



July 19-22, 2009 › Las Vegas, NV

ameriface presents

NACFC

north american  
craniofacial  
family conference

Educate *Inspire*  
SERVE LEAD

*Making a world of difference in a world of facial differences*



**The Jorge Posada Foundation  
is a proud sponsor of the  
2009 North American  
Craniofacial Family Conference!**

P.O. Box 20541  
New York, NY 10021

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1.866.823.8005  
[www.jorgeposadafoundation.org](http://www.jorgeposadafoundation.org)

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 19, 2009

Dear Friends,

Welcome to our fifth annual North American Craniofacial Family Conference. Yes, that's right. NACFC is five years old! What a great milestone; and each year the conference gets bigger and better.

This year we are especially proud of the timing since July has been designated as Cleft/Craniofacial Awareness & Prevention Month. Congratulations to Debbie Oliver and her team for many years of hard work for this recognition.

To celebrate our 5th family conference, we have arranged a very special program of excellent and informative speakers that will help us all to navigate the world of craniofacial differences. We have even invited back a few of our most popular speakers from previous conferences to join the fun.

Thanks to The Tuscany for their generous support again this year and of course to Executive Director Debbie Oliver, the AmeriFace board, the Action Team, and all of you for another great year. And as I always 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*

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**Joyce Bentz**  
*Action Team Coordinator*



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## SEEING THE BEAUTY IN IMPERFECTION



Committed to raising public awareness of those affected  
by cleft lip and palate through positive storytelling.

[www.digitalbreakout.tv](http://www.digitalbreakout.tv)

702.683.5101

video production

post-production editing

graphic design



### 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.

# SCHEDULE

## SUNDAY, JULY 19, 2009

- **12:00 NOON**      **NACFC Registration**  
**Florentine Foyer**

Check-in at the Registration Desk for those attending the pre-conference Pathfinder Outreach Workshop.

- **12:30 PM**      **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) immediately following the Pathfinder Outreach Workshop, scheduled to adjourn approximately 5:00 PM.

- **1:00 - 5:00 PM**      **Pathfinder Outreach Workshop**  
**Florentine C**      *Debbie Oliver*  
*Executive Director, AmeriFace*

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.

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

Pick up your conference packet and the 2009 NACFC Exhibitor Guidelines at the Registration Desk. Please note the name card displayed at your table in Florentine D.

- **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.

## MONDAY, JULY 20, 2009

- **7:00 - 8:00 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.

## MONDAY, JULY 20, 2009

- **7:30 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 5:30 PM.

- **8:00 AM**      **Getting to Know You Icebreakers!**  
**Florentine F**      *AmeriFace Staff & Volunteers*

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

- **8:00 AM**      **NACFC Welcome**  
**Florentine C**      **David J. Reisberg, DDS**  
*President, AmeriFace*

**Presentation**  
**Debra Wagler, MA**  
*Maternal & Child Health*  
*Program Manager*  
*Nevada State Health Division*

**Proclamation**  
**Cleft/Craniofacial Awareness & Prevention Month**

- **8:30 AM**      **Keynote**  
**Florentine C**      **Drew Schnitt, MD**  
*Plastic Surgeon*  
*Craniofacial Specialist*  
*Diplomate, American Board of Plastic Surgery*

### Cleft & Craniofacial Treatment in The 21st Century

The keynote presentation will discuss anatomy, physiology and operative techniques in cleft lip, palate and craniofacial surgery. The details of how these surgeries are performed and the timing of surgery will be addressed.

Dr. Drew Schnitt specializes in pediatric craniofacial surgery. He serves as Vice President of the Florida Cleft Palate-Craniofacial Association and is the Former Director of the Vascular Malformation and Microtia Teams at Joe DiMaggio Children's Hospital in Florida. He attended George Washington University and earned his medical degree from Eastern Virginia Medical School (EVMS), Norfolk, Virginia. Dr. Schnitt's surgical education and training includes General Surgery Internship and Residency at Louisiana State University Medical Center; Plastic Surgery Chief Resident at the University of Oklahoma Health Sciences Center; and Fellowship at the Australian

# SCHEDULE

## MONDAY, JULY 20, 2009

Craniofacial Unit under the direction of Mister David David, Women's and Children's Hospital Adelaide.

Dr. Schnitt is also involved in Medical and Non-Medical Device Design and has collaborated with Stryker Cranio-maxillofacial, KLS Martin and others on the development and testing of various devices. A member of the American Cleft Palate-Craniofacial Association, Dr. Schnitt's most recent humanitarian surgical work has taken him to India, Ghana, Egypt and Peru. He also served as an Education Coordinator with Operation Smile.

