The Jorge Posada Foundation is a non-profit organization established by the New York Yankees’ All-Star Catcher, Jorge Posada, and his wife, Laura. Their son, Jorge Jr., was diagnosed with Craniosynostosis when he was just ten days old and had to undergo five major surgeries to correct the condition.

P.O. Box 2038
New York, NY 10159-2038

Toll Free: 1.866.823.8005
Email: foundation@jorgeposada.com

Is proud to be a part of the 2006 North American Craniofacial Family Conference!
July 23, 2006

Dear Friends,

Welcome to our second North American Craniofacial Family Conference. We are excited to have you with us and know you will find the next few days to be both enjoyable and educational.

Once again we have an excellent program highlighted by renowned speakers. Many thanks to Debbie Oliver and Rickie Gill for their hard work in organizing this year’s conference. I also want to thank our sponsors for their support of the conference and of our mission. It’s a great team effort.

Of course, thank you for attending. Please take the opportunity to renew friendships, make new ones, share experiences, and enjoy being together.

Sincerely,

David J. Reisberg, DDS
President
SUNDAY, JULY 23, 2006

10:00 AM – Noon
AboutFace USA
Apollo 5
Leadership Meeting
Invited participants only, please.

Noon – 1:00 PM
Pre-Conference Check-In
Apollo Foyer

12:30 – 5:15 PM
Kids’ Camp Child Care
Apollo 8
(Ages 0 – 6)
Child care is available for NACFC participants only. Please do not leave the Alexis Park Resort premises if your child is in the care of our volunteers/staff. A signed waiver is required. Please pick up your children immediately following the workshop, scheduled to end approximately 5:00 PM.

1:00 – 5:00 PM
Pathfinder Outreach
Apollo 5
Workshop
Debbie Oliver
Program Director
The Pathfinder Outreach Network is comprised of families and individuals offering support and resources on a variety of subjects. Workshop topics will include communication, diversity, dissemination of information, and how to launch and maintain a support network on a local/regional basis. Focus groups will allow new and established Pathfinders to share ideas and establish goals for the coming year.

1:00 – 5:00 PM
Vendor/Exhibitor Check-In
Apollo Foyer
Pick up your copy of the 2006 NACFC Exhibitor’s Guidelines at the Registration Desk. Please note the name card attached to your table in the Apollo Conference Area (Apollo 1 and 2).

6:00 – 8:00 PM
Conference Check-In
Apollo Foyer
Apollo 1 & 2
Welcome Reception
After check-in at the Registration Desk, enjoy some meet-and-greet time with other conference participants and exhibitors in the Apollo Conference Area!

MONDAY, JULY 24, 2006

7:00 AM
Conference Check-In
Apollo Foyer

Apollo 1 & 2
Continental Breakfast with Vendors/Exhibitors

7:30 AM
Kids’ Camp Child Care
Apollo 8
(Ages 0 – 6)
Child care is available for NACFC participants only. Please do not leave the Alexis Park Resort premises if your child is in the care of our volunteers/staff. A signed waiver is required. Please pick up your child(ren) during the lunch break and immediately following the afternoon joint session, scheduled to end approximately 5:00 PM.

8:00 AM
Getting to Know You - Icebreakers!
Teens (14 – 17), Pre-Teens (11 – 13) and Explorers (7 – 10) will participate in this Getting to Know You kick-off event.

8:00 AM
Conference Welcome
Athena

8:15 AM
Keynote
Thomas C. Hart, DDS, PhD
Chief and Clinical Director
Human Craniofacial Genetics Section, NIDCR
Facial Imaging as a Diagnostic Tool
Dr. Thomas Hart, Clinical Director, Division of Intramural Research at the National Institute of Dental and Craniofacial Research, holds a DDS, a certificate in Periodontics and a PhD in Human Genetics. Prior to joining the NIDCR, Dr. Hart was Director of Clinical Research, University of Pittsburgh School of Dental Medicine and Director of the Center for Craniofacial and Dental Genetics. He also was an associate professor in the Department of Genetics and the Department of Oral Biology at the University of Pittsburgh.

It is estimated that 30 percent of the 5,000 known genetic conditions are marked by changes in the structures of the craniofacial area. The mission of the Human Craniofacial Genetics Section (HCGS) is to explore the expression and function of defective genes that are associated with oral health. This section also studies normal and abnormal growth of oral tissues to develop novel treatments for genetic diseases, as well as diseases in patients without known genetic mutations.
SCHEDULE

MONDAY, JULY 24, 2006

9:15 – 10:00 AM Workshop Modules

Apollo 4 Module I – Adults and Insurance
       Module II – Parents

Frank Nolimal, CLU, ChFC
Employee Benefits Consultant, Assurance Ltd.

This workshop will focus on commonly-asked questions about health insurance policies, including pre-existing conditions, open enrollment, creditable coverage and policyholder rights of appeal. The session will also compare and contrast benefits found in individual medical policies, fully-insured and self-insured employer group policies and health maintenance organization (HMO) plans.

Apollo 3 Module III – Explorers’ Club
(Ages 7 – 10)

Jacqui Rivait
Student Services Specialist
Dearborn Public Schools
Office of Student Services and Special Programs

A bully can tease you, squeeze you or even sneeze on you. In this workshop we’ll talk about ways to brush that bully away, face our feelings and our fears, and learn how to de-bullify the beast within.

Apollo 5 Module IV – Pre-Teens
(Ages 11 – 13)

David Roche

Storytelling Workshop

Everyone has a message, based on their personal experience, to bring to the world. Everyone has wisdom to impart to others. David Roche will provide a safe environment for you to express deep truths drawn from your life experience, and will offer coaching tailored to the particular needs and desires of the group. Come as prepared as you can be to speak your truth. It is fine to have anxiety about this, because that is a sign of the stirring of creative spirit (even if it is uncomfortable!). We will focus on telling stories of brief transformative moments in our lives. David promises you that your stories will change your lives and the lives of others!

10:00 AM Break

Apollo 1 & 2

Enjoy a treat while browsing through the Apollo Conference Area and meeting with our exhibitors!

10:30 – 11:15 AM Workshop Modules

Apollo 4 Module I – Adults and Module V – Teens (Ages 14 – 17)

I’ve sent in my resume...now what?
Jan Haase, SPHR

Jan Haase tackles that no-man’s land between sending in your resume and getting a call for an interview. With over 20 years experience as a job counselor, job developer and recruiter, Jan offers a unique perspective on that elusive animal “a really good resume”, as well as tips for responding to ads, and preparing for your interview. She has created and facilitated job workshops while employed by Washington State, and has been a guest speaker for the association of Business and Professional Women, military outplacement programs, and for various business courses at the Community College of Southern Nevada (CCSN). Jan holds a Bachelor’s degree in Business Administration and Management, is a member of the Society of Human Resources, and is certified as a Senior Professional in Human Resources.

TRANSMISSIONS

Kathy Treants, Transitions Specialist
Nevada PEP

All young adults face tremendous challenges as they prepare to leave high school and enter the adult world. They, along with families, must make difficult decisions about the future. Some of the decisions students face include additional education/training, employment, living arrangements, money management and recreational activities. This workshop will explore each of these areas, with an emphasis on the importance of self-awareness and self-advocacy skills for youth with disabilities. Each participant will receive the “Where Am I Going? How Will I Get There?” handbook for students and families and the “You Can Do It! Students with Disabilities Preparing for College” guide.
MONDAY, JULY 24, 2006

Apollo 7  Module II – Parents

Your Early Childhood Rights and Responsibilities
Theresa Brooks, Training Specialist
Nevada PEP

When families find they have a need for early intervention services, the laws that support these services can be confusing and overwhelming. Join us as we look at IFSPs/IEPs and provide an understanding on the rights of infants, preschoolers and their families. Parents will have the opportunity to ask questions and gain a better understanding of their roles on IFSP and IEP teams and school/program responsibilities.

Apollo 3  Module III – Explorers’ Club
(Ages 7 – 10)

How’s School?
Joni Warinner,
EJ May Elementary School, CCSD

Understand how to set goals and the important components that are critical for success. Participants will have the opportunity to practice this important skill using worksheets and examples from the presenter.

