

July 21-23, 2008 • Las Vegas, NV

NORTH AMERICAN CRANIOFACIAL FAMILY CONFERENCE

Making a world of difference in a world of facial differences



EDUCATE › INSPIRE › SERVE › LEAD



**The Jorge Posada Foundation
is a proud sponsor of the
2008 North American
Craniofacial Family Conference!**

P.O. Box 20541
New York, NY 10021

1.866.823.8005
foundation@jorgeposada.com

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 Luis, was diagnosed with Craniosynostosis when he was just ten days old and has undergone eight major surgeries to correct the condition.

July 20, 2008

Dear Friends,

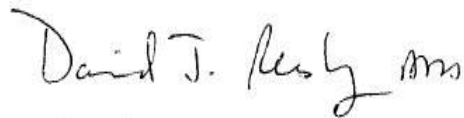
Welcome to our fourth annual North American Craniofacial Family Conference!

Since last year, much has happened. A new meeting site that is bigger and better. And even more noteworthy is our new name, **AmeriFace**. As I mentioned in my letter announcing this name change...new name, same great organization.

What is said about any organization is that it is only as good as the people associated with it. Well, you know this adage must be true just by looking at the all of the people involved with **AmeriFace**. Many thanks to Debbie Oliver, the **AmeriFace** board, our Action Team, the generous conference sponsors and exhibitors, and to the many volunteers and generous donors who make all of this happen.

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

Sincerely,



David J. Reisberg, DDS
President

**AmeriFace
Board of Directors**

David J. Reisberg, DDS
President

Christina Corsiglia
Vice President

Teresa Grillo
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Executive Director

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Program Director

Robin Remele

Action Team Coordinator



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The Daniel Patrick Roby Award for Excellence in Advocacy and Outreach



Dan Roby was an incredible young man ~ loved by his family, adored by his friends. By all accounts, he was a fun-loving guy who lived life to its fullest.
He was also a man born with a facial difference.

The Daniel Patrick Roby Award for Excellence in Advocacy and Outreach was developed to honor the memory of Daniel Patrick Roby and his commitment to the craniofacial community and the mission and programs of AmeriFace.

Nominations for the annual award will be accepted each February, beginning in 2009; the honoree will be notified each April.

All Nominees must have:

Committed themselves to the mission of AmeriFace for no fewer than two (2) years at the time of nomination;

Been non-compensated; that is, the nominee shall not have been paid via salary, hourly wage or independent contract for their service.

Shown exemplary commitment to the mission of AmeriFace.

Complete details of the 2009 DPR Award program will be available at www.ameriface.org on October 1, 2008.

ameri face | the
formerly AboutFace USA | cleft/craniofacial
advocates

Nomination Committee
Daniel Patrick Roby Award for Excellence in Advocacy and Outreach
AmeriFace, PO Box 751112, Las Vegas, NV 89136-1112
(888) 486-1209 • DPRAward@ameriface.org

SCHEDULE

SUNDAY, JULY 20, 2008

- **3:00 - 5:00 PM** Exhibitor Check-In
Florentine D

Pick up your conference packet and the 2008 NACFC Exhibitor Guidelines at the Registration Desk. Please note the name card displayed at your table in Florentine D.

- **4:00 - 6:00 PM** Leadership Meeting
Rotunda

Board members, Action Team members and Staff only, please.

- **6:00 - 8:00 PM** NACFC Registration
Florentine Foyer

Florentine D Welcome Reception

Check-in at the Registration Desk, then enjoy some meet-and-greet time with conference attendees and exhibitors. Taco buffet and beverages will be served. Cash bar available.

MONDAY, JULY 21, 2008

- **7:30 - 8:30 AM** NACFC Registration
Florentine Foyer

Florentine D Breakfast
with Exhibitors

Check-in at the Registration Desk, then enjoy some meet-and-greet time with conference attendees and exhibitors. A full breakfast will be served.

- **8:30 AM** Kids' Camp Child Care
Siena (Ages 0-6)

Child care is available for NACFC participants only. Please do not leave the Tuscany Suites & Casino 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 adjourn approximately 5:00 PM or the optional Pathfinder workshop, scheduled to adjourn approximately 6:00 PM.

- **9:00 AM** Getting to Know You
Icebreakers!
Florentine F
Savannah Howell, Instructor
Taylor Krempel, Instructor
Little Pastry Chefs
Las Vegas, NV

Teens (14-17), Pre-Teens (11-13) and Explorers (7-10) will participate in this very special Getting to Know You kick-off event!

MONDAY, JULY 21, 2008

- **9:00 AM** NACFC Welcome
Florentine C
David J. Reisberg, DDS
President, AmeriFace

Keynote William N. Williams, PhD
Professor and Director
University of Florida
Craniofacial Center
Gainesville, FL

What's the Big Deal about Velopharyngeal Insufficiency? What Does a Little Hypernasality Matter?

The keynote presentation will describe why velopharyngeal insufficiency (VPI), an often relatively small opening into the nasal cavity, can cause such troubling speech problems. Information will be presented on the importance of speech sounding "normal," and what happens to speech (resonance, articulation and voice) when the soft palate is not capable of closing off the opening (velopharyngeal port). Information also will be presented in commonly used strategies in correcting VPI including various surgical techniques, oral prosthetic devices, and/or speech therapy. The presentation will focus on how to best evaluate information provided by the team about velopharyngeal dysfunction, and understanding the reason for a specific treatment plan.

Dr. Bill Williams is Director and Professor of the University of Florida Craniofacial Center. He is a Fellow of the American Speech-Language-Hearing Association (ASHA) and is past president of the Florida Cleft Palate-Craniofacial Association. He is a recipient of the Florida Speech-Language-Hearing Association's Clinical Achievement Award, and the Honors of the Florida Cleft Palate-Craniofacial Association. He has published extensively on the topic of communicative disorders associated with craniofacial malformations. Dr. Williams is currently serving as principal investigator of an international NIH/NIDCR clinical trial investigating velopharyngeal function for speech for patients undergoing the von Langenbeck and the Furlow double z-palatoplasty in repairing cleft lip and palate.

- **10:15 AM** Break
Florentine D

Enjoy a beverage and be sure to visit the NACFC sponsors and exhibitors!

Cover Photo by Zorana Nikolich

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AmeriFace hosted Healing Art with Metin Bereketli at the 2007 North American Craniofacial Family Conference. Support AmeriFace with your purchase of an event poster at the Hospitality Desk for donation of \$5.00 or more!

Learn more about Healing Art!
www.metinbereketli.com

SCHEDULE

MONDAY, JULY 21, 2008

■ 10:45 - 11:45 AM Workshop Modules

Rotunda

Module I – Adults

The Adult Identity and Experience: Traveling Through the World with a Facial Difference

*Lisa K. Gist, MA
Director of Family Services
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.

Florentine C

Module II – Parents

Speech, Language, Articulation, Voice, Resonance and Intelligibility: Aren't These Basically All the Same Thing?

*William N. Williams, PhD
Professor and Director
University of Florida
Craniofacial Center
Gainesville, FL*

This workshop will be parent directed. However, to start the session a brief overview will be provided describing the parameters of speech, language, articulation, voice, resonance and intelligibility, and how a child with a cleft lip/palate might have a problem with each.

OPTIONAL: Pathfinder Outreach Workshop

Part A - Monday, July 21, 5:15 - 6:00 PM, Florentine C
Part B - Tuesday, July 22, 7:45 - 8:45 AM, Florentine G

Please let Kids' Camp Child Care know if you require extended child care for these workshops!

MONDAY, JULY 21, 2008

Executive Boardroom

Module III – Explorers' Club (Ages 7-10)

I Am the Only Me!

*Kristina Huddleston
Psychosocial Rehabilitation
Coordinator
Majestic Behavioral Health
Marriage/Family
Therapy Program, UNLV*

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

Florentine G

Module IV – Pre-Teens (Ages 11-13)

Module V – Teens (Ages 14-17)

Experience Music Therapy!

*Emily Wiggins, Music Therapist
Center for Creative
Therapeutic Arts, Las Vegas, NV*

Come experience music therapy hands-on – playing instruments, creating songs, and expressing your inner music!

■ 11:45 – 1:00 PM On-Your-Own Lunch

For your convenience, the Tuscany Suites and Casino has several dining choices on-site, whatever your taste! Take advantage of this opportunity to stay in, stay cool and be on-time for the afternoon sessions.