### ■ 9:45 AM Break Florentine D

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

### ■ 10:15 - 11:30 AM Workshop Modules

#### Rotunda Module I – Adults

**Adult Identity**  
*Louise Ashby*  
*Actress, Author, Life Coach*

Participants will share experiences and identify some of the social challenges associated with having a facial difference. There will be a focus on identifying obstacles, sharing strategies and developing skills to ensure positive social experiences.

Facilitator Louise Ashby acquired a facial difference as an adult. The author of *The Magic of the Mask*, she is also an actress and life coach.

#### Florentine C Module II – Parents

**Special Oral Health Considerations for Children with Craniofacial Disorders**  
*Robert O. Cooley, DDS, MS*  
*Diplomate of the American Board of Pediatric Dentistry*  
*Professor Emeritus,*  
*Northwestern University*

Due to the obvious physical appearance of a child born with a craniofacial disorder, it is easy and perhaps natural to overlook some of the facets that may seem minor in the beginning. However, in the long run, aspects of care such as feeding, speech, hearing, oral disease and several other disciplines are important in the ideal treatment program for your child. Daily oral health care is essential in preserving both the primary and permanent dentition free from disease. Parents play a significant role in many daily tasks that permit health professionals to achieve their best result. Today's discussion will center around the various oral and dental considerations

## MONDAY, JULY 20, 2009

that require both professional and parental teamwork. A team concept will be discussed, but if a craniofacial team is not accessible, what should a parent do?

Dr. Cooley is the former head of the Division of Dentistry at Children's Memorial Medical Center Chicago, and the former Director of Pediatric Dentistry Residency Programs at Children's Memorial Hospital. He is a Past President, College of Diplomates of the American Board of Pediatric Dentistry and was a Craniofacial Team Member at Northwestern University and Shriners Hospital for Children, Chicago. Dr. Cooley is the Former Director of the Pediatric Dentistry Residency Training Program for the University of Nevada School of Medicine, Las Vegas, Nevada and served on staff at Sunrise Children's Hospital.

#### Florentine G 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!

Shannon Osborne has presented Wee Can Sign programs and workshops for the Clark County School District and the Clark County Young People's Library Summit, and has helped implement sign language programs in several childcare facilities, including Nellis Air Force Base Child Development Centers and the Lone Mountain Creative Learning Center. Shannon's desire is to teach parents and caregivers how to incorporate signs into their daily habits with pre-verbal babies and young children, as well as advance the research and benefits of a multi-sensory approach to language development for pre-verbal children.

#### Florentine F 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.

AmeriFace thanks **Shannon Osborne** of **Wee Can Sign** for her continued commitment to the NACFC!  
**[www.weecansign.com](http://www.weecansign.com)**

# SCHEDULE

## MONDAY, JULY 20, 2009

### Florentine E

### Module V – Teens (Ages 14-17)

### M.A.G.I.C. - Mastering Attitude Generates Increased Confidence Star Alexander

How we see ourselves and what we believe to be possible has a great deal to do with the outcome of any situation. This unique combination of magic and interactive discussion is designed to teach life skills and build character while participants learn about magic as an art form and gain an appreciation for professional performance.

Formerly known as I AM MAGIC, the M.A.G.I.C. program was born in 1990 to help children develop a strong sense of character and positive self image. Star Alexander presents M.A.G.I.C. to schools, YMCA day camps, spring breaks, youth retreats and parks and recreation programs, incorporating "magical" illustrations while promoting self-esteem, responsibility, motivation and teamwork.

### ■ 11:30 – 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.

### ■ 12:30 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 last afternoon session, scheduled to adjourn approximately 5:30 PM.

### Special Thanks to the AmeriFace Action Team

**Robin Remele**  
*Program Director*

**Joyce Bentz**  
*National Action Team Coordinator*

**Kiku Collins • Sandi Daniels • Milli Davis  
Kelly Luckey • Robert Oliver • Karin Perry**

## MONDAY, JULY 20, 2009

### 1:00 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)*

### Genetics: What You Need to Know

This presentation will include a basic overview of genetics and then focus specifically on information for families with a child with cleft lip/palate, craniosynostosis, or other facial difference. The importance of a medical genetics evaluation and of knowing your family health history will also be 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.

**The World Craniofacial Foundation  
is pleased to support the  
2009 North American  
Craniofacial Family Conference.**

**Please visit our website**

**[www.worldcf.org](http://www.worldcf.org)**

**for more information on our  
nonprofit and programs.**

# SCHEDULE

## MONDAY, JULY 20, 2009

- **1:00 - 2:15 PM Workshop Modules**
- Florentine G**      **Module III – Explorers' Club**  
(Ages 7-10)
- Module IV – Pre-Teens**  
(Ages 11-13)
- Module V – Teens**  
(Ages 14-17)
- Totally Awesome Talented Kids!**  
*Shannon Osborne*  
*Wee Can Sign*
- Joelle Jenson*  
*Singer/Songwriter*  
*Lead Magic Assistant to*  
*Lance Burton*

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

Shannon Osborne has presented Wee Can Sign programs and workshops for the Clark County School District and the Clark County Young People's Library Summit, and has helped implement sign language programs in several childcare facilities, including Nellis Air Force Base Child Development Centers and the Lone Mountain Creative Learning Center. Shannon's desire is to teach parents and caregivers how to incorporate signs into their daily habits with pre-verbal babies and young children, as well as advance the research and benefits of a multi-sensory approach to language development for pre-verbal children.

Joelle Jenson is an accomplished singer/songwriter and the lead magic assistant to Master Magician Lance Burton, having been with the show for the past 17 years. As a professional dancer, she also appeared in the world famous "Les Folies Bergere" at the Tropicana Hotel in Las Vegas. Joelle has performed in Africa, Japan, and the Caribbean, but is happiest when she's working at home in Las Vegas. A devout Christian, one of Joelle's great passions is writing original worship songs for the Women's Ministry through Canyon Ridge Christian Church.

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

[www.givemeabreakinc.com](http://www.givemeabreakinc.com)

## MONDAY, JULY 20, 2009

- **2:30 - 3:30 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.

***The Church of 80% Sincerity***  
*by David Roche*  
**On Sale Today**  
**in Florentine D!**

**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).

# SCHEDULE

## MONDAY, JULY 20, 2009

- **2:30 - 3:30 PM Workshop Modules**
- Florentine E**      **Module III – Explorers' Club**  
(Ages 7-10)
- Module IV – Pre-Teens**  
(Ages 11-13)
- M.A.G.I.C. - Mastering Attitude Generates Increased Confidence**  
*Star Alexander*

How we see ourselves and what we believe to be possible has a great deal to do with the outcome of any situation. This unique combination of magic and interactive discussion is designed to teach life skills and build character while participants learn about magic as an art form and gain an appreciation for professional performance.

Formerly known as I AM MAGIC, the M.A.G.I.C. program was born in 1990 to help children develop a strong sense of character and positive self image. Star Alexander presents M.A.G.I.C. to schools, YMCA day camps, spring breaks, youth retreats and parks and recreation programs, incorporating "magical" illustrations while promoting self-esteem, responsibility, motivation and teamwork.

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

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

- **4:00 - 5:30 PM Workshop Modules**
- Florentine C**      **Module I – Adults**
- Module II – Parents**
- Storytelling Workshop**  
*David Roche*  
*Inspirational Humorist*

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!

## MONDAY, JULY 20, 2009

- Florentine G**      **Module III – Explorers' Club**  
(Ages 7-10)
- Module IV – Pre-Teens**  
(Ages 11-13)
- Module V – Teens (Alternative)**  
(Ages 14-17)
- Celebration!**  
*AmeriFace Staff & Volunteers*

Hey, kids...can you keep a secret? Don't give away the details until the big reveal on Tuesday night!

- **6:00 - 8:00 PM Deli Buffet Dinner**  
**Florentine D**

Beat the heat! Enjoy dinner and some great family fun before you head to the pool!

## TUESDAY, JULY 21, 2009

- **7:00 - 8:00 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.

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

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**Special Thanks to**  
**Bill Buczinsky**  
*Founder, A Child's Voice Poetry*

The Ultimate  
Children's Poet and Performer  
**[www.childs-voice-poetry.com](http://www.childs-voice-poetry.com)**

# SCHEDULE

## TUESDAY, JULY 21, 2009

**8:00 – 9:15 AM**  
**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)*

### Craniosynostosis: What It Is and How It Occurs

Craniosynostosis is an abnormality of the skull caused by premature fusion of one or more cranial sutures, the fibrous connections between adjacent bones in the skull. These sutures allow passage of the head through the birth canal and permit the rapid brain growth that occurs early in life. Craniosynostosis occurs in approximately one in 2,000 births and usually requires surgical correction. Untreated, it can lead to an abnormal head shape, restriction of brain growth, and increased intracranial pressure.

Craniosynostosis can be classified by which suture(s) prematurely closed (sagittal, coronal, lambdoid, metopic, or multiple) and by whether it is isolated or accompanied by other major defects or a syndrome (that is, a single-gene disorder or chromosome abnormality). Craniosynostosis has been associated with over 100 syndromes. Genetic and environmental risk factors for craniosynostosis have been identified, but in most cases, the cause is unknown. In this presentation, we will provide an overview of craniosynostosis, