NORTH AMERICAN CRANIOFACIAL FAMILY CONFERENCE

Making a world of difference in a world of facial differences

“Energy”  Metin Bereketli
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.

Is proud to be a part of the 2007 North American Craniofacial Family Conference!

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

Toll Free: 1.866.823.8005
Email: foundation@jorgeposada.com
July 22, 2007

Dear Friends,

Welcome to our third annual North American Craniofacial Family Conference.

When I think back several years ago to the original suggestion that we even have such an event, I am so proud of the AF USA team and what we have accomplished. Much thanks is owed to Debbie Oliver, the AboutFace USA board, our Action Team and the many volunteers and generous donors who have made all of this happen.

Last year’s conference outdid our first and by all indications, this year will be even better.

We are so pleased that you could join us this year. As I have said in the past, please take the opportunity to renew old friendships, make new ones, share experiences, and enjoy being together.

Sincerely,

David J. Reisberg, DDS
President
## SCHEDULE

### SUNDAY, JULY 22, 2007

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
</tr>
</thead>
<tbody>
<tr>
<td>8:00-11:30 AM</td>
<td>Healing Art with Apollo 5 Metin Bereketli</td>
</tr>
<tr>
<td></td>
<td>Invited participants only, please. Learn more about Healing Art at <a href="http://www.metinbereketli.com">www.metinbereketli.com</a>.</td>
</tr>
<tr>
<td>12:00-1:00 PM</td>
<td>Leadership Meeting Apollo 3</td>
</tr>
<tr>
<td></td>
<td>Invited participants only, please.</td>
</tr>
<tr>
<td>12:00-1:00 PM</td>
<td>Pre-Conference Check-In Apollo Foyer</td>
</tr>
<tr>
<td>12:45-5:15 PM</td>
<td>Kids’ Camp Child Care Apollo 7 (Ages 0-6)</td>
</tr>
<tr>
<td></td>
<td>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) immediately following the workshop, scheduled to end approximately 5:00 PM.</td>
</tr>
<tr>
<td>1:00-5:00 PM</td>
<td>Pathfinder Outreach Workshop Apollo 3</td>
</tr>
<tr>
<td></td>
<td>Debbie Oliver Executive Director, AboutFace USA</td>
</tr>
<tr>
<td></td>
<td>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.</td>
</tr>
<tr>
<td>1:00-5:00 PM</td>
<td>Vendor/Exhibitor Check-In Apollo Foyer</td>
</tr>
<tr>
<td></td>
<td>Pick up your copy of the 2007 NACFC Exhibitor’s Guidelines attached to your table in the Apollo Conference Area (Apollo 1 and 2, Apollo Foyer).</td>
</tr>
<tr>
<td>6:00-8:00 PM</td>
<td>Conference Check-In Apollo Foyer</td>
</tr>
<tr>
<td></td>
<td>Apollo 1 &amp; 2 Welcome Reception</td>
</tr>
</tbody>
</table>

### MONDAY, JULY 23, 2007

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
</tr>
</thead>
<tbody>
<tr>
<td>7:00 AM</td>
<td>Conference Check-In Apollo Foyer</td>
</tr>
<tr>
<td></td>
<td>Apollo 1 &amp; 2 Continental Breakfast with Vendors/Exhibitors</td>
</tr>
<tr>
<td>7:30 AM</td>
<td>Kids’ Camp Child Care Apollo 7 (Ages 0-6)</td>
</tr>
<tr>
<td></td>
<td>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 5:15 PM.</td>
</tr>
<tr>
<td>8:00 AM</td>
<td>Getting to Know You - Icebreakers!</td>
</tr>
<tr>
<td></td>
<td>Teens (14-17), Pre-Teens (11-13) and Explorers (7-10) will participate in this Getting to Know You kick-off event!</td>
</tr>
<tr>
<td>8:00 AM</td>
<td>Conference Welcome Athena</td>
</tr>
<tr>
<td>8:15 AM</td>
<td>Keynote Kennedy</td>
</tr>
<tr>
<td></td>
<td>Ronald P. Strauss, DMD, PhD</td>
</tr>
<tr>
<td></td>
<td>Dental Friends Distinguished Professor, Chair, Department of Dental Ecology Professor of Social Medicine, University of North Carolina School of Dentistry</td>
</tr>
<tr>
<td></td>
<td>Only Skin Deep: Quality of Life, Stigma and Facial Appearance</td>
</tr>
<tr>
<td></td>
<td>A New Paradigm for Thinking about Children with Craniofacial Conditions</td>
</tr>
<tr>
<td></td>
<td>Imagine a different view of the impact of cleft lip/palate and craniofacial conditions that locates “blessings in disguise,” where disabilities and limitations were previously envisioned. Is it possible that there is wisdom in the song “Beauty’s Only Skin Deep”; that we need to look again at how appearance and facial difference impact the lives of affected persons with awareness that most such persons live healthy, full and satisfying lives? Could it be that a simple shift of vantage-point would allow us to see “being different,” as being unique; to see coping with stigma as a healthy human adaptation? Could we open the possibility that sometimes seeing the world from the position of a person with a facial difference may afford wisdom and perspective not other-</td>
</tr>
</tbody>
</table>
wise available? This talk considers a shift in how researchers might view children with special needs and how clinicians might approach families. This proposed shift in theory and viewpoint would have us focus on health and resilience in persons with craniofacial conditions—as opposed to problems, disabilities or issues.

