic Ocean...  
Miles of white sand beaches...  
World-class golf courses...  
Oceanfront resort...*

On behalf of the 2005 Local Arrangement Committee it is my pleasure to invite you to ACPA's 62nd Annual Meeting to be held April 4-9, 2005 at the Kingston Plantation in Myrtle Beach, South Carolina. Myrtle Beach is a beautiful seaside resort located in the heart of the 60 mile coastline known as the Grand Strand. It is home to over 120 golf courses, several of which are ranked top in the country. Flying to Myrtle Beach is quick and effortless with many well-known carriers including AirTran, ASA/Delta/Comair, Continental, Spirit, Northwest, Vacation Express, USAirways, and the lesser known Myrtle Beach's own Hooters Air!



*Myrtle Beach, SC — A Seaside Resort at the Heart of the Grand Strand.*

The scientific meeting is being held at the world-class resort Kingston Plantation. The 255 all-suite oceanfront Embassy Suites Hotel offers beautiful views, the comforts and amenities of home, and a daily complimentary buffet breakfast and nightly complimentary access to the state of the art 50,000 square foot sports club that offers an indoor lap pool, lighted tennis courts, racquetball courts, aerobics studio, weight training and cardiovascular equipment, sauna, whirlpool and locker room. The SPLASH! Beach Club facility, open to all guests, is perfect for family fun with a huge water playground, PGA putting green and volleyball court. The Arcadian Shores Golf Club, designed by leading course designer Rees Jones, offers natural beauty and challenges for every level of player, and has long been a favorite of Grand Strand golfers. Kingston Plantation offers an on-site "Golf-Concierge" who will help map out and coordinate the golf experience that is right for you.

Myrtle Beach can be whatever you want it to be. If you are looking for a relaxing coast ambience, you never need to leave the gated Kingston Plantation for superb beaches, beautiful sunsets, early morning strolls along Plantation paths, and great golfing. For a more energetic experience, a dozen theaters hosting country music, variety shows and national comedy acts, numerous amusement parks for the whole family, fishing piers and nightclubs are all within a few miles. For the shoppers among us, malls and the best selection of outlet stores abound. Myrtle Beach boasts the newest and largest mall on the East Coast – the Coastal Grand – with over 1 million square feet of shopping space!

For our more adventurous members, just one hour from Myrtle Beach is Brookgreen Gardens; one of the country's leading cultural and educational institutions and a National Historic Landmark. It includes the Lowcountry History and Wildlife Preserve,

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## For Your Information

The Newsletter of the American Cleft Palate-Craniofacial Association and the Cleft Palate Foundation is published four times each year. Publication dates will be February, May, August, and November. Materials for the February 2005 publication must be received by January 1, 2005.

Information of interest to the membership, including editorials and meeting announcements, should be sent to the ACPA Communications Officer, David L. Jones, PhD, University of Wyoming, Division of Communication Disorders, P.O. Box 3311, Laramie, WY 82071-3311. Phone 307-766-5712, fax 307-766-6829, email: dljones@uwyo.edu. Classified advertising space is available for purchase. Contact Rafael Goldberg, Member Services Coordinator, membership@acpa-cpf.org or 919-933-9044 for more information

## Myrtle Beach to Host Meeting

(continued from page 1)

the Huntington Sculpture Garden and the Center for American Sculpture – the largest open-air museum in the U.S. Here you may travel back in time through maritime and longleaf forests and let your imagination open a door to the past. Ride along an oak-lined avenue to view remnants of a plantation slave cemetery. Climb aboard a pontoon boat, glide through natural creeks and enjoy a magnificent view of the Waccamaw River. View long-abandoned fields where over time thousands of slaves labored to produce millions of pounds of rice. The Carolina Gold as it was known was the basis for an entire way of life that vanished after the Civil War.

Finally, for the city lovers, Charleston is a two hour drive by car. A historic and charming city, Charleston is a special jewel of the South that everyone should have a chance to visit. The Charleston preservation society has done a magnificent job keeping an extended part of the Charleston peninsula practically as it was two centuries ago. The early American architecture with occasional French influence is seen everywhere. The well-kept gardens add a

touch of simple elegance. Charleston is a friendly-walking city with good restaurants that fit your budget.

Our social events will be reflective of Myrtle Beach traditions. Our Friday night “Beach Party at the Pavilion” will be a casual party on the Kingston Plantation grounds. A live band will help us dance the night away! Be prepared to dance the “SHAG” — a traditional smooth, cool, dance from the '50s that has recently risen in popularity south of the Mason Dixon line.

The Local Arrangements Committee is excited to host a resort experience that the attendees of the American Cleft Palate-Craniofacial Association's 62nd annual meeting will cherish for a long time to come. In April we enjoy pleasant spring weather with an average high of 75°F and 70% sunshine. The azaleas will be blooming to greet you upon your arrival! We know you will enjoy learning about the South Carolina heritage, seeing its natural beauties, meeting its gentle people, and experiencing its well known Southern Hospitality!

Look forward to seeing y'all real soon!

## Introducing the ACPA Service Center



We are pleased to introduce you to our newest website feature, the **ACPA Service Center (ASC)**.

In the **ASC**, you can pay your membership dues and register for ACPA events online, as well as access heaps of “members only” content. To access the **ASC**, go to [www.acpa-cpf.org](http://www.acpa-cpf.org) and click the “Members Only” link.

When you access **ASC** content you will be required to “login.”

### ACPA Service Center Login Instructions:

**User ID** = your 5 digit ACPA Member ID Number. Your Member ID Number can be found at the top of your ACPA Newsletter Address label, above your name on your ACPA Dues Invoice, on your Journal Address Label, or by emailing or calling the National Office.

**Password** = the first 4 characters of your last name PLUS your Member ID Number. If your last name has less than four characters, use your entire last name.

Examples:

EX1: If your member id= **98765**, and

your last name= **frankle**, then your ACPA Service Center User ID = **98765**, password = **fran98765**

EX2: Member ID = **23456**, last name = **al-berham** —> ACPA Service Center User ID = **23456**, password = **al-b23456**

EX3: member id=**24689**, last name = **kim** —> ACPA Service Center User ID = **24689**, password = **kim24689**

## Member News

**Dr. Judith Trost-Cardamone**, California State University at Northridge, has followed Dr. Mary Pannbacker's lead and established an annual student award of a one year student membership in ACPA. The award is granted to the graduate student who ranks highest in the class on Structural Organic Disorders of Speech. The first award has been granted to Laura Skibo.

Congratulations to **Karsten K.H. Gundlach, MD, DDS, MSD** who was granted the title of Doctor honoris causa by the Stradins University of Riga, Latvia.

# The Sri Ramachandra Cleft and Craniofacial Center

by Dr. Jyotsna Murthy  
Team Director

The Sri Ramachandra Cleft and Craniofacial Center functions as a part of the Sri Ramachandra Medical Center and the SRMC and Research Institute (Deemed University). Located in suburban Chennai in Tamil Nadu, South India, the university campus includes a health care university and a major hospital. The university has approximately 3000 students enrolled in various health care programs. In addition to the multi-specialty corporate hospital, the center also houses a 600 bed hospital for poor patients where services are provided at no cost to patients.