Apollo 5  Module IV – Pre-Teens
(Ages 11 – 13)

Transitions
Kathy Treants, Transitions Specialist
Nevada PEP

Teaching pre-teens and their families about transitions helps them face the changes that occur in their lives. This workshop will discuss changes and some specific activities that parents and students can do together to prepare for the adventure of middle school and high school. Discussions will take place on self-awareness and self-advocacy skills for youth with disabilities. Each participant will receive the “Where Am I Going? How Will I Get There?” handbook for students and families.

MONDAY, JULY 24, 2006

11:30 – 1:00 PM  On-Your-Own Lunch
Pegasus at the Alexis Park Resort

For your convenience, a deli buffet will be available at the Pegasus at the Alexis Park Resort, located off the main lobby. Adults - $11.95; children under 12 - $7.95 (includes beverage). Take advantage of this opportunity to stay in, stay cool and be on-time for the afternoon workshops!

Kids’ Camp Child Care will re-open at 12:45 PM

1:15 PM  Special Guest –
Athena Back by Popular Demand!
Humorist David Roche
“My Face – A Gift”

Humorist and keynote speaker David Roche has performed his signature one-man show, “The Church of 80% Sincerity,” at the White House and across the country, as well as around the world, including Australia, England, Canada, New Zealand and Moscow. He has transformed the lessons of lifelong facial disfigurement into a compelling message filled with courage, inspiration and laughter. David is featured in “SHAMELESS: the ART of Disability,” the new National Film Board of Canada feature-length documentary directed by Bonnie Klein, scheduled for release this fall in the US.

2:15 – 3:00 PM  Workshop Modules

Athena  Module I – Adults,
Module II – Parents and
Module V – Teens

Storytelling Workshop
David Roche
(Part A of a Two-Part Series)

Part A - Everyone has a message, based on their personal experience, to bring to the world. Everyone has wisdom to impart to others. David Roche will provide a safe environment for you to express deep truths drawn from your life experience, and will offer coaching tailored to the particular needs and desires of the group. Come as prepared as you can to speak your truth. It is fine to have anxiety about this, because that is a sign of the stirring of creative spirit (even if it is uncomfortable!). We will focus on telling stories of brief transformative moments in our lives. David promises you that your stories will change your lives and the lives of others!
MONDAY, JULY 24, 2006

Apollo 3 Module III – Explorers’ Club
(Ages 7 – 10)

Sign Language Fun!
Shannon Osborne, Wee Can Sign

This fun and interactive workshop will include teaching dozens of signs for animals, colors, food and activities using songs, books and toys. Wee Can Sign offers classes and products for learning signs with children of all ages. Visit our vendor table for more information on early signing, even for pre-verbal babies and toddlers!

Apollo 5 Module IV – Pre-Teens
(Ages 11 – 13)

Goalsetting
Joni Warinner,
EJ May Elementary School, CCSD

Understand how to set goals and the important components that are critical for success. Participants will have the opportunity to practice this important skill using worksheets and examples from the presenter.

■ 3:00 PM Break
Apollo 1 & 2

Enjoy a treat while browsing through the Apollo Conference Area and meeting with our exhibitors!

■ 3:30 – 4:15 PM Workshop Modules

Athena Module I – Adults, Module II – Parents and Module V – Teens

Storytelling Workshop
David Roche
(Part B of a Two-Part Series)

Part B - Everyone has a message, based on their personal experience, to bring to the world. Everyone has wisdom to impart to others. David Roche will provide a safe environment for you to express deep truths drawn from your life experience, and will offer coaching tailored to the particular needs and desires of the group. Come as prepared as you can be to speak your truth. It is fine to have anxiety about this, because that is a sign of the stirring of creative spirit (even if it is uncomfortable!). We will focus on telling stories of brief transformative moments in our lives. David promises you that your stories will change your lives and the lives of others!

■ 4:30 – 5:00 PM Joint Session
Athena Housekeeping/Agenda Items

■ 6:30 – 10:30 PM Recognition Dinner
Parthenon 4

Join us for an evening of fun and frolic! A brief program will be presented during dinner and dessert, followed by entertainment provided by local disc jockey Robert Reed.
TUESDAY, JULY 25, 2006

On-Your-Own Breakfast
Pegasus at the Alexis Park Resort

A breakfast buffet is available beginning at 6:00 AM at the Pegasus at the Alexis Park Resort, located off the main lobby. Adults - $11.95; children under 12 - $7.95.

7:30 AM  Pathfinder Coordinators Meeting
Apollo 5
Invited participants only, please.

8:00 AM  Kids’ Camp Child Care
Apollo 8
(Ages 0 – 6)
Child care is available for NACFC participants only. Please do not leave the Alexis Park Resort premises if your child is in the care of our volunteers/staff. A signed waiver is required. Please pick up your child(ren) during the lunch break and immediately following the afternoon joint session, scheduled to end approximately 5:00 PM.

8:30 AM  Special Guest
Athena
Amber Hammond
Overcoming Obstacles - Even I Have Bad Hair Days!

Barbara Kammerer Quayle, MA started the first school re-entry program for burn-injured children in California. She is a consultant and speaker/trainer regarding image enhancement and behavioral skills programs to enable people with facial and body differences to manage questions, stares, teasing, and create a positive outer image. She created the BEST Program to teach healthcare professionals how to establish a hospital-based program to assist patients with Behavioral & Enhancement Skills Training. Barbara received the Curtis P. Artz Distinguished Service Award from the American Burn Association, was inducted into the California Governor’s Hall of Fame for People with Disabilities, and has won numerous other awards. She is on the Board of Directors of The Phoenix Society and is president of the Orange County Burn Association.

Barbara will also offer an Image Enhancement workshop to teens and adults with facial differences. The session will include color analysis and a creative cosmetic session to develop a positive image.

11:30 – 1:00 PM  Buffet Lunch
Parthenon 4  NACFC Sponsors

Kids’ Camp Child Care will re-open at 12:45 PM

1:15 – 2:00 PM  Workshop Modules
Apollo 5  Module I – Adults,
Module IV – Pre-Teens and
Module V – Teens

Image Enhancement Skills
Barbara Kammerer Quayle

Creative cosmetic sessions will be offered to teen and adult attendees with facial differences. The sessions will demonstrate how to increase facial harmony and create a more positive image. Each individual will receive a Book of Image Enhancement with an accompanying CD/Video to refer to after the session.

Special thanks to the AF USA Action Team:

Joyce Bentz
Kiku Collins
Milli Davis
Kelly Lanham
Robert Oliver
Marcia Stark
TUESDAY, JULY 25, 2006

Apollo 7  Module II – Parents

Is Your Child the Target of Bullying?
Jacqui Rivait
Student Services Specialist
Dearborn Public Schools
Office of Student Services and Special Programs

Confidence and healthy friendships are your child’s best defense against bullies. Learn ten simple ways to help your child handle bullies and examine some of the old beliefs about bullying such as, getting bullied is normal; bullies are always boys, and the best way to handle bullies is to ignore them or to fight back...NOT!

Apollo 3  Module III – Explorers’ Club
(Ages 7 – 10)

Gimme a Break!

It’s time to take a break and have a little fun with your new friends!

2:15 – 3:00 PM  Workshop Modules

Apollo 7  Module I – Adults,
Module II – Parents and
Module V – Teens

Secondary Treatment and Surgery
John Menezes, MD
Assistant Professor/
Head Craniofacial Surgery
University of Nevada School of Medicine

Jaleh Pourhamidi, DMD, MDSc
Assistant Professor of Clinical Sciences
UNLV School of Dental Medicine

It is sometimes necessary to revise previous reconstructive surgery or complete treatment during adulthood. We will discuss the role of orthodontics in craniofacial care, when secondary surgery might be indicated, state-of-the-art procedures, and the pros and cons of revising previous surgery.

TUESDAY, JULY 25, 2006

Apollo 3  Module III – Explorers’ Club
(Ages 7 – 10)

Understanding Your Care
Cathy Coleman, BS, CCLS,
UMC Children’s Services

Angela Harris, BS, CLS,
Sunrise Children’s Hospital

Kelley Kiesling, CCLS,
UMC Children’s Services

This will be a group session facilitated by three Child Life Specialists from University Medical Center (UMC) and Sunrise Children’s Hospital, Las Vegas, NV. Learn what you can do to understand your surgery and your hospitalization. We’ll have fun with group games and activities. Come with questions and experiences!

Apollo 5  Module IV – Pre-Teens
(Ages 11 – 13)

Bully-Proof!
Jacqui Rivait
Student Services Specialist
Dearborn Public Schools
Office of Student Services and Special Programs

Have you ever been bullied or teased? Learn practical, easy-to-use skills and solutions for dealing with bullies, such as building your self-confidence, staying calm and seeking the help of a caring adult. We’ll also talk about why some people bully and dispel some of the myths grown-ups have told us about bullying.

3:00 PM  Break
Apollo 1 & 2

Enjoy a treat while browsing through the Apollo Conference Area and meeting with our exhibitors!

Forward Face
317 East 34th Street
Suite 901A
New York, NY 10016
Telephone: (212) 684-5860
Fax: (212) 684-5864
Email: info@forwardface.org
SCHEDULE

TUESDAY, JULY 25, 2006

■ 3:30 – 4:15 PM  Workshop Modules

Apollo 3  Module I – Adults

Employment/ADA Law
Robert Spretnak, Attorney

Harassing someone because of his or her disability-related physical appearance is more than just bullying. When it happens on the job, it is against the law. The Americans with Disabilities Act, known as the “ADA,” protects qualified individuals from discrimination in employment and in matters of public accommodation due to one’s disability. This is a rapidly evolving and changing area of discrimination law and this presentation will update you on the current state of the law. Robert Spretnak is a private attorney who represents employees in disputes with their employers. Spretnak regularly handles cases under the ADA, including representing a woman diagnosed with partial lipodystrophy, a condition which altered his client’s facial structure by preventing fat storage in the upper body.

Apollo 7  Module II – Parents
Module III – Explorers’ Club (Ages 7 – 10)
Module IV – Pre-Teens (Ages 11 – 13)

Taking the Fear Out of Hospitalization
Cathy Coleman, BS, CCLS, UMC Children’s Services

The focus of this workshop is on family-centered care, the members that make up the healthcare team and how you can be more involved with that team. Learn what to look for in a health care facility that can help take the fear out of hospitalization.

Apollo 5  Module V – Teens (Ages 14 – 17)

Who’s Really the Loser?
Jacqui Rivait
Student Services Specialist
Dearborn Public Schools
Office of Student Services and Special Programs

The bully feels insecure; needs to feel he/she is in control; demands a lot of attention; has a low opinion of themselves. They seek out people to bully, tease and verbally or physically hurt because they don’t feel good about themselves. In this workshop you’ll learn how to deal with bullies and begin to understand why they do what they do.

TUESDAY, JULY 25, 2006

■ 4:30 – 5:00 PM  Joint Session/Closing Remarks
Athena

WEDNESDAY, JULY 26, 2006

(OPTIONAL)

AboutFriends Day! Get together with your new friends and see the sights of Southern Nevada. We’ve highlighted three fabulous activities and included brochures and coupons in this packet for your convenience.

See the AboutFriends Day information in this packet.

Additional Information

This program is subject to change.

Kids’ Camp Childcare – Child care is available for NACFC participants only. You will be required to sign a permission/release form to utilize NACFC child care services (ages 0 – 6). Parent(s) and/or adult guardians may not leave the Alexis Park Resort at any time while child(ren) they are responsible for are being cared for at Kids’ Camp. Please be prepared to provide a cell phone or pager number so we can reach you during NACFC sessions, if needed. Please be prepared to provide photo identification when picking up your child(ren).

NACFC Photography – Please be prepared to sign a waiver and release pertaining to photographs taken by our official event photographer. AboutFace USA, cleftAdvocate and NACFC sponsors will utilize some event photos in our press releases, promotional materials and newsletters. If you do not wish to be photographed, please inform the NACFC Registration Desk (Apollo Foyer). Your name badge will be appropriately and inconspicuously tagged to alert our official event photographer that you do not wish to be photographed.

Drink Plenty of Water! We have an extremely dry climate here in Las Vegas, so make an extra effort to keep yourself hydrated. During your stay, drink plenty of water, and limit sugary drinks and alcoholic beverages. Please make sure your children are well-hydrated, too!

Don’t Jaywalk! Every year many tourists are killed or injured as they cross Las Vegas streets outside of marked pedestrian crossings. Please cross at major intersections and obey the pedestrian traffic signals. Hold the hands of young children and utilize pedestrian crossovers on the Strip. Stay safe!
Thank You — We couldn’t have done it without you!

AboutFace USA Board of Directors
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American Anaplastology Association
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Maurice Stein
Sunrise Hospital
Paul Tanner
Texas Children’s Hospital
Kathy Treants
University Medical Center, Las Vegas
Rosa Waitman
Wee Can Sign
Betsy Wilson
OUR VISION —

At AboutFace USA, our vision is to foster acceptance of people with facial differences so they may participate fully in society with self-worth and dignity. Everyone wants to be valued for who they are as individuals – for our talents, our interests, our personalities, our strengths.

MISSION —

Our mission is to provide information and emotional support to individuals with facial differences and their families. We work to increase public understanding through awareness programs and education on behalf of those we serve.

We support individuals whose facial differences are present at birth, such as cleft lip and palate, Apert, Crouzon, Treacher Collins and Moebius syndromes, vascular malformations, as well as other conditions. We also serve those who have acquired facial differences as a results of illness, disease or trauma, such as stroke, cancer, accident and fire.

Metin Bereketli

Official Artist of the 2006 North American Craniofacial Family Conference

Metin Bereketli is an internationally acclaimed Los Angeles-based artist whose contemporary works have been featured in museums, galleries, and exhibitions worldwide including the Smithsonian Institution, the National Museum of Art Library, Sotheby's London, California Science Center, Exposition Park, Universal Studios, Paramount Pictures Studios, Peterson Automotive Museum, Playboy Mansion, House of Blues, Pacific Design Center, and Hollywood & Highland. His style has earned the esteem of many American leaders, such as Presidents Clinton, Bush and Carter, various members of Congress and the US Senate, numerous State Governors and Senators, and members of the US Supreme Court.

Metin has also received critical acclaim in articles published in Cosmopolitan, Comucopia, M acro, Donna, Skylife, Maison Francaise, Vizyon, Art Decor, M ozaik, Decor, Science of Mind, Positive Living, Impacto, N Y Times, Morning Star, and the Daily Breeze. Metin believes divine inspiration plays a great part in the creation of his paintings. His art appeals to the eyes and the heart. His images communicate important human messages about healing and the promotion of world peace.

To promote healing through giving, Metin has generously supported several charities with his artwork. He is an artist who has dedicated himself to the evolution of mankind with his themes. His paintings are not only a display of vivid colors and powerful imagery, but also a celebration of oneness with the Human Family in the Circle of Life.

Metin's art work has been seen in numerous movies and television shows, including Two-And-A-Half Men, the Gilmore Girls, W ill & G race, ER, Friends, Frasier, and General Hospital. To learn more about Metin Bereketli and the Healing Art program, visit www.metinbereketli.com.

Cover: Bridging the Gap, Copyright Metin Bereketli, All Rights Reserved
Congratulations on a Great Conference from the Team at

The Craniofacial Center
The University of Illinois Medical Center at Chicago
811 South Paulina Street (MC 588)
Chicago, Illinois
312-996-7546
www.uillinoismedcenter.org/craniofacial

“We Help People Face The Future.”

Thank You

The Family-to-Family Connection listserv is hosted by

Genetic Alliance

Sharon F. Terry, MA • President and CEO
4301 Connecticut Ave., NW • Suite 404 • Washington DC 20008
www.geneticalliance.org

Mission

Genetic Alliance is an international coalition comprised of more than 600 advocacy, research, and healthcare organizations that represent millions of individuals with genetic conditions and their interests. As a broad-based coalition of key stakeholders, we leverage the voices of millions of individuals living with genetic conditions. With an 18-year history as a 501(c)(3) not-for-profit organization, the Alliance identifies solutions to emerging problems and works to reduce obstacles to rapid and effective translation of research into accessible technologies and services that improve human health.
Moebius Syndrome
“Faces of Distinction”

What is Moebius Syndrome?
Moebius Syndrome is a rare disorder characterized by lifetime facial paralysis. People with Moebius Syndrome can’t smile or frown, and they often can’t blink or move their eyes from side to side. The most apparent symptoms are related to facial expressions and function. In newborn infants, the first sign is an impaired ability to suck. Excessive drooling and crossed eyes may be present. Two important nerves - the sixth and seventh cranial nerves - are not fully developed, causing eye muscle and facial paralysis. Many of the other 12 cranial nerves may also be affected. In addition, there can be deformities of the tongue and jaw, and even some limbs, including club foot and missing or webbed fingers. Most children have low muscle tone, particularly of the upper body. Moebius Syndrome is sometimes accompanied by Pierre Robin Syndrome, Poland's anomaly and/or Autism Spectrum Disorder.

The mission of the Moebius Syndrome Foundation is to provide information and support to individuals with Moebius Syndrome and their families, promote greater awareness and understanding of Moebius Syndrome, and to advocate for scientific research to advance the diagnosis and treatment of Moebius Syndrome and its associated conditions.

For more information contact
The Moebius Syndrome Foundation (660) 834-3406
www.moebiussyndrome.com

CarePages is a service for patients and families that allows family and friends to stay in touch before, during and after hospitalization. Patients and families are able to create and update a FREE, private and personalized web page to share their latest news with friends and family, and receive messages of support.

CarePages let patients and families:
• Update everyone at the same time without repeated phone calls or emails
• Share up to 52 photos with friends and family members
• Create web pages that they can update themselves

CarePages are fully secured, password protected and comply with all patient privacy regulations.

To access CarePages, visit
www.carepages.com/cleftadvocate

Help is available for the CarePages by contacting support@carepages.com or by calling 1-888-852-5521 Monday through Friday 8 a.m. to 6 p.m., Central time.
THE NATIONAL CRANIOFACIAL ASSOCIATION

W elcomes You to the North American Craniofacial Family Conference!

Be sure to come by our exhibit and see how our family can serve your family.....

Networking

“Networking among other parents has been the most meaningful to me.”
J. Adams, Pennsylvania

“Networking with others has been very helpful. It is nice to meet families facing similar situations.”
E. West, Kansas

Newsletters

“Newsletters give us hope and support.”
R. Marshall, Missouri

“Reading your newsletters and hearing from the other parents the positive stories of their special children.”
E. West, Kansas

Research Information

“Research Information and updates on new treatments have been the most helpful.”
R. Marshall, Missouri

“Research Information and updates on new treatments help me understand my child’s condition.”
E. West, Kansas

Travel Assistance

“Travel Assistance has been a blessing to our family.”
J. Adams, Pennsylvania

Information Packets

“The Information Packets have been very helpful in providing information about our condition.”
R. Marshall, Missouri

Research Information

“The Research Information has been very informative.”
E. West, Kansas

Craniofacial Center Information

“Craniofacial Center Information has been very helpful in guiding us through the medical journey.”
J. Adams, Pennsylvania

P O Box 11082 • Chattanooga, Tennessee 37401
www.faces-cranio.org • faces@faces-cranio.org
800-3FACES3
We envision a world where all people are accepted for who they are, not how they look.

Cher, CCA’s Honorary Chairperson, with CCAkid, Elizabeth

Children’s Craniofacial Association is a proud sponsor of the North American Craniofacial Family Conference

CCA programs and services include:
- Quarterly Newsletter
- Syndrome Booklets
- Physician List
- Toll-free Number
- Financial Assistance Program
- Cher’s Family Retreat
- Networking & Support
- Advocacy & Public Awareness
- Fund Medical Research

Learn about these programs, sign up for our free newsletter, read about our kids, their families and what others are doing to support our mission by visiting our Website: www.ccakids.org or call us toll-free at 1-800-535-3643.

www.ccakids.org

Empowering and giving hope to facially disfigured individuals and their families

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