Ron Strauss is a Sociologist of Medicine and a Dentist, with doctoral training in both from the University of Pennsylvania. In 1974, he joined the faculty of the University of North Carolina at Chapel Hill, where he is currently Dental Friends Distinguished Professor and Chair in the School of Dentistry’s Department of Dental Ecology and Professor in the School of Medicine’s Department of Social Medicine. Since 1977 he has been the Dental Director of the UNC Craniofacial Center. Ron Strauss’s research focus has been on the social impacts of chronic health problems with specific interests on stigma, craniofacial anomalies, and HIV/AIDS. His works on the psychological and social impacts of cleft lip/palate and other craniofacial anomalies reflect a combination of clinical and social science/ethical interests.

I 9:15-10:00 AM Workshop Modules

Apollo 3 Module I-Adults
The Adult Identity and Experience: Traveling Through the World with a Facial Difference
Lisa K. Gist, MA
Cleftline Manager, Cleft Palate Foundation

By the time we’ve come to see ourselves as adults, we’ve learned a great many things about how to move through the world with a facial difference. We may have acquired adaptive skills that help us engage in our lives, our communities, and our relationships in productive and satisfying ways. We may hold on to assumptions, beliefs, and expectations that simultaneously protect us but also keep us from engaging in life in the ways we’d like. In this solution-focused session we will:

1) Identify some of the social challenges experienced by adults with facial differences;
2) Ask participants to share their own skills and strategies for successful social experiences;
3) Examine some of the assumptions, beliefs, and expectations that can become obstacles, and;
4) Develop alternative ways over, under, and around those obstacles so that we find satisfying paths through the world.

Apollo 4 Module II-Parents
Everything You Wanted to Know About Your Child’s Teeth (But Didn’t Know to Ask)
David J. Reisberg, DDS
Professor and Medical Director, The Craniofacial Center
University of Illinois Medical Center at Chicago

Proper care of your child’s teeth from birth through adolescence with emphasis on special concerns relative to the cleft/craniofacial patient.

Apollo 5 Module III-Explorers’ Club (Ages 7-10)
The BULLY Breath Beast!
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 6 Module IV-Pre-Teens (Ages 11-13)
Module V-Teens (Ages 14-17)
I Am the Only Me!
Kristina Huddleston
Developmental Specialist, Nevada Early Intervention Services

What makes you unique? Come share your hidden talents and interests by creating an expressive work of art.

I 10:00 AM Break

Apollo 1 & 2

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

AboutFace USA thanks Wee Can Sign for its participation at the 2007 NACFC.
www.weecansign.com
SCHEDULE

MONDAY, JULY 23, 2007

■ 10:30-11:15 AM Workshop Modules

Apollo 4 Module I-Adults

Dental Management for the Adult Cleft Craniofacial Patient
David J. Reisberg, DDS
Professor and Medical Director,
The Craniofacial Center
University of Illinois Medical Center at Chicago

An overview of the dental/oral concerns for the adult cleft/craniofacial patient.

Apollo 3 Module II-Parents

Hey! Where Did Our Life Go? Nurturing a Family Life and a Couple’s Connection: A Field Guide to Life after Crisis
Lisa K. Gist, MA
Cleftline Manager,
Cleft Palate Foundation

In the middle of what seems like a comfortable and manageable routine comes something we aren’t expecting. Maybe it is a major health issue or job relocation or the death of a family member or friend. Or maybe we were expecting a baby that looks like every other baby and what we got was a baby that looked a little different. Before we know it, we seem to be spending a lot of our time learning to simply feed our baby and visiting doctors and the comfortable, manageable routine is lost to surgery schedules and accumulated hours on hold with the insurance company. Hey! Where did our life go?

In this solution-focused session we will:

1) Explore the phases of transition of major life events (having a child counts, having a child with a craniofacial birth defect counts double);
2) Figure out where we are in our own transitions (appreciating where we are while remembering that we’ll be somewhere else real soon);
3) Brainstorm new skills and identify existing strengths that make happy happen now rather than later (teaching a two-year old to pronounce ‘hemangioma’, teaching a six-year old to spell it).

■ 11:30-1:00 PM Danya International Apollo 3 & Apollo 5 Invite groups only, please.

Invited participants only, please. Parents of children with facial differences ages six (6) months through six (6) years of age who have previously registered with Danya International will participate in this research module. Child care will be provided for focus group participants only.

■ 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 - $13.95; children under 12 - $8.95. 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 1:00 PM
**SCHEDULE**

**MONDAY, JULY 23, 2007**

- **1:15-2:00 PM** Workshop Modules
  - **Apollo 3** Module I-Adults & Module II-Parents
    - The Art of Corrective/ Camouflage Make-Up
    - Linda Seidel, Author
    - Aesthetic Rehabilitation Specialist

  **Part A** - Linda Seidel’s on-going mission is to help people with the most challenging skin conditions-trauma and burn survivors, individuals with congenital craniofacial conditions and others-through the art of corrective and camouflage make-up. When she first began her work in 1974, the corrective make-up industry was non-existent. The cosmetics industry focused on glamour, but Linda developed her own techniques and products to assist individuals who wanted to camouflage post-surgical bruising, skin grafts, port wine stains, uneven skin tones, surgical scars and more.

  During this hands-on workshop, Linda will demonstrate skin-tone matching and application techniques with the gracious assistance of volunteers with various types of skin discoloration and scarring.

  **Apollo 4** Module II-Parents (Alternative)

  - **A Father’s Perspective**
    - Carl Dennison

  **A workshop for dads only.** Here’s your chance to share with other fathers your personal experiences with your child’s special circumstances. We will discuss the impact on our other family relationships (wife, other children, parents); role expectations and unique stressors for Dad; obstacles in securing medical and educational resources; financial pressures; as well as other areas of general interest to the group. Perhaps you’ve never really had the chance to talk with other fathers about your own reactions and feelings. Please join us in learning from each other!

  **Apollo 5** 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!

- **2:15-3:00 PM** Workshop Modules
  - **Apollo 3** Module I-Adults
  - **Module II-Parents**
  - **Module V-Teens**

  **Transitions**
  - **Karin Perry, Special Educator**
  - Framingham Public Schools, Framingham, MA

  Understand how to set goals and other important components critical for your success as we prepare for the adventure of the middle school and high school experience.
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!

■ 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

Early Starts: Implications of Prenatal Diagnosis for the Care of Craniofacial Conditions
Ronald P. Strauss, DMD, PhD

This session is about starting craniofacial care as early as is possible … in the realm of the prenatal era. We will explore the landscape of the social and ethical issues raised by the earliest possible start of caring. The introduction of early cleft and craniofacial diagnosis and treatment raises many social and ethical questions about how families, craniofacial teams, and society respond when a diagnosis is made and whether prenatal knowledge leads to an enhancement of the child’s and family’s quality of life. This talk will consider the societal impact of early treatment and prenatal diagnosis in terms of tolerance for human difference and will examine the issues that are likely to arise for parents, professionals and craniofacial centers.

Apollo 5
Module III-Explorers’ Club
(Ages 7-10)
Module IV-Pre-Teens (Ages 11-13)

Singing with Our Hearts, Hands and Voices
Karin Perry & Shannon Osborne

Part A - Young stars will have the chance to sing and dance away some energy during this workshop. We will learn some really funny songs, some sign language and some very funny dance moves and we'll be performing after dinner for all conference participants!

■ 4:30-5:15 PM Workshop Modules
Apollo 4
Module I-Adults & Module V-Teens (Ages 14-17)

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 her client’s facial structure by preventing fat storage in the upper body.

AboutFace USA thanks CDW Corporation for its support of outreach programs in the Southern Nevada region (www.cdw.com)
MONDAY, JULY 23, 2007

Apollo 3 Module II-Parents

Tips for Parents Whose Child is Bullied Because They Are Wonderfully and Uniquely Different
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 5 Module III-Explorers’ Club
(Ages 7-10)
Module IV-Pre-Teens
(Ages 11-13)

Singing with Our Hearts, Hands and Voices
Karin Perry & Shannon Osborne

Part B - Young stars will have the chance to sing and dance away some energy during this workshop. We will learn some really funny songs, some sign language and some very funny dance moves and we’ll be performing after dinner for all conference participants!

Apollo 7 Kids’ Camp Child Care
(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.

TUESDAY, JULY 24, 2007

On-Your-Own Breakfast
Alexis Gardens 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.

Danya International
Apollo 3 Focus Group

Invited participants only, please. Parents of children with facial differences ages seven (7) years through thirteen (13) years of age who have previously registered with Danya International will participate in this research module. Child care will be provided for focus group participants only.

8:30 AM Kids’ Camp Child Care
(Ages 0-6)

9:00 AM Special Guest
Athena Cindi Broaddus
Author, Motivational Speaker

A Random Act
An Inspiring True Story of Fighting to Survive and Choosing to Forgive

Cindi Broaddus, sister-in-law of Dr. Phil McGraw and a member of the Board of Directors of the Dr. Phil Foundation, will share her inspirational story. Cindi acquired facial and body differences in 2001 when she and a companion were driving down the highway and an unknown assailant dropped a gallon jar of sulfuric acid from an overpass, crashing through their windshield, causing severe burns.

Cindi has written a book and appeared on many national television shows, such as Larry King Live, Hour of Power and of course, Dr. Phil. Her story has appeared in numerous publications, including Good Housekeeping and Reader’s Digest, and she is responsible for pushing through the Cindi Broaddus Act in her home state of Oklahoma, which makes it a felony to throw anything from a bridge or overpass in that state.
TUESDAY, JULY 24, 2007

■ 10:00 AM  Break
Apollo 1 & 2

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

■ 10:15-11:00 AM  Workshop Modules

Athena  Module I-Adults
Support Networks for Adults
Debbie Oliver
Executive Director, AboutFace USA

In this workshop we’ll discuss how AboutFace USA can best support the adult craniofacial community. We’ll explore what particular types of educational and social activities are of interest to you and welcome your suggestions about future activities and outreach opportunities.

Apollo 4  Module II-Parents

Paper Trail Notebook
Robin Gibson
Parent Navigator, Stone Soup Group

The Paper Trail Notebook provides a way to simplify record keeping for children with special health care needs. It is a system to assist parents collect and organize the important papers and documents that accumulate as a child grows. The Paper Trail Notebook is designed to be useful for many years on the journey through childhood and beyond.

Apollo 3  Module III-Explorers’ Club
(Dates 7-10)

Danya International Focus Group

Invited participants only, please. Children with facial differences ages seven (7) years through ten (10) years of age who have previously registered with Danya International will participate in this research module.

Apollo 5  Module III-Explorers’ Club
(Alternative)
(Dates 7-10)

What I’d Like You to Know
AboutFace USA Staff

Sometimes it’s difficult sharing our feelings and ideas with others. During this workshop, we’ll take some time to reflect on what it is we wish others knew about us.

TUESDAY, JULY 24, 2007

Apollo 6  Module IV-Pre-Teens
(Ages 11-13)

Module V-Teens
(Ages 14-17)

Gimme a Break!

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

■ 11:15 AM-Noon Workshop Modules

Athena  Module I-Adults

What I’d Like You to Know
AboutFace USA Staff

Sometimes it’s difficult sharing our feelings and ideas with others. During this workshop, we’ll take some time to reflect on what it is we wish others knew about us.

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

The Evolution of Special Education
Elizabeth Crosby, MS, Special Education Orthopedic Impairment Specialist, Low Incidence Disabilities
Clark County School District, Las Vegas, NV

For parents of children age 3 and older. In this workshop we’ll take a look at changes in special education due to IDEA and the process for accessing services.

Apollo 4  Module II-Parents (Alternative)

Your Early Childhood Rights and Responsibilities
Joyce Bentz
Program Director, AboutFace USA

For parents of children ages birth to 3 years. 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.

Apollo 7  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 and the Shriners clowns!
TUESDAY, JULY 24, 2007

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

Danya International Focus Group

Invited participants only, please. Children with facial differences ages eleven (11) years through thirteen (13) years of age who have previously registered with Danya International will participate in this research module.

Apollo 6  Module IV-Pre-Teens (Alternative) (Ages 11-13)

Module V-Teens (Ages 14-17)

What I’d Like You to Know

AboutFace USA Staff

Sometimes it’s difficult sharing our feelings and ideas with others. During this workshop, we’ll take some time to reflect on what it is we wish others knew about us.

- 12:00-1:30 PM Buffet Lunch
  Parthenon 4  NACFC Sponsors

- Kids’ Camp Child Care will re-open at 1:00 PM

- 1:45-2:30 PM Workshop Modules
  Athena  Module I-Adults & Module II-Parents

Insurance

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.

TUESDAY, JULY 24, 2007

Apollo 5  Module III-Explorers’ Club (Ages 7-10)

Module IV-Pre-Teens (Ages 11-13)

Understanding Your Care
Kelley Kiesling, CCLS, UMC Children’s Services
Angela Harris, BS, CLS, Sunrise Children’s Hospital
Jodi Marumcic, BA, CLS, Sunrise Children’s Hospital

Part A - 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 3  Module V-Teens (Ages 14-17)

Support Networks for Teens
Debbie Oliver
Executive Director, AboutFace USA

In this workshop we’ll discuss how AboutFace USA can best support the adult craniofacial community. We’ll explore what particular types of educational and social activities are of interest to you and welcome your suggestions about future activities and outreach opportunities.

- 2:45-4:15 PM Workshop Modules
  Athena  Module I-Adults, Module II-Parents, Module V-Teens (Ages 14-17)

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

AboutFace USA thanks Chicago White Sox Charities for its support of outreach programs in the Chicagoland area (www.chisox.com)
TUESDAY, JULY 24, 2007

Jeff E. Moxley, DDS, PC
Oral and Maxillofacial Surgery
Diplomate American Board of Oral/Maxillofacial Surgery
Kelley Kiesling, CCLS
University Medical Center
Children’s Services

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.

Apollo 5
Module III-Explorers’ Club
(Ages 7-10)

Module IV-Pre-Teens
(Ages 11-13)

Understanding Your Care
Kelley Kiesling, CCLS,
UMC Children’s Services

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

Jodi Marumcic, BA, CLS,
Sunrise Children’s Hospital

Part B - 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!

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

We’ll wrap up the 2007 North American Craniofacial Family Conference with farewells and an ice cream sundae for the road!

WEDNESDAY, JULY 25, 2007 (OPTIONAL)

AboutFriends Day!
Get together with your new friends and explore 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 Child Care
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 guardian(s) 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/Videography
Please be prepared to sign a waiver and release pertaining to video and photographs taken by official event photographers, both contracted and volunteer. AboutFace USA, cleftAdvocate, and NACFC presenters, sponsors and vendors will utilize event video and photographs in 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!

Special Thanks to the AFUSA Action Team
Joyce Bentz - Program Director
Robin Remele - Action Team Coordinator
Kiku Collins • Milli Davis • Kelly Lanham
Kelly Luckey • Robert Oliver
Karin Perry • Marci Stark

AboutFace USA thanks 3dMD for its support of the 2007 North America Craniofacial Family Conference.
(www.3DMD.com)
Thank You — We couldn’t have done it without you!