■ 1:00 PM Siena

Kids' Camp Child Care (Ages 0-6)

Child care is available for NACFC participants only. Please do not leave the Tuscany Suites & Casino 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 afternoon joint session, scheduled to end approximately 5:00 PM or the optional Pathfinder workshop, scheduled to adjourn approximately 6:00 PM.

Please plan ahead! Kids' Camp will be extended only for those attending the optional Pathfinder Outreach Workshop scheduled to adjourn at 6:00 PM. Please let our volunteers know if you require extended care to participate in this workshop.

SCHEDULE

MONDAY, JULY 21, 2008

1:15 PM
Florentine C

General Session

Sonja A. Rasmussen, MD, MS
Senior Scientist
Division of Birth Defects and
Developmental Disabilities
National Center on Birth Defects
and Developmental Disabilities
Centers for Disease Control
and Prevention (CDC)

Advancing the Understanding of Craniofacial Anomalies

This presentation will include a discussion of activities at the US Centers for Disease Control and Prevention (CDC) in the area of craniofacial anomalies, with a focus on research activities. The goal of these research activities is to identify factors that increase or decrease the chance that a baby is born with a craniofacial anomaly. In this presentation, Dr. Rasmussen will discuss the National Birth Defects Prevention Study, a large, multi-site, case-control study aimed at understanding genetic and non-genetic (environmental) factors for birth defects, including orofacial clefts. Other CDC activities that address craniofacial anomalies will also be briefly discussed.

Dr. Sonja Rasmussen received her Master's degree in Medical Genetics from the University of Wisconsin and her MD degree with honors from University of Florida College of Medicine. She completed her pediatrics residency training at Massachusetts General Hospital and her fellowship training in clinical genetics at Johns Hopkins Hospital and University of Florida. She is board certified in Pediatrics, Clinical Genetics and Genetic Counseling. Dr. Rasmussen joined the Centers for Disease Control and Prevention (CDC) in Atlanta in 1998 and currently serves as Senior Scientist for CDC's Division of Birth Defects and Developmental Disabilities. She has published nine book chapters and over 80 papers in the peer-reviewed literature. Her research interests include the identification of genetic and environmental risk factors for birth defects, mortality associated with genetic conditions, and the impact of infections on the pregnant woman and her fetus.

■ **1:15 - 2:15 PM** **Workshop Modules**

Floretine G

Module III – Explorers' Club *(Ages 7-10)*

Experience Music Therapy!
Emily Wiggins, Music Therapist
Center for Creative
Therapeutic Arts, Las Vegas, NV

Come experience music therapy hands-on – playing instruments, creating songs, and expressing your inner music!

MONDAY, JULY 21, 2008

Florentine F

Module IV – Pre-Teens *(Ages 11-13)*

Module V – Teens *(Ages 14-17)*

I Am the Only Me!
Kristina Huddleston
Psychosocial Rehabilitation
Coordinator
Majestic Behavioral Health
Marriage/Family
Therapy Program, UNLV

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

■ **2:30 - 3:30 PM** **Workshop Modules**

Rotunda

Module I – Adults

Module V – Teens (Alternative) *(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 his client's facial structure by preventing fat storage in the upper body.

Florentine C

Module II – Parents

Everything You Wanted to Know About Your Child's Teeth (But Didn't Know to Ask)
David J. Reisberg, DDS
Professor/Medical Director
The Craniofacial Center
University of Illinois
Medical Center at Chicago

For parents of children ages 0-3. Proper care of your child's teeth from birth through adolescence with emphasis on special concerns relative to the cleft/craniofacial patient. **See Wednesday's schedule for parents of children ages 3+.**

SCHEDULE

MONDAY, JULY 21, 2008

Florentine G

**Module II – Parents
(Alternative)**

Demystifying the IEP Process

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

For parents of children ages 3+. This workshop will provide an overview of the of writing and implementing an Individualized Educational Plan for your child with special needs.

**Executive
Boardroom**

**Module III – Explorers' Club
(Ages 7-10)**

The Bravest of the Brave!

*Lisa K. Gist, MA
Director of Family Services
Cleft Palate Foundation*

Sometimes it's tough being brave! In this workshop we'll explore how we feel about our healthcare experiences, and develop skills to help us better communicate with our doctors and parents about our care.

Florentine F

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

**Module V – Teens (Alternative)
(Ages 14-17)**

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!