The SRMC cleft team was initiated when Dr. Jyotsna Murthy joined the SRMC after her return from Europe in 1998. She had worked with Dr. Rene Malek in Paris and completed the BAPS (British Association of Plastic Surgeon) fellowship. The Sri Ramachandra Cleft and Craniofacial Center was established in 2000. At present the team includes plastic surgeons, a maxillofacial surgeon, a pediatrician, nutritionists, speech pathologists, audiologists, pedodontists, orthodontists, otolaryngologists, a pediatric cardiologist, a neurosurgeon, a social worker, a nurse coordinator and administrator. Each team member is affiliated with his or her parent department but is a dedicated and designated member of the cleft care team.

Our team members are encouraged to utilize every opportunity to upgrade their skills, develop interdisciplinary interaction, network with national and international centers, and undertake research. Dr. Murukesan, an orthodontist, completed 6 months of fellowship at the Chang Gung Memorial Hospital, sponsored by the Noordhoff Craniofacial Foundation in 2002. Dr. Altaf Hussain, a plastic surgeon and the first cleft and craniofacial fellow at our center, visited the Craniofacial Center, Chang Gung Memorial Hospital, to enhance his experience in surgical management of CLP. His eight-week visit was sponsored by the Smile Train. Professor Roopa Nagarajan served as a member of an international working group of speech



*Sitting (left to right) Ms. N Srivithya, Ms. Kunthala Ravi, Dr. Jyotsna Murthy, Prof. Roopa Nagaraj, Ms. Sunitha Raman*  
*Standing (left to right) : Ms. Hema Latha, Mr. Cristi Doss, Mr. Kartick Chandram, Dr. S Murukesan, Dr. Jayakar Sargunar, Dr. Altaf Hussain, Dr. Madhu Sanker, Dr. K Senthil, Dr. MM Kumersan, Ms. Jansi Rani*

pathologists to develop material to train community health workers. Visits by internationally-known professionals in this field Dr. Jeffrey Marsh, Dr. Linda D'Antonio, Dr. Ian Jackson, Dr. Samuel Noordhoff, Dr. Ken Salyer, Dr. Rolf Tindlund and his team, Tara Whitehill and Rosemary Watts have been invaluable for the in-house training of our team members.

The mission of our cleft program has been three fold:

1. To provide high quality clinical services (including identification, prevention, and intervention) for individuals with CLP,
2. To serve as a center for training in different specialties related to cleft and craniofacial care, and
3. To undertake research activities aimed at improving the quality of life of individuals with clefts.

Our clinical services got a boost after the partnership with the Smile Train which started in November 2000. The Smile Train

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*About 400-450 new patients are seen and approximately 700 different types of cleft-related surgical procedures are performed each year.*

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currently supports more than 95% of the surgeries. Nutritional counseling, speech language assessment and intervention, orthodontic management, and ENT care are all supported by our hospital with a majority of patients receiving these services at no cost. Since its inception, over 2500 patients have

been registered under our care. About 400-450 new patients are seen and approximately 700 different types of cleft-related surgical procedures are performed each year. Currently 20% of those registering at our center are below 2 years and 45% below 5 years. As our caseload includes a significant number of older patients, we have adapted techniques to meet their needs, e.g., our surgical protocols include palate closure before the lip repair in children above one year of age and pre-maxillary setback with palate repair (if pre-maxilla is protruding) in older children with complete bilateral cleft lip and palate. Record keeping of the data is given the utmost

importance and we developed Cleft Audit software which is being used for recording multidisciplinary data for all the patients. We have also developed both printed and audiovisual materials for speech assessment and therapy, for teaching parents how to

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*A very important focus of our team has been the training, sensitization and orientation of community health workers in collaboration with the government health network.*

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feed their children, nutrition guidelines, surgical care and speech therapy in local languages.

A very important focus of our team has been the training, sensitization and orientation of community health workers in collaboration with the government health network. These have included doctors from primary health care centers and village health nurses. The program aims to empower these grassroots workers to identify children with clefts, support parents and encourage follow-up. The feedback and success of the program has encouraged us to develop projects for community-based rehabilitation.

The center is committed to the development of human resources in the different specialties in cleft care teams. Many initiatives have been taken up to promote

*(continued on page 6)*

# Fourth Comprehensive Membership Survey Results

## Part II – About the ACPA Annual Meeting and Cleft Palate-Craniofacial Journal

Every few years, ACPA conducts a comprehensive survey of its membership. The primary purpose is for educational needs assessment and to determine what current ACPA functions are most valuable to you. The participants' perceptions of the organization's strengths and weaknesses are used to help the leaders of ACPA shape future priorities to meet the changing needs of the membership more effectively. Input is requested in several general as well as specific subject areas such as overall impression of ACPA (Part I published in the Summer 2004 Newsletter), the Annual Meeting, the *Cleft Palate-Craniofacial Journal*, Research, etc.

This is the second in a series of reports on the 2003 membership survey. A summary of some key results is presented below regarding the Annual Meeting and the *Cleft Palate-Craniofacial Journal*. For comparison purposes, if the same question was asked in the 1998 survey, the result is italicized and in parentheses ( ).

A total of 580 responses were received out of 2100 mailed.

### ABOUT THE ANNUAL MEETING

**1) Did you attend the annual meeting in Seattle? (*Baltimore*)**

Yes 35.4% (29%) No 64.6% (71%)

**2) For the annual meeting components you attended, please indicate whether or not you found them worthwhile.**

| Attended:   | Worthwhile:                                       |
|-------------|---|
| 95.7% (93%) | 99% General Sessions                              |
| 89.0% (82%) | 99% Concurrent Specialty Sessions                 |
| 32.4% (26%) | 91% Post-Conference Symposia                      |
| 69.8% (57%) | 97% Study Sessions                                |
| 48.5% (44%) | 96% Eye Openers                                   |
| 68.3% (57%) | 94% Show and Tell                                 |
| 80.1% (61%) | 98% Panel Discussions                             |
| 86.0%       | 96% Poster Session                                |
| 82.8% (60%) | 95% Exhibits                                      |
| 75.6% (62%) | 96% Welcoming Reception                           |
| 79.1% (69%) | 95% Annual Awards Luncheon                        |
| 61.9% (55%) | 80% Space Needle Gala ( <i>B&amp;O Railroad</i> ) |
| 38.0%       | 86% CPF Good Sports Event ( <i>Winetasting</i> )  |

**3) If you did not attend the 2002 ACPA meeting, when did you last attend an ACPA annual meeting?**

26.3% 1-2 years ago  
 18.1% 3-4 years ago  
 25.2% 5-10 years ago  
 30.4% I've never attended a meeting

**4) If you did not attend the 1998 ACPA meeting, please indicate reason(s) why (primary reason is given):**

43% Conflict with personal schedule  
 19% Could not take time off from work  
 14% Conflict with other meeting(s)  
 10% Location too far  
 5% Program not relevant to my needs  
 4% Institution no longer reimburses for meetings  
 2% Registration too costly  
 1% Meeting announcement and/or information not available in time

Less than 1% Quality of programs offered of insufficient merit  
 Abstract not accepted for presentation  
 Lodging too expensive

**5) What is your overall perception of the educational content of the annual meeting?**

40% Excellent  
 51% Good  
 8% Fair  
 1% Poor

**6) Please indicate the degree of importance the following factors have on your decision whether to attend the annual meeting.**

1 = Very Important 3 = Of Minor Importance  
 2 = Moderately Important 4 = Not at all Important

1.5 (1.3) Content of Annual Meeting Program  
 2.0 (2.1) Total Cost  
 2.1 (2.3) Desirability of location  
 2.2 (2.3) Continuing Education Credit  
 2.2 (2.5) Length of meeting  
 2.4 (2.5) Pre-conference symposium topic and/or speakers  
 2.6 (2.8) Whether my employer will pay  
 2.6 (2.7) Proximity to home  
 2.9 (2.7) Whether or not you are presenting