3dMD
AboutFace USA Board of Directors
AboutFace USA Action Team
Alexis Park Resort
American Cleft Palate-Craniofacial Association
Matt Archibald, BSc
Avent
Baby’s Bliss Gripe Water
Julia Barry, BSc
Joyce Bentz
Metin Bereketli
Deb Breslow
CDW Corporation
Canica Design, Inc.
Chicago White Sox
Cindi Broaddus
CarePages
Deborah Carrillo
Maryann Casale
Child Care
Scherrie Adams-Ambré
Courtenay Adams-Ambré
Chardonnay Adams-Ambré
Glenn Allen, Sr.
Sharon Dockter
Janet Clackum
April Clackum
Dianna Barrett
Tamala Williams
Mark Conway
Echo Jones
Kate McGrawh
Children’s Craniofacial Association
Clark County School District
Cleft Palate Foundation
Cathy Coleman, BS, CCLS
Kiku Collins
The Craniofacial Center at UIC
Elizabeth Crosby, MS
Danya International
  Cynthia Baker, PhD
  Karen Gavin-Evans, PhD
  Greta Tresman
Milli Davis
Carl Dennison
Disney Stores, a Division of Children’s Place
FACES
FNIDCR
Family TIES of Nevada
Mike Fox & Company DJ Service
Genetic Alliance
Robin Gibson
Alan and Rickie Gill
Lisa K. Gist, M.A
Give Me A Break (GAB), Inc.
Angela Harris, BS, CLS
Kristina Huddleston
InDepth Graphics & Printing
Innovation
Kelley Kiesling, CCLS
Kelly Lanham
Las Vegas Convention and Visitors Authority
Let’s Face It
Scherr Lillico
Kelly Luckey
Jodi M arumíc, BA, CLS
Gina M atson
MedCAD
The Medi-Kid Co., Inc.
John M enezes, MD
Norma M ilne
Moebius Syndrome Foundation
Jeff E. M oxley, DDS, PC
Steve M uncy
Neostatra Company, Inc.
Nevada Early Intervention Services
Nevada PEP
JJ Nolan Craniofacial Support Group
Frank Nolimal, CLU, ChFC
Amanda Oliver
Jeffrey Oliver
Robert Oliver
Russell Oliver
Shannon Osborne
Parry Romberg Foundation
Karin Perry
The Jorge Posada Foundation
Jaleh Pourhamidi, D.M.D., M.D.Sc
Chase and Stephanie Pratt
Jennifer Ramiscal
Robin Remede
Jacqui Rivait
Judy Ryan
Erin Scott
Henry Schein, Inc.
Linda Seidel Professional
  Linda Seidel
  Stella Meister
M. Linda Siwek
Special Operations Associates, Inc.
Robert Spretnak
Marc Stark
Stone Soup Group
Ronald P. Strauss, D.M.D., PhD
Sunrise Children’s Hospital, Las Vegas
University Medical Center, Las Vegas
Wee Can Sign
Zelzah Shrine Center
Metin Bereketli

**Official Artist of the 2007 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, Mais on Francaise, Vizyon, Art Decor, M ozaik, Decor, Science of M ind, Positive Living, Impacto, NY 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 G eneral Hospital. To learn more about Metin Bereketli and the Healing Art program, visit www.metinbereketli.com.

Cover: “Energy”, Copyright Metin Bereketli, All Rights Reserved.
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.
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.”

The newest option for controlling and approximating cleft lips

Elastic tape slowly and gently guides tissue into position for surgery

• N.A.M. compatible
• Easy for parents to use
• Less tension on repair
• Less frequent change-outs
• Better placement of prolabium and premaxilla
• Post-operative tension relief on sutures
• Tape stretches as the mouth moves

DynaCleft™
Dynamic Cleft Approximation

To order product, call toll free 1-888-705-8310 or visit our website www.canica.com
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.

Thank You

The Family-to-Family Connection listserv is hosted by

Genetic Alliance

Sharon F. Terry, M A • President and CEO
4301 Connecticut Ave., N W • Suite 404 • Washington DC 20008
www.geneticalliance.org

linda seidel’s
natural cover system

Natural Cover Cream Foundation is
• Highly concentrated - a little goes a long way!
• Available in 20 true skin tone shades
• Silky smooth, feels virtually weightless on the skin
• The best concealer for all types of skin discoloration
• Dermatologist-tested - safe for the most sensitive skin

and when combined with Performing Powder
• creates a surface that is 100% waterproof and sweatproof
• looks and feels like a “second skin”
• stays on until you take it off - no annoying touch-ups!

Linda Seidel Professional is proud to support AboutFace USA.
Watch their website for more information in the coming weeks about how
Linda Seidel and Natural Cover can work for you!

linda seidel professional

10210 S. Dolfield Rd • Owings Mills, MD 21117 • 800-471-2601
Danya’s mission is to impact global public health and education through the development and implementation of innovative health communication, research, and technology programs.

Funded by the National Institute of Dental and Craniofacial Research, Danya is developing Facing Cleft, a program designed to support parents of children with cleft lip and palate from infancy through adolescence. Danya would like to thank cleftAdvocate for supporting the Facing Cleft project.

For more information, please contact:

Karen Gavin-Evans, Ph.D.
Principal Investigator
kgavin-evans@danya.com
240-645-1759

---

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 of 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

Moebius Syndrome Foundation, PO Box 147, Pilot Grove, MO 65276
vickimec@iland.net
The Latest in **Pediatric and Adult Immobilizers** from The Medi-Kid Company. Our immobilizers are ideal following surgeries, night splinting and for additional support while performing therapeutic exercises.

Be sure to browse our online catalog for an array of uses for our Pedi-Wrap pediatric arm and leg immobilizers and Medi-Wrap adult arm and leg immobilizers.
We envision a world where all people are accepted for who they are, not how they look.

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