■ **3:30 PM
Florentine D**

Break

Enjoy a treat and be sure to visit the NACFC sponsors and exhibitors!

Give Me A Break, Inc.
*Thank you for your dedication
to AmeriFace and the NACFC!*

www.givemeabreakinc.com

MONDAY, JULY 21, 2008

4:00 – 5:00 PM

Workshop Modules

Florentine G

**Module I – Adults
Dental Management for the
Adult Cleft/Craniofacial
Patient**

*David J. Reisberg, DDS
Professor/Medical Director
The Craniofacial Center
University of Illinois
Medical Center at Chicago*

This workshop will provide an overview of the dental/oral concerns for the adult cleft/craniofacial patient.

Florentine C

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
Director of Family Services
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).

AmeriFace thanks **Shannon Osborne**
of **Wee Can Sign** for her continued
commitment to the NACFC!
www.weecansign.com

SCHEDULE

MONDAY, JULY 21, 2008

Florentine F **Module III – Explorers' Club**
(Ages 7-10)

Module IV – Pre-Teens
(Ages 11-13)

Module V – Teens
(Ages 14-17)

**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 at the Celebration Dinner for all conference participants!

■ **5:15 - 6:00 PM** **Optional**

Florentine C **Pathfinder
Outreach Workshop**
*Debbie Oliver
Executive Director
AmeriFace*

Part A - The Pathfinder Outreach Network is the largest, most active support network of its kind for individuals with facial differences and their families. Pathfinders offer 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.

Visit pathfinders.ameriface.org for information about working with us to build your own local/regional support network.

TUESDAY, JULY 22, 2008

■ **7:30 - 8:30 AM** **NACFC Registration**
Florentine Foyer

Florentine D **Continental Breakfast
with Exhibitors**

Enjoy some meet-and-greet time with conference attendees and exhibitors. Continental breakfast will be served.

■ **7:30 AM** **Kids' Camp Child Care**
Siena (Ages 0-6)

Child care for those attending the optional Pathfinder Outreach Workshop only, please.

TUESDAY, JULY 22, 2008

■ **7:45 - 8:45 AM** **Optional**

Florentine G **Pathfinder
Outreach Workshop**
*Debbie Oliver
Executive Director
AmeriFace*

Part B - Focus groups will allow new and established Pathfinders to share ideas and establish goals for the coming year.

■ **8:30 AM** **Kids' Camp Child Care**
Siena (Ages 0-6)

Please do not leave the Tuscany Suites & Casino 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 adjourn approximately 5:00 PM.

■ **9:00 AM** **Special Guest**
Florentine C **Renée Rosen**
Author, Marketing Consultant

**Every Crooked Pot
Everyone has a Past...
It's Called Childhood!**

This session will include participation by Pre-Teens (11-13) and Teens (14-17)!

Renée Rosen used her experiences of growing up with a hemangioma to craft her critically acclaimed debut novel, *Every Crooked Pot*. Growing up in Akron, OH during the 1970s, she was often teased and ridiculed by classmates because of her birthmark and underwent several experimental medical procedures including laser treatments which were in their infancy at the time. Renee will discuss her novel and her journey to overcome the physical and emotional scars of her birthmark, along with the hidden blessings that arise from being "different."

Ms. Rosen has studied fiction writing with authors Susan Minot, Carol Anshaw, and Pulitzer Prize winning novelist Michael Cunningham. She has contributed to many magazines and newspapers, including the *Chicago Tribune*, *Complete Woman*, *DAME Magazine*, *Publishers Weekly*, and *Chicago Magazine*. She is a freelance writer and marketing consultant in Chicago and is currently working on a new novel.

Published by St. Martin's Press, *Every Crooked Pot* is a 2007 Booklist Editors' Choice pick, and has recently been nominated for a top spot on the 2008 Teen's Top Ten List.

SCHEDULE

TUESDAY, JULY 22, 2008

Florentine G **Module III – Explorers' Club**
(Ages 7-10)

Solving Problems
Debbie Oliver

In this workshop we'll take a look at some of the ways we can work through difficulties together - at home, at school and on the playground.

■ **10:15 AM** **Break**
Florentine D

Enjoy a beverage and be sure to visit the NACFC sponsors and exhibitors!

■ **10:45 - 11:45 AM Workshop Modules**

Executive Boardroom **Module I – Adults**

Facial Difference Over a Lifetime
Robin Dieda, LCSW
Transforming Images

Who would you be without a facial difference? How are you better, and worse, because of it? Come and explore how your experiences have changed you, and learn how others facing similar challenges have been changed. Can the act of self-examination actually impact your present and future? Come join us and find out. Bring your humor and creativity!

Florentine C **Module II – Parents**

My Team Journal: An Organized Way to Help in Your Child's Medical Journey
Jenny Gregory, CDT
Clinical Coordinator
Lancaster Cleft Palate Clinic

Having a child with a facial difference can be an overwhelming and emotional experience. It can also be difficult and confusing for parents to manage the many appointments and tons of paperwork they'll accumulate over the next 18 years.

The Lancaster Cleft Palate Clinic has developed a system to help parents keep track of team visits, hospitalizations and the paper trail throughout their child's care. Attendees will leave with a complete binder system that can be modified to individual needs.

TUESDAY, JULY 22, 2008

Rotunda **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!

Florentine F **Module III – Explorers' Club**
(Ages 7-10)

What I'd Like You to Know
AmeriFace Staff & Volunteers

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.

Florentine G **Module IV – Pre-Teens**
(Ages 11-13)

Module V – Teens
(Ages 14-17)

How's School?
Karin Perry, Special Educator
Framingham Public Schools
Framingham, MA

Understand how to set goals critical for your success in school, even when your health care may take you away from the classroom. Learn how to answer the hard questions. Talk to other kids in similar situations and see how they managed difficult situations in the classroom.

■ **11:45 – 1:00 PM On-Your-Own Lunch**

For your convenience, the Tuscany Suites and Casino has several dining choices on-site, whatever your taste! Take advantage of this opportunity to stay in, stay cool and be on-time for the afternoon sessions.

Every Crooked Pot
by Renee Rosen
The Church of 80% Sincerity
by David Roche
On Sale Today in Florentine D!

SCHEDULE

TUESDAY, JULY 22, 2008

■ **1:00 PM** **Kids' Camp Child Care**
Siena *(Ages 0-6)*

Please do not leave the Tuscany Suites & Casino 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 adjourn approximately 5:00 PM.

■ **1:15 PM** **Special Guest**
Florentine C **David Roche**
Inspirational Humorist

"My Face – A Gift"

This session will include participation by Teens (14-17)!

David Roche is an inspirational humorist, motivational speaker and performer who has transformed the lessons of lifelong facial disfigurement into a compelling message filled with courage, inspiration and laughter. Publishing his first book in February 2008 by the same name, he has performed his signature one-man show, *The Church of 80% Sincerity*, across the United States and in Canada, England, New Zealand, Australia, and Russia. In June 2008, he performed on the Millennium Stage at the John F. Kennedy Center for the Performing Arts in Washington DC.

David has appeared at the Clinton White House and headlined at the Olympics Arts Festival in Sydney, Australia. He and his wife Marlena Blavin present Love at Second Sight, a program for adolescents about appearance, acceptance and diversity. He has been featured in four films, including Shameless, a 2006 feature-length documentary by Bonnie Sherr Klein from the National Film Board of Canada. The Perfect Flaw, a 2005 documentary about David by Mike Grundmann, won first place awards at the Canadian International Annual Film & Video Festival and the Da Vinci Film & Video Festival. Two other award-winning films featuring David, Face First (Mike Grundmann, 1999) and Able to Laugh (Michael J. Dougan, 1993) have been seen worldwide.

■ **1:15 - 2:15 PM** **Workshop Modules**
Florentine F **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!

TUESDAY, JULY 22, 2008

Florentine G **Module IV – Pre-Teens**
(Ages 11-13)

What I'd Like You to Know
AmeriFace Staff & Volunteers

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.

■ **2:30 - 3:30 PM** **Workshop Modules**
Florentine C **Module I – Adults**

Module II – Parents

Module V – Teens
(Ages 14-17)

Storytelling Workshop
David Roche
Inspirational Humorist

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 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!

Florentine F **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!

Florentine G **Module IV – Pre-Teens**
(Ages 11-13)

Gimme a Break!

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

SCHEDULE

TUESDAY, JULY 22, 2008

- **3:30 PM** Break
Florentine D

Enjoy a beverage and be sure to visit the NACFC sponsors and exhibitors!

- **4:00 - 5:00 PM** Workshop Modules
Florentine C
Module I – Adults
Module II – Parents
Storytelling Workshop
David Roche
Inspirational Humorist

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!

- Florentine G** **Module III – Explorers' Club**
(Ages 7-10)
- Module IV – Pre-Teens**
(Ages 11-13)
- Module V – Teens**
(Ages 14-17)
- 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 at the Celebration Dinner for all conference participants!

Special Thanks to Channel 13 Action News!



For continued local coverage and support of our programs and the families we serve!

TUESDAY, JULY 22, 2008

- **6:30 - 10:30 PM** Celebration Dinner
Florentine D

Join us for an evening of fun and frolic! A brief program will be presented during dinner and dessert, including Singing with Our Hearts, Hands and Voices, a production by the children and teens attending the 2008 North American Craniofacial Family Conference.

Enjoy music and entertainment by Mariah's Sound Occasions! Visit www.soundoccasions.com.

As a special treat for NACFC guests, Kenneth & Barbara Gunn of BK Photography LLC are donating their time and expertise to take family portraits during the Celebration Dinner. Many thanks!

Whether you're dressing up for a more formal feel or you want to wear matching t-shirts for a more casual look, take this opportunity to remember the 2008 NACFC with a very special portrait. A digital file will be forwarded to you after the conference, suitable for printing with your local studio, print shop or even at home.

Professional prints from BK Photography LLC are available at a discount! See Kenneth and Barbara Gunn for additional details.

Be sure to visit www.bkfinephoto.com.

Special Thanks to

Bill Buczinsky

Founder, A Child's Voice Poetry

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Special Thanks to the AmeriFace Action Team

Joyce Bentz
Program Director

Robin Remele
National Action Team Coordinator

Kiku Collins • Milli Davis • Kelly Lanham
Kelly Luckey • Robert Oliver
Karin Perry • Marci Stark

SCHEDULE

WEDNESDAY, JULY 23, 2008

■ On-Your-Own Breakfast

Rest up from the Celebration Dinner or enjoy breakfast on your own at Marilyn's Café (open 24 hours) or Beachfront Coffee (open at 6:00 AM) at the Tuscany Suites and Casino.

■ 8:30 AM Kids' Camp Child Care Siena (Ages 0-6)

Please do not leave the Tuscany Suites & Casino 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 adjourn approximately 3:30 PM, when we'll all come together for a final farewell.

■ 9:00 AM General Session Florentine C

Valerie M. Rosalin, RN, BSN, MS, CPUR
*Director
Governor's Office for Consumer Health Assistance*

The Governor's Office for Consumer Health Assistance provides Nevada residents with information, referral resources and assistance with health-related issues and concerns. Services include assistance with insurance denials, hospital and provider billing, uninsured/underinsured, access to care, and advocacy issues. Similar services are available in many states.

■ 9:00 - 10:15 AM Workshop Modules Florentine F Module III – Explorers' Club (Ages 7-10)

How's School?
*Karin Perry, Special Educator
Framingham Public Schools
Framingham, MA*

Understand how to set goals critical for your success in school, even when your health care may take you away from the classroom. Learn how to answer the hard questions. Talk to other kids in similar situations and see how they managed difficult situations in the classroom.

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

Storytelling Workshop
David Roche

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 en-

WEDNESDAY, JULY 23, 2008

vironment 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!

Florentine G Module V – Teens (Ages 14-17)

What I'd Like You to Know
AmeriFace Staff & Volunteers

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.

■ 10:15 AM Break Florentine D

Enjoy a beverage and be sure to visit the NACFC sponsors and exhibitors!

■ 10:45 - 11:45 AM Workshop Modules

Rotunda Module I – Adults

Support Networks for Adults
*Debbie Oliver
Executive Director, AmeriFace*

In this workshop we'll discuss how AmeriFace 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.