**7) Are continuing education credits an important aspect of your ACPA membership?**

57% Yes  
 43% No

**8) If continuing education credits are an important aspect of your membership in ACPA, please rate how this need can be met with 1 being the most preferred and 5 being the least preferred.**

1.6 Attending the annual meeting  
 2.3 Attending regional symposia  
 2.6 Reading journal articles  
 2.8 Self-study programs  
 3.6 Participating in teleconferences

**9) What percentage of the program do you feel should be devoted to cleft lip/palate, craniofacial anomalies, and/or application of basic research issues?**

46% (48%) Cleft lip/palate  
 25% (31%) Craniofacial  
 29% (21%) Application of Basic Research Issues

**In which subject areas?**

23% Etiology/Pathogenesis  
 40% Diagnosis and Treatment  
 37% Management and Follow-Up

**10) Please select three areas/subjects of interest you would like to see included in future programs:**

| Rank | Percentage       |                          |
|------|------------------|--------------------------|
| 1    | 59.6% (#2 - 58%) | Outcome Studies          |
| 2    | 56.8% (#1 - 64%) | Techniques for Treatment |

|    |       |              |                              |
|----|-------|--------------|------------------------------|
| 3  | 48.3% | (#3 - 51%)   | Multidisciplinary Treatment  |
| 4  | 25.1% | (#7 - 22%)   | Funding of care              |
| 5  | 23.4% | (#5 - 26%)   | Research techniques/issues   |
| 6  | 23.3% | (#4 - 30%)   | Etiology                     |
| 7  | 16.2% | (#6 - 24%)   | Technology/computer advances |
| 8  | 13.1% | (#10 - 14%)  | Psychosocial issues          |
| 9  | 12.2% | (#8 - 17%)   | Ethics                       |
| 10 | 12.1% | (#9 - 16%)   | Imaging in Medicine          |
| 11 | 6.6%  | (#11 - 2.0%) | Government Issues            |
| 12 | 2.3%  | (#12 - .2%)  | Other                        |

**11) Do you feel your specialty is represented by “state-of-the-art” presentations at the ACPA meetings?**

|     |       |           |
|-----|-------|-----------|
| 52% | (50%) | Yes       |
| 12% | (11%) | No        |
| 36% | (39%) | Sometimes |

**12) Please list the top five places in North America where you would like to have ACPA meetings:**

- |                  |                                      |
|------------------|--------------------------------------|
| 1) San Francisco | 6) Boston                            |
| 2) New York      | 7) Orlando                           |
| 3) Chicago       | 8) Hawaii                            |
| 4) San Diego     | 9) Vancouver                         |
| 5) New Orleans   | 10) Tied — Miami, Toronto, Wash., DC |

**ABOUT THE CLEFT PALATE-CRANIOFACIAL JOURNAL**

**1) Have you ever submitted a manuscript to the CPCJ?**

|         |       |        |       |
|---------|-------|--------|-------|
| Yes 34% | (34%) | No 66% | (66%) |
|---------|-------|--------|-------|

**2) Do you feel the review process was timely?**

|         |       |        |       |
|---------|-------|--------|-------|
| Yes 80% | (83%) | No 20% | (17%) |
|---------|-------|--------|-------|

**3) Do you feel the reviews were constructive?**

|         |       |        |       |
|---------|-------|--------|-------|
| Yes 89% | (87%) | No 11% | (13%) |
|---------|-------|--------|-------|

**4) As you decide which journal to submit a manuscript to, how would you rank the importance of each of the following factors in your decision making process? (1 = most important, 6 = least important).**

- 1.8 Quality of journal/Journal impact factor
- 2.2 Makeup of journal readership
- 2.9 Size of journal readership
- 2.9 Profile/Expertise of Editorial Board
- 3.0 Acceptance to publication time
- 3.0 Length of peer review process

**5) If you do not consider the CPCJ to be your first choice for publishing in the area of craniofacial anomalies, please select your reasons from the following criteria:**

|       |  |
|-------|--|
| 29.6% | Makeup of journal readership             |
| 18.5% | Quality of journal/Journal impact factor |
| 18.5% | Size of journal readership               |
| 9.8%  | Length of peer review process            |
| 9.1%  | Acceptance to publication time           |
| 6.4%  | Profile/expertise of Editorial Board     |
| 8.1%  | Other                                    |

**6) Would you be interested in being a reviewer for the Cleft Palate-Craniofacial Journal?**

|         |
|---------|
| Yes 43% |
| No 57%  |

**CALL FOR EMAIL ADDRESSES!!!**

Please help us keep you up-to-date on the latest ACPA news by making sure we have your current email address on file. This year the following important items will be emailed to ACPA members:

- Members Only Section Updates
- Website Link for 62nd Annual Meeting Registration Materials
- Website Link for Online Payment of Membership Dues

**Email: [membership@acpa-cpf.org](mailto:membership@acpa-cpf.org)**

**Call for Newsletter Submissions**

We are presently requesting ACPA member news for the *ACPA/CPF Newsletter*. Please consider submitting an item for publication in an upcoming newsletter. Possible items for submission include:

- A profile of your cleft palate-craniofacial team (with a team photo)
- News or updates regarding your team (e.g. has your team reached a milestone recently; have you or your team colleagues received grant funding to pursue a research study?)
- A story that you may want to share about a patient... or one that a patient (or patient’s family) may want to share
- Stories or profiles of a patient-family support group in your area
- Any issues, experiences, or “controversies” related to delivery of team care that you might want to share with your fellow members

Submit a “hypothetical patient” and solicit responses from colleagues in your discipline regarding approaches to treatment. (Due to HIPPA regulations, it is important that the submission truly be a hypothetical case.)

If there are other items or regular features that you would like to see in the Newsletter, please share your ideas with us.

The *ACPA/CPF Newsletter* is published quarterly and reaches 2500 ACPA members and 200 friends of the Cleft Palate Foundation. This is a wonderful opportunity for you to reach colleagues across the globe involved in cleft care.

Thank you for your consideration.

Sincerely, David Jones, PhD  
 Division of Communication Disorders  
 University of Wyoming  
 ACPA Communications Officer  
[dljones@uwyo.edu](mailto:dljones@uwyo.edu)

## Sri Ramachandra

(continued from page 3)

training for all categories of professionals. The University offers post graduate programs in plastic surgery, maxillofacial surgery, orthodontics, speech language and hearing sciences, ENT, pediatrics, clinical nutrition and clinical psychology. Students in these programs complete a rotation in cleft lip and palate as a part of their training. One-year fellowship programs to gain experience in management of cleft lip and palate is offered at our hospital for a qualified plastic surgeon or maxillofacial surgeon.

We organized a national symposium on cleft palate disorder and this is followed by a yearly program for training of speech pathologists and students of the same. We have also hosted the 2nd annual conference of the Indian Society of Cleft Lip, Palate & Craniofacial Anomalies. Dr. Murthy serves as an honorary secretary of the society at present. The Smile Train also supported a five-day workshop for 20 speech

pathologists from all over India to develop material and hands on experience for working with individuals with clefts in India. This program received continuing education credits from the Rehabilitation Council of India. The Department of Speech was a recipient of a \$10,000USD equipment grant from Kay Elemetrics for their research project titled "Quantification

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*Our center can provide the encouragement to other centers in the developing countries that a lot and the best can be done in spite of many constraints!*

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of perceived nasality and nasolance scores in Tamil-speaking individual, with cleft lip and palate." Our team boasts more than 40 presentations and four publications in international journals.