Florentine C Module II – Parents

Everything You Wanted to Know About Your Child's Teeth (But Didn't Know to Ask)
*David J. Reisberg, DDS
Professor/Medical Director
The Craniofacial Center
University of Illinois
Medical Center at Chicago*

For parents of children ages 3+. Proper care of your child's teeth from birth through adolescence with emphasis on special concerns relative to the cleft/craniofacial patient. **See Monday's schedule for parents of children ages 0-3.**

SCHEDULE

WEDNESDAY, JULY 23, 2008

Florentine F

Module II – Parents (Alternative)

Your Early Childhood Rights and Responsibilities

*Donna Wolfbrandt
Family Specialist
Nevada Early Intervention Svcs.*

For parents of children ages 0-3. 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 and provide an understanding of the rights of infants, toddlers and their families.

Executive Boardroom

Module III – Explorers' Club (Ages 7-10)

How Much Do You Know About Bullies?

*Robin Remele
AmeriFace*

Do you know what bullying is? Do you know what it isn't? We'll take a look at how bullies operate, positive ways we can stop them in their tracks, and how to recognize when it's time to ask an adult for help.

Florentine G

Module IV – Pre-Teens (Ages 11-13)

Module V – Teens (Ages 14-17)

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.

■ 11:45 AM Florentine D

Buffet Lunch

Join us for a hearty pizza lunch buffet! Complete your conference evaluation form and return it to a staff member for a free raffle ticket! Explorers, Pre-Teens and Teens should complete an evaluation form, as well, to include their personal views about the NACFC event.

One evaluation form/raffle ticket per conference attendee, please. The drawing will be held at our afternoon farewell gathering.

WEDNESDAY, JULY 23, 2008

■ 1:00 PM Siena

Kids' Camp Child Care (Ages 0-6)

Child care is available for NACFC participants only. Please do not leave the Tuscan Suites & Casino 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 last joint session and workshops, scheduled to end approximately 3:30 PM. Families will be together for tasty treats, raffle prizes, gift bags and final farewells at the closing session in Florentine C.

■ 1:15 - 2:15 PM Workshop Modules

Florentine C

Module I – Adults

Module II – Parents

Module V – Teens (Ages 14-17)

Oral/Maxillofacial Surgery

*Jeff E. Moxley, DDS, PC
Oral and Maxillofacial Surgery
Diplomate American Board of
Oral/Maxillofacial Surgery*

We will discuss the role of the oral/maxillofacial surgeon on the cleft/craniofacial team, various types of oral/maxillofacial surgery, when jaw surgery and/or distraction osteogenesis might be indicated and state-of-the-art procedures.

Florentine G

Module III – Explorers' Club (Ages 7-10)

Module IV – Pre-Teens (Ages 11-13)

Module V – Teens (Alternate) (Ages 14-17)

Understanding Your Care

*Child Life
UMC Children's Services
Sunrise Children's Hospital*

Part A - This will be a group session facilitated by 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!

SCHEDULE

WEDNESDAY, JULY 23, 2008

■ 2:30 - 3:30 PM Workshop Modules

Florentine C

Module I – Adults

Module II – Parents

Module V – Teens (Alternate) (Ages 14-17)

Team Panel

*Jeff E. Moxley, DDS, PC
Oral and Maxillofacial Surgery
Diplomate American Board of
Oral/Maxillofacial Surgery*

*William N. Williams, PhD
Professor and Director
University of Florida
Craniofacial Center
Gainesville, FL*

*John Menezes, MD
Assistant Professor
Head Craniofacial Surgery
University of Nevada
School of Medicine*

*Cathy Coleman, BS, CCLS
UMC Children's Services*

Open forum - your questions are welcome!

Florentine G

Module III – Explorers' Club (Ages 7-10)

Module IV – Pre-Teens (Ages 11-13)

Module V – Teens (Alternate) (Ages 14-17)

Understanding Your Care

*Child Life
UMC Children's Services
Sunrise Children's Hospital*

Part B - This will be a group session facilitated by 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!

■ 3:30 PM

Closing Remarks

We'll wrap up the 2008 North American Craniofacial Family Conference with farewells, gift bags, a raffle and sweet treats for the road!

THURSDAY, JULY 24, 2008 (OPTIONAL)

Get together with your new friends and see the sights of Southern Nevada. Or maybe you'll just hang out at the pool. Whatever your mood, there's plenty to do in Las Vegas before you travel home...enjoy!

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 Tuscan Suites & Casino 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. AmeriFace, 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 (Florentine 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!