Over and above doing orthognathic and distraction osteogenesis procedures, we have

done a few intracranial procedures. The craniofacial work is progressing slowly due to financial constraints and we are very keen to expand so that we can help many patients who are eagerly waiting for our help. The World Craniofacial Foundation will help us to train our anesthetist and neurosurgeon to improve the quality and safety of craniofacial work. Our team is also actively working with an international organization to start a genetic study on a large scale.

Our patients have been our greatest strength. It is our mission that no child, however poor, should be deprived of treatment that would enhance the quality of his/her life. Our center can provide the encouragement to other centers in the developing countries that a lot and the best can be done in spite of many constraints!

Dr. Jyotsna Murthy  
Director, Cleft & Craniofacial Center  
Associate Prof., Dept. of Plastic Surgery,  
Sri Ramachandra Medical College  
& RI(DU)  
Chennai, India

## ANNOUNCEMENTS – *In Brief*

### 2005 Parent-Patient Leadership Award

The Cleft Palate Foundation's Parent-Patient Leadership Award Committee is soliciting nominations of individuals who have provided exemplary leadership on behalf of parents and patients with cleft and craniofacial conditions. The recipient will be honored at the 2005 Annual Luncheon in Myrtle Beach, SC, and will receive \$500 for travel to the meeting. Nomination forms are available online at <http://www.cleftline.org/ppl/> or from the National Office. **Deadline: January 15, 2005.**

### APPLICATIONS AVAILABLE: 2006 Visiting Scholar Program

The Visiting Scholar Program is designed to identify individuals from outside the United States who have the potential to establish and/or direct interdisciplinary teams for comprehensive care of individuals with cleft and craniofacial anomalies in their home countries. The recipient may visit up to three ACPA-registered cleft palate/craniofacial centers and attend the ACPA Annual Meeting. Funding of up to \$5000 is provided for the scholar's expenses by Stryker-Leibinger, Inc. Application forms are available online at the News and Programs section of [www.acpa-cpf.org](http://www.acpa-cpf.org) or from the National Office. **Deadline: Applications for the 2006 scholarship are due by January 15, 2005.**

### 2005 CPF Research Grants

The Cleft Palate Foundation will be awarding four research grants totaling \$35,000 in 2005. The Junior Investigator Research Grant (\$5000) and the Etiology Grant (\$10,000) are supported by the Peer Foundation. The Cleft Lip/Palate and Craniofacial Anomalies Research Grant (\$10,000) is supported by the American Association of Oral and Maxillofacial Surgeons. The Children's Craniofacial Association Research Grant (\$10,000) is supported by the Children's Craniofacial Association of Dallas, TX. Awards will be announced at the 2005 Annual Meeting in Myrtle Beach, SC April 4-9. Application forms are available online at <http://www.cleftline.org/grants/> or from the National Office. **Deadline: January 15, 2005.**

### 2005 Donna Pruzansky Memorial Fund: Nurse Scholarship

We are pleased to announce the availability of funds to assist a nurse who wishes to attend the 62nd Annual Meeting of the American Cleft Palate-Craniofacial Association in Myrtle Beach, SC from April 4-9, 2005. This competitive grant is awarded from the Donna Pruzansky Memorial Fund for Maternal and Child Health Nursing and is sponsored by the Cleft Palate Foundation. The grant pays for registration fees for the meeting and provides \$500 for expenses.

Nurses who devote at least 50% of their work time to the care of patients with cleft lip/palate and other craniofacial anomalies and who wish to increase their knowledge of the field are encouraged to apply. Members of the American Cleft Palate-Craniofacial Association (ACPA) are not eligible. As part of the award, the winner will receive one free year of membership in ACPA. The total value of the DPMF Grant is approximately \$1,200. Applications are available online at <http://www.cleftline.org/dpmf/> or from the National Office. **Deadline: January 15, 2005.**

# International Workshop to Develop Universal Reporting Parameters for Speech

by Gunilla Henningsson, David Kuehn,  
Debbie Sell, Triona Sweeney,  
Judith Trost-Cardamone, Tara Whitehill

## Purpose of the Workshop

The National Institute on Deafness and Other Communication Disorders (NIDCD) and the NIH Office of Rare Diseases (ORD) cosponsored a workshop held in Washington D.C. April 30th - May 2nd, 2004 on "Universal Reporting Parameters for the Speech of Individuals with Cleft Palate." Sixteen invited experts in cleft palate and speech from various countries plus NIDCD Program Director, Dr. Lana Shekim, participated in the workshop. The purpose of the workshop was to develop a universal parameter system for reporting on the major speech characteristics observed in individuals born with cleft palate, regardless of their spoken native language.

## Background

There are many clear benefits of a universal system of reporting speech outcome measures in individuals born with cleft palate, including the possibility of globalized clinical trials involving collaborative groups from different geographic regions. It is not the purpose of this report to provide a detailed historical review of such efforts, but several noteworthy activities should be mentioned. At the 8th International Congress on Cleft Palate and Related Craniofacial Anomalies in Singapore in 1997, Robert Shprintzen organized several task forces to address standardized procedures and functional outcomes of cleft lip and palate surgery with special reference to speech results. Gunilla Henningsson and Birgit Hutters presented an international task force report at that Congress titled "Perceptual assessment of cleft palate speech, with special reference to minimum standards for inter-centre comparisons of speech outcome." Later, at the 9th International Congress on Cleft Palate and Related Craniofacial Anomalies in 2001 in Goteborg, Debbie Sell addressed similar issues in a keynote presentation and Anette Lohmander chaired a panel session on different approaches to speech measurement.

In spite of best efforts to do so, universal measures are difficult to achieve partly because local practitioners have utilized systems for a long time in their own practices and they may be reluctant to give up their own system in favor of a different one. In

2002, at the ACPA annual meeting in Seattle, David Kuehn, Judith Trost-Cardamone, and Debbie Sell presented a 3-stage plan that involves universal parameters as the third stage. The first stage, "Evaluation," involves the usual assessment procedure that local teams perform routinely.

The second stage, "Mapping," proposes to use the measures obtained from the Evaluation stage and convert those measures to the third "Reporting" stage. The aim of the third stage is to include a relatively small number of salient perceptual parameters that are truly universal and that can characterize the speech of individuals born with cleft palate, regardless of the native language spoken by the individual patient. Therefore, a key component of this effort is an exemplary set of speech sound stimuli and sampling procedures that can be applied globally, across world languages, to capture the speech parameters most vulnerable in response to cleft palate. It is important that the speech sampling procedure is unbiased diagnostically, that is, neither in a positive nor a negative direction, which the particular language spoken could influence. At this point in time, knowledge of how cleft palate would influence speech sound production is based primarily on well-known languages that have been studied and described most extensively in the clinical and scientific literature.

The goal of the 3-stage system is to summarize speech outcomes in a standardized manner for individuals born with cleft palate. It is intended that this should be based on clinical data collected according to local detailed speech evaluation



Workshop Attendees

### Front row left-to-right:

Sandra Neumann, Berlin, Germany  
Elisabeth Willadsen, Århus, Denmark  
Cindy Dobbeltsteyn, Halifax, Nova Scotia, Canada  
Judith Trost-Cardamone, Northridge, CA, USA

### Second row left-to-right:

Yuri Fujiwara, Osaka, Japan  
Antonio Ysunza, Mexico City, Mexico  
Marilyn Heine, Wellington, New Zealand  
Tara Whitehill, Hong Kong, China

### Triona Sweeney, Dublin, Ireland

### Third row left-to-right:

Brenda Louw, Pretoria, South Africa  
Gunilla Henningsson, Stockholm, Sweden  
Debbie Sell, London, England

### Back row left-to-right:

David Fitzsimons, Westmead NSW, Australia  
David Zajack, Chapel Hill, NC, USA  
Lana Shekim, NIDCD  
Tim Bressmann, Toronto, Ontario, Canada

protocols administered in the native spoken language and that it provide a common approach in describing and reporting clinical speech outcomes. The system developed to date is solely for the purpose of reporting clinical outcomes. It is not intended, nor should it be used, to report audit or research outcomes without demonstrated reliability and validity of the data that are used from the evaluation stage.

## ACPA Involvement

The incentive for this current effort on universal reporting parameters stems, in part, from the past international work mentioned above and also in relation to the Research Education Committee of the ACPA. The chair of the Research Education Committee at the beginning of this work was Susan Lief and the current chair is Kathleen Russell. One of the standing charges to the committee is to "facilitate increased collaborative research efforts." Clearly, a standardized and agreed upon method of reporting speech outcomes would be a big step forward in that regard. ACPA Research Education Committee member, David Kuehn, reported regularly to the committee regarding the activities leading up to the speech workshop. It appears that the workshop initiative also will be of considerable interest to other ACPA

(continued on page 9)

## Team News

### *Pittsburgh's Cleft Palate-Craniofacial Center Moves to Children's Hospital*

By Matthew D. Ford, MS

Established in the 1950's, the **Pittsburgh Cleft-Craniofacial Center** has provided unwavering dedication to over 1200 patients each year. As the largest Center of its kind in the region, the recent relocation to Children's Hospital of Pittsburgh has been a success in all aspects. Since the move, access to a wide variety of healthcare specialists and services is easily attainable.

As of January 2004, the Cleft-Craniofacial Center made its official move from the Dental School "down the hill" to Children's Hospital and into the Division of Pediatric Plastic Surgery. With the move, the team has been augmented and re-organized with multiple new additions. Now totaling 14 subspecialty providers, we meet every Monday for a full day interdisciplinary clinic. From that clinic a team letter, outlining the treatment plan for the year, will be sent to the family as well as to the child's pediatrician.

The Cleft-Craniofacial Center's "Team Approach" allows a patient to have a multi-

disciplinary visit to address all of their needs and see the appropriate specialists in one visit to our center. This is an attempt to decrease the burden of care on patients and families, as well as ensure that services are being coordinated and timed appropriately. The current team consists of multiple providers with special training and experience in the care and treatment of a wide variety of cleft and craniofacial conditions.

Under the leadership of our new director, Joseph E. Losee, M.D., FACS, FAAP, the team strives to advance the care provided to each of our patients. Matthew Ford, MS, CCC-SLP, works as the team coordinator to assure that patients are seen by the appropriate providers, and orchestrates the care with primary care providers and outlying specialists.

The Children's Hospital of Pittsburgh Cleft-Craniofacial Center's new contact number is (412) 692-8650. Email correspondence may be directed to the Coordinator at [matthew.ford@chp.edu](mailto:matthew.ford@chp.edu).

## Important Announcement!

Our New Address Forwarding Order is about to Expire!

Fifty-percent of our mail is still being addressed to our former office on Estes Drive.

**Please note the National Office's new address:**

**1504 East Franklin St., Ste. 102  
Chapel Hill, NC 27514-2820**

**Website: [www.acpa-cpf.org](http://www.acpa-cpf.org)**

**Email: [info@acpa-cpf.org](mailto:info@acpa-cpf.org) or**

**[membership@acpa-cpf.org](mailto:membership@acpa-cpf.org)**

**\*\*\*Remember to inform your institution's administrative and financial office, particularly if your membership dues and meeting registration are mailed using their database records\*\*\***

## An Update from the Craniofacial Outcomes Registry

We are in the process of moving the Registry to a new location. Unfortunately, this is taking much more time than we anticipated. Until arrangements are finalized we are unable to give you directions for obtaining a new IRB for your team's participation. You will be receiving information and directions as soon as new arrangements are completed. During this interim you can continue to collect outcome data, but will need to hold it until you are able to obtain a new IRB approval for your participation in the Registry. If you have any questions please contact me at my e-mail address: [bjphilips@bellsouth.net](mailto:bjphilips@bellsouth.net).

Betty Jane Philips, Director, Craniofacial Outcomes Registry

## Outstanding Recruiters!

*Extra special thanks to the following ACPA members who have sponsored 3 or more new members in a calendar year. 2004 so far...*

| <b>Sponsor</b>                       | <b># of New Members</b> |
|--------------------------------------|-------------------------|
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## Do You Know About ACPA's Exclusive Listserve Cleftserve?

The American Cleft Palate-Craniofacial Association invites you to take advantage of an exciting and useful member benefit. As a member of ACPA you are eligible to subscribe to Cleftserve, ACPA's exclusive listserve. Subscribers are able to broadcast subjects ranging from clinical management questions to searches for support groups across an interdisciplinary membership of users.

Recent topics of conversation on Cleftserve have been:

- Occlusion of Palatal Fistula
- Orthodontic Cranio-Cleft Fellowship
- Craniofacial Registry

We hope you will be able to enjoy this added ACPA member benefit. If you wish to subscribe please send an email to [membership@acpa-cpf.org](mailto:membership@acpa-cpf.org) with your full name and email address. Please include "Add to Cleftserve" in the subject line. Once you are subscribed you will receive an email with instructions for broadcasting on Cleftserve.

## CPF Annual Fund

*The Board of Directors would like to thank the following individuals for their contributions to the annual fund received 7/27/2004 through 11/15/2004.*

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*In Honor of Nancy Smythe  
Rosario F. Mayro, DMD, DDS*

### CONGRATULATIONS TO OUR NEW LIFE MEMBERS!

The following members have been in ACPA for 20+ years, retired from remunerative practice and have been granted Life Membership.

Rodger M. Dalston, PhD  
Clifford VanBlarcom, DDS, MSD

## International Workshop

*(continued from page 7)*

committees, especially the Task Force on Clinical Trials Outcome Studies and the International Outreach Committee.

### Current Status and Future Direction

Details and a summary of the workshop are available at: <http://www.nidcd.nih.gov/funding/programs/cp/summary.asp>. The authors of the present article functioned as the steering committee for the speech workshop. The steering committee was charged with redrafting the universal speech parameters and the respective subcategory definitions for the parameters that were deliberated at the workshop. In addition, the steering committee is refining Universal Parameters definitions and redrafting the Subject Identification Form that is used in conjunction with the universal parameters and the Guidelines that are commensurate with the parameters.

It is the intent of the workshop participants to continue work on these universal parameters within a broader context involving additional countries and languages and to work more extensively with colleagues in their own countries. There is a need not only for standardized reporting of speech results (Lohmander and Olsson, CPCJ, Vol. 41, page 64) but also for standardized measures in all aspects of care for individuals born with craniofacial anomalies (Shaw, CPCJ, Vol. 41, page 238). It is anticipated that results pertaining to universal measures developed by an international speech group eventually could complement similar results of international groups working in other areas of professional expertise. Participation in international venues, such as the forthcoming 10th International Congress on Cleft Palate and Related Craniofacial Anomalies, will be very important in that regard.

Readers are encouraged to contact any of the authors of this article for questions, ideas, or suggestions related to the topic of this report.

## Free Publication for Your Patients

ACPA Members – Please remember to give the **1-800-24-CLEFT** toll-free telephone number to your patients with cleft lip and palate and their families. Families can receive free publications by calling the **Cleftline**. If you are interested in ordering publications for your clinic please visit <http://www.cleftline.org/publications/> to download an order form.

# Happy Anniversary ACPA Members!!!

*The following members celebrate milestone anniversaries in ACPA for 2004.*

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To-Nao Wang, MD (Piedmont, CA)  
Bruce C. Wetmore, DDS (Broomfield, CO)  
Duane K. Yamashiro, DDS, MS (Park City, UT)

## 10 Years

Mary Ellen Alexander, RN, MSN (New Orleans, LA)  
Cassandra L. Aspinall, MSW, LICSW (Seattle, WA)  
Richard A. Bartlett, MD, BSE (Boston, MA)  
Benedicte Bayet, MD (Brussels, Belgium)  
Robert B. Beecher, MS (Milwaukee, WI)  
Richard J. Beil, MD (Ann Arbor, MI)  
Richard L. Bendor-Samuel, MD (Halifax, NS, Canada)  
Michael D. Bindman, DDS, BSc (Calgary, AB, Canada)  
Stephen R. Boggs, PhD (Gainesville, FL)  
Dennis A. Bosco, DDS, MS (Niagara Falls, ON, Canada)  
William C. Brown, PhD, MD (Denver, CO)  
Steven R. Buchman, MD (Ann Arbor, MI)  
Kevin Bush, MD, BSc (Vancouver, BC, Canada)  
Lucie Capek, MD (Latham, NY)  
Emma Ciafone, MD (Milano, Italy)  
Edward S. Cohn, MD (Omaha, NE)  
Jeffrey W. Colyer, MD, MS (Overland Park, KS)  
Marcos L. del Valle, MD, DMD (Ponce, PR)  
Michael J. Denk, MD (Virginia Beach, VA)  
F. Michael Emery, MD (Cedar Rapids, IA)  
Jeanne-Nicole Faille, DEC, DMD (Montreal, PQ, Canada)  
Claire S. Ferrari, DDS, MSD (Berkeley, CA)  
Timothy F. Foley, DDS (London, ON, Canada)  
William C. Giles, MD (Columbia, SC)  
Jeffrey L. Gilmore, DDS, MS (Marietta, OH)

Alex M. Greenberg, DDS (New York, NY)  
Maria I. Grigos, PhD (Brooklyn, NY)  
Joseph Haddad, Jr., MD (New York, NY)  
Lora A. Hindenburg, RN, MSN (Falls Church, VA)  
Ronald R. Hollins, DMD, MD (Omaha, NE)  
Elena M. Hopkins, RN, MS, PNP (Palo Alto, CA)  
Martin H.S. Huang, MBBS, FRCS, MMedSurg (Singapore, Singapore)  
Eric H. Hubli, MD (Roanoke, VA)  
Setsuko Imatomi, MA (Tokyo, Japan)  
Robin Jaye-Elfont, MS (Walnut Creek, CA)  
Ronald K. Kampas, DDS (Zelienople, PA)  
Vasiliki Karlis, DMD, MD (NY, NY)  
Gregory J. Keiser, DMD (Morristown, NJ)  
Steven M. Kelly, DDS, MS (Marion, IA)  
Jong-Ryoul Kim, DDS, PhD, MSD (Pusan, Korea, Republic Of)  
Ava-Lee Kotler, MS (Toronto, ON, Canada)  
Stephanos Kyrkanides, DDS, PhD (Rochester, NY)  
Chen Lee, MD (Montreal, PQ, Canada)  
Jean-Francois Lefaivre, MD (Columbia, SC)  
James R. Lessig, DDS (Centennial, CO)  
Jeffrey S. Lewis, DMD, MD (Ithaca, NY)

## 5 Years

Ghada Y. Afifi, MD (Newport Beach, CA)  
Stephen B. Baker, DDS, MD (McLean, VA)  
Wiro Bato, MD (Bilzen, Belgium)  
Mislen Bauer, MD (Miami, FL)  
Wendy S. Bell, MA (Oakland, CA)  
Patricia L. Bender, MSN, RN (Cincinnati, OH)  
Vincent V. Benivegna, DDS (East Lansing, MI)  
Joseph M. Bernstein, MD (New York, NY)  
Heather L. Beveridge, MSW (Toronto, ON, Canada)  
Adriene L. Blayton, RN, PHN, BSN (Loma Linda, CA)  
Slim Bouchoucha, DDS (Oakland, CA)  
Jeffrey N. Brownstein, DDS (Litchfield Park, AZ)  
Tonia J. Bryans, MA (Windsor, ON, Canada)  
Peggy K. Buchholz, BSN (Milwaukee, WI)  
Angelo Capozzi, MD (Sacramento, CA)  
Armando Caru, MD (Milano, Italy)  
Guillermo E. Chacon, DDS (Powell, OH)  
Kaare Christensen, MD, PhD (Odense C, Denmark)  
Kathleen T. Cox, PhD (Greenville, NC)  
Artemus J. Cox, III, MD (Birmingham, AL)  
Michael L. Cunningham, MD, PhD (Seattle, WA)  
David H. Darrow, MD, DDS (Norfolk, VA)  
Kathleen E. Dauer, MS (St Paul, MN)  
Suzi Drevensek, BAppSc, BSc (Gosford West, Australia)  
Yadranko Ducic, MD (Fort Worth, TX)  
Randy K. Ellis, DDS, MS (Pearland, TX)  
David M. Fisher, MB, FRCS, FACS (Toronto, ON, Canada)  
Christopher R. Forrest, MD, MSc, FRCS (Toronto, ON, Canada)  
Paul W. Gidley, MD (Houston, TX)

Elio Gizzi, MD, FAAP (Oakland, CA)  
Leslie E. Glaze, PhD (Minneapolis, MN)  
Siew-Ging Gong, PhD (Ann Arbor, MI)  
Arthur J. Green, JD (Peacham, VT)  
Shelley A. Green, MS, EdD (Peacham, VT)  
J. Mark Griffies, DDS (Raeford, NC)  
Stephen J. Grud, DDS, MS (Berwyn, IL)  
Debra Harmady, MD (Ocean, NJ)  
Stephen U. Harris, MD (West Islip, NY)  
Leslie B. Heffez, DMD, MS (Chicago, IL)  
Pamela S. Hoffmann, RN, PHN (Los Angeles, CA)  
David A. Jansen, MD (New Orleans, LA)  
Chintamani V. Kale, MDS (Mahim, India)  
Nara Kang, DDS, MSD (Gyeonggi-Do, Korea, Republic Of)  
Christos Katsaros, DDS, DMD, PhD, Odont Dr (Nijmegen, Netherlands)  
Bruce A. Kaufman, MD (Milwaukee, WI)  
Brenda J. Kraus (Kansas City, MO)  
Budi Kusnoto, DDS, MS (Chicago, IL)  
George H. Landis, MD (Plymouth, MN)  
Roberto Lasserre, DDS (Santiago, Chile)  
Deborah A. Leach, MA, CCC-SLP (Phoenix, AZ)  
Kerry E. Lewis, PhD (Reno, NV)  
Timothy R. Littlefield, MS (Tempe, AZ)  
Angelina Y.C. Loo, DMD (Vancouver, BC, Canada)  
Jay H. Lucas, MD, DDS (Knoxville, TN)  
Anthony F. Markus, FDSRCS, FDSRCPs (Poole, United Kingdom)  
Susan C. Martin, MA (Flagstaff, AZ)  
Jyotsna Murthy, MBBS, MS, MCh (Chennai, India)  
Py Owman-Moll, DDS, Odont. Dr. (Göteborg, Sweden)  
Michael K. Papademetriou, DMD, MS (Nicosia, Cyprus)  
Ernesto Pepe, MD, PhD (Torino, Italy)  
Jonathan A. Perkins, DO (Seattle, WA)  
Chad A. Perlyn, MD (Boca Raton, FL)  
Caroline J. Plamondon, MD, MSc (Providence, RI)  
Judith A. Plum, MS, RN (Chicago, IL)  
Martin Romero, DMD, MD, PhD (Madrid, Spain)  
Andrew H. Rosenthal, MD (Ann Arbor, MI)  
Deborah C. Rothschild, MSW (Santa Monica, CA)  
Ramon L. Ruiz, DMD, MD (Fort Myers, FL)  
Cheryl M. Salter, RN (Minneapolis, MN)  
Edmundo C. Santos, MD (Pareda, Portugal)  
Patricia H. Schiffman, DMD (Philadelphia, PA)  
Maya B. Shahani, MBBS (Chicago, IL)  
David Sorensen, PhD (Pocatello, ID)  
Anthony E. Sudekum, MD, MS (St Louis, MO)  
Michael J. Sundine, MD (Orange, CA)  
Susan R. Tobin, MA (Washington, DC)  
Maria H. Torres (Bogotá, DC, Colombia)  
Tara L. Whitehill, PhD (Hong Kong, China)  
Gregory J. Wiet, MBS, MD (Columbus, OH)  
Sharon L. Wood, MS (Omaha, NE)

## Welcome New Members

ACPA would like to extend a warm welcome to its newest members as of 10/31/2004 and recognize their sponsors (in parentheses).

Anne R. DeLaney, MD, *Plastic Surgery*, San Rafael, CA (Jann Johnson, MD)  
Hiroyuki Mishima, DDS, PhD, *Research*, Iowa City, IA (Andrew C. Lidral, DDS, PhD)  
Kimberly St. Lawrence, MSW, *Social Work*, Philadelphia, PA (Marilyn A. Cohen, BA, LSLP)

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## A Letter From Your Membership Committee Chair

Dear Fellow ACPA Member:

Please take a moment to think of a colleague, resident, or mentor who you think would make a great ACPA member...someone who, like you, is dedicated to cleft and craniofacial care. Someone who, like you, wants to read about research in their specialty. OK, do you have the perfect person in mind?

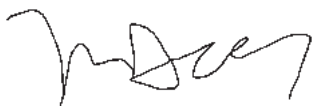
If your colleague uses this Newsletter membership application and applies by February 1, 2005, we will waive their \$25 Entrance Fee and enter your name as their sponsor in the annual sponsor raffle to be held at the 2005 Annual Meeting luncheon.

Don't forget to tell them about some of the great benefits of ACPA membership: the bi-monthly Cleft Palate-Craniofacial Journal (now available in both print form and online to all members), the Membership-Team Directory, reduced registration fees for the ACPA Annual Meeting, and access to CLEFTSERVE and the ACPA Database tracking software.

Thank you for taking this opportunity to sponsor someone who you think will make a great addition to the ACPA community.



Warmly,



Michael G. Cedars, MD  
Chair, Membership Committee

Dear ACPA Applicant:

Thank you for expressing an interest in joining the American Cleft Palate-Craniofacial Association (ACPA). Please find enclosed a membership application and a copy of the ACPA Code of Ethics.

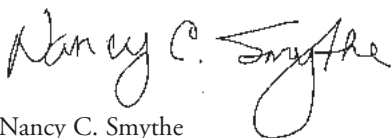
The application review process takes approximately eight weeks. Following acceptance by the ACPA Membership Committee, you will be notified and billed for your dues and one-time entrance fee (if applicable). For the 2005 calendar year dues are:

| Member Status         | Dues                     | Entrance Fee                      | 1st Year Total |
|-----------------------|--------------------------|-----------------------------------|----------------|
| Active                | \$150                    | Waived for Newsletter Application | \$150          |
| Associate             | \$150                    | Waived for Newsletter Application | \$150          |
| International         | \$185 (\$35 airmail fee) | Waived for Newsletter Application | \$185          |
| International Student | \$110 (\$35 airmail fee) | Waived                            | \$110          |
| Student               | \$ 75                    | Waived                            | \$75           |

If you are applying for Student or International Student Member status, you must be a full-time student or resident, and you need to obtain a letter from your department chair to verify your enrollment. In addition, please note that sponsor signatures are required on all but International and International Student applications. The National Office is happy to provide assistance to applicants seeking sponsors.

If you have any questions at any time during the application review process, feel free to contact me or Rafael Goldberg, Membership Services Coordinator, via the above number or at [membership@acpa-cpf.org](mailto:membership@acpa-cpf.org). We look forward to hearing from you!

Sincerely,



Nancy C. Smythe  
Executive Director

Enclosures



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**Team Affiliations**

(e.g., Nurse Coordinator, ABC Cleft Palate-Craniofacial Team, Capitol City, North Carolina)

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**Institutional and/or Professional Affiliations**

(e.g., private practice; Asst Prof., Department of Prosthodontics, University of Iowa)

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**Professional Organizations**

(Give names of other professional organizations in which you are a member in good standing, representing your area of expertise).

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**Professional Accreditation**

What accreditation or certification do you hold? In what areas? (State whether board eligible or certified, and give date.)

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**Interest in the Rehabilitation of Persons Affected by Cleft Lip, Cleft Palate and Craniofacial Anomalies**

Describe your professional activities in cleft palate-craniofacial rehabilitation. Include information concerning the nature of your work, and your interests regarding this population.

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I am applying for (check one):     Active Member             International Member  
    Student Member\*         International Student Member\*  
    Associate Member

**\*Students: A written validation of student status must be provided by the department chair and accompany this application.**

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**Sponsor's Form (To Be Completed by Sponsor)**

(Sponsor must be a member of the American Cleft Palate-Craniofacial Association)

I have reviewed this application. To the best of my knowledge, the information supplied by the applicant is true and accurate. Based on this information and my professional relations with the applicant, I support his/her application for membership in the American Cleft Palate-Craniofacial Association.

Additional Comments: \_\_\_\_\_

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Sponsor's Name (please type or print) \_\_\_\_\_ Sponsor's Signature \_\_\_\_\_

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If approved for membership, I hereby agree to abide by the Code of Ethics.

Date: \_\_\_\_\_ Applicant's Signature \_\_\_\_\_

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|   |
|---|
| <p><b>Please remember to:</b><br/>1) Sign the application<br/>2) Have your sponsor sign (if applicable)<br/>3) Enclose your student status letter (if applicable)</p> |
|---|

**Return to:** American Cleft Palate-Craniofacial Association  
1504 East Franklin Street, Suite 102  
Chapel Hill, NC 27514 USA  
Fax: 919.933.9604 Phone: 919.933.9044

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**THANK YOU! We look forward to receiving your application.**

nltr

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# AMERICAN CLEFT PALATE-CRANIOFACIAL ASSOCIATION CODE OF ETHICS

*Prepared by the Ad Hoc Ethics Committee, Edward Elmendorf, III, M.D., Chair*

*Approved by the membership present at the Annual Business Meeting, April 26, 1996, San Diego, California*

## **Preamble**

As stated in its constitution, the American Cleft Palate-Craniofacial Association ("Association") is organized to stimulate specialist and public interest in, and a more exact knowledge and improved practice of, the science and art of the rehabilitation of persons with cleft lip/palate and other craniofacial anomalies (hereafter described as "craniofacial anomalies"). The mission of the association is to optimize care of persons affected by craniofacial anomalies through professional education, stimulation of research, and the promotion of interdisciplinary collaboration and team care. In addition, the association desires to improve communication and cooperation among professionals interested in craniofacial anomalies and to develop the public's understanding of, and support for, the needs of these individuals.

Membership in the association is open to individuals of all disciplines interested in craniofacial anomalies. Ethical behavior is expected of members and teams and is guided by a Code of Ethics. Members and teams are responsible and accountable for their actions and words as well as the public use of their names. Thus they are expected to act in accord with the principles of the Code of Ethics in all contacts with patients, peers, and the general public.

## **Ethical Principles**

The following principles are the aspirational goals which guide the behavior of all individual members and listed teams. These principles are meant to foster exemplary behavior.

- I. The primary objective of the members and listed teams is to render appropriate service to all persons who seek care with full respect for human dignity. Members and teams should respect the trust and confidence of patients in their care, rendering to each a full measure of service and dedication.
- II. Members and teams should strive to improve patient care through clinical knowledge and skill and must make available to their patients and colleagues the benefits of this knowledge.
- III. Members and teams should seek to safeguard their patients from harm.
- IV. Members should uphold the dignity and honor of their individual specialty's professional Code of Ethics and accept its self-imposed disciplines.
- V. Members and teams should provide care to all persons without regard to race, religion, ethnicity, gender, or ability to pay. Members and teams should make every effort to find funding or a source of service for financially disadvantaged patients.
- VI. Members and teams should respect patient autonomy while exercising sound clinical judgment and skill.
- VII. Members and teams should seek or offer outside consultations upon the request of the patient or family in doubtful or difficult cases, or whenever it appears that the quality of service may thereby be enhanced.
- VIII. Patient confidentiality should be respected unless members or teams are required to break confidentiality by law.
- IX. Members who participate in volunteer medical missions outside their home country should provide only the type of care for which they have training and credentials in their home country.
- X. Members and teams should assist the public in obtaining information and services regarding the care and treatment of individuals with craniofacial anomalies.
- XI. Members and teams should honestly and accurately represent their professional qualifications and the services or characteristics of their team to the public and to the association.
- XII. Research, clinical presentations, and published articles are to be based on scientific principles and conducted in an ethical manner. Financial interest of any type in the conduct of research is to be clearly stated in publications and presentations.

## **Ethical Applications**

The following are ethical rules for all members and listed teams. A team is expected to function in an ethical manner. The team director is ultimately responsible for the conduct of a team in its relationship to the association.

- I. Members should obey all laws and avoid illegal activities.
- II. Members should be in good standing in their organization of primary certification.
- III. Members should be in good standing with their state or national licensing boards.
- IV. Members and teams should not engage in inaccurate or dishonest solicitation of patients.
- V. Members and teams should provide complete records to other professionals or teams when requested by the patient or family.
- VI. Professional advertisements should not be dishonest, false, or misleading either in writing or in photographs. Members and teams should be able to substantiate material objective claims made in advertising.
- VII. The Association team listing designation and logo should not be used in advertising.
- VIII. Members and teams should not pay nor receive a commission for referral of patients.
- IX. Disclosure of professionally related commercial interests and any other interest that may influence decision making is required in communications to patients, the public, and to colleagues. Patients should not be exploited in any manner when a member has a financial interest in a commercial venture.
- X. The source(s) of research funding must be acknowledged in presentations and publications.
- XI. Members should not be involved in misrepresentation, unethical behavior, or fraud in research and presentations.
- XII. Teams should honestly represent their services in reports to the Association.

## Mark Your Calendar

### FUTURE ACPA MEETINGS

2005

**62nd Annual Meeting** • April 4-9  
The Kingston Plantation • Myrtle Beach, SC  
Program Chair Peter M. Spalding,  
DDS, MS, MS

**Pre-Conference Symposium:** April 4-5, 2005  
What's New with 22q?  
Co-Chairs Donna McDonald-McGinn, MS,  
CGC and Kathy Kapp-Simon, PhD

2006

**63rd Annual Meeting** • April 3-8  
Westin Bayshore Resort & Marina  
Vancouver, BC, Canada

2007

**64th Annual Meeting** • April 23-28  
Omni Interlocken Resort  
Denver (Broomfield), CO

### CPF EVENTS

2005

**Connections Conference** • April 9  
The Kingston Plantation • Myrtle Beach, SC

**2nd Annual 5K Miles For Smiles** • May 21  
Chapel Hill, NC

### RELATED ORGANIZATIONS' MEETINGS

January 14-16, 2005

**The Florida Cleft Palate-Craniofacial Association's Winter Symposium and Annual Membership Meeting** will be held January 14-16, 2005 in Daytona Beach, FL at the Adam's Mark Resort. Keynote Speaker: Steven R. Buchman, MD. Pre-Conference Symposium on the multidisciplinary treatment team approach will be held January 14th.

For more information please contact FCPA Program Chair Laura Moreno-Chavez, Psy.D., LHMC: [lmorenochavez@aol.com](mailto:lmorenochavez@aol.com).

February 25-27, 2005

**The Miami Craniofacial Anomalies Foundation presents A Cleft Palate Weekend Seminar with Dr. Samuel Berkowitz** to be held at the Doubletree Hotel, Miami, FL. All participants will be given 38 hours of PowerPoint lectures on CDROM covering all aspects of cleft palate treatment which can be used for teaching students in all specialties. For information and registration, Tel: (305)667-3126; Fax: (305)667-3140; Email: [sberk@aol.com](mailto:sberk@aol.com)

March 10-13, 2005

**2nd International Conference on Advanced Digital Technology in Head and Neck Reconstruction** will be held at the Fairmount Banff Springs Hotel and Conference Center March 10-13, 2005. For information and/or

registration contact: RES Seminars, Tel: 858.272.1018; Fax: 858.272.7687; Email: [res-inc@email.msn.com](mailto:res-inc@email.msn.com); Website: [www.res-inc.com/advanced\\_technology.htm](http://www.res-inc.com/advanced_technology.htm)

May 20-21, 2005

**5th Congress of the Italian Society for the Study and Treatment of Cleft Lip, Palate and Craniomaxillofacial Malformations** will be held in Genoa, Italy May 20-21, 2005. For further information please contact Proff. Dott. Giuseppe Verrina; Tel: 39.0.10.563.4230; Fax: 39.0.10.563.4236; Email: [Giuseppe.verrina@galliera.it](mailto:Giuseppe.verrina@galliera.it)

August 29-September 2, 2005

**17th International Conference on Oral and Maxillofacial Surgery** will be held at the International Convention Center, Hofburg, Vienna, Austria. For information contact: MZK, Email: [icoms@medacad.org](mailto:icoms@medacad.org), [www.icomsvienna2005.org](http://www.icomsvienna2005.org), Tel: 0043.1.405.13.83.0, Fax: 0043.1.407.82.74.

September 4-8, 2005

**10th International Congress on Cleft Palate and Related Craniofacial Anomalies "Cleft Care for All"** will be held from September 4-8, 2005 in Durban, South Africa. Emails for Congress Secretariat: [savic@nu.ac.za](mailto:savic@nu.ac.za), [klopperj@nu.ac.za](mailto:klopperj@nu.ac.za) Website: [www.cleft2005.co.za](http://www.cleft2005.co.za)



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