MISSION

EDUCATE › INSPIRE › SERVE › LEAD

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

We support individuals whose facial differences are present at birth, as well as those who have acquired facial differences as a result of illness, disease or trauma, such as stroke, cancer, accident and burns.

THE HISTORY OF AMERIFACE

Dear Friends,

It is my pleasure to share some very exciting news with you about our organization.

As you know, AboutFace USA was founded in 1991 to provide support for those with facial differences and their families. What began as a small group in Pennsylvania has grown into a truly national organization, reaching out to people all across America.

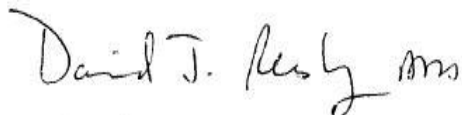
Over the years we have seen our membership grow and programs expand. Based upon many accomplishments, we have been fortunate to receive increased recognition and support from the medical community, the media, and from the general public for the great work done by the organization. More recently, we have made even greater strides; the unions with cleftAdvocate, the Crouzon and Goldenhar Syndrome Support Networks and the Treacher Collins Connection, the annual North American Craniofacial Family Conference, family support and education events throughout the country, annual fundraising events, our cooperative efforts with such celebrities as Montel Williams, Miss USA Crystle Stewart, Carmit Bachar of the Pussycat Dolls, artist Metin Bereketli, and even a local/regional connection to Oprah's Big Give.

With these many successes, our organizational growth, and so many exciting plans on the horizon now and in the future, our Board of Directors felt that a new name and logo should be chosen to reflect the upbeat, positive, forward movement of the organization. The name we've decided upon is AmeriFace....a new name but the same great organization and people.

I want to thank the Pathfinders, the Action Team, the Board, and of course, our executive director, for their unanimous support of this endeavor. It is a pleasure and a privilege to work with such a dedicated group. I also want to thank all of the other organizations with whom we work for their support as we all move ahead together toward a common goal.

AmeriFace looks forward to many more years of success.

Sincerely,



David J. Reisberg, DDS
President

PARTNERS

Thank You!

We couldn't have done it without you...

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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.

The Deaf and Hard of Hearing
Advocacy Resource Center (DHHARC)
welcomes you to Las Vegas!



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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

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Danya's mission is to impact global
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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.



MOEBIUS
SYNDROME
FOUNDATION

For more information contact

The Moebius Syndrome Foundation (660) 834-3406
www.moebius syndrome.com



Moebius Syndrome Foundation, PO Box 147, Pilot Grove, MO 65276
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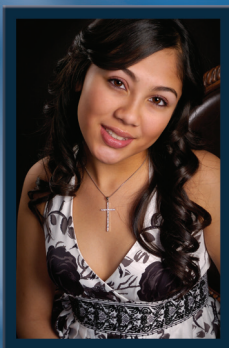
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The Organization with One Message:

Advancing Oral Health Research for a Better Quality of Life

Oral Health is Critical to Our Health as a Whole

The knowledge and treatments we take for granted today are only possible because of oral health investigators who devoted a lifetime in search of better answers.

A Coalition of Concerned Members

The Friends of the National Institute of Dental and Craniofacial Research (FNIDCR), a non-profit 501 C3 organization, is a broad-based coalition of:

- Corporations
- Dental Schools
- Dental Societies
- Individuals
- Patient Advocate Organizations

... who understand the critical importance of dental, oral and craniofacial research to the better health and well-being of society.

A Strong Patient Advocacy Agenda

Our mission is to educate the public and key decision makers about the importance of investing in the NIDCR (National Institute of Dental and Craniofacial Research) at the National Institutes of Health. We blend leaders from the scientific and professional communities with oral health patient advocacy groups to provide a common voice for our patient advocacy agenda.

Keeping Washington Committed to Research Funding

The Friends of the NIDCR works to ensure that oral health research is a priority in Washington. Proper federal funding of NIH and the NIDCR will transform the future of medical and dental practice to benefit our fellow citizens and will ease the burden on our nation's healthcare system. After all, translating what we learn in the lab to bring better patient care to the dentist's office ultimately affects health and quality of life for all of us.



Yes, I want to Support FNIDCR!
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Support FNIDCR: Your Voice for Oral Health Research!

Show your support of proper funding for dental and craniofacial research to ensure that major breakthroughs which position the United States as a global leader in medical research continue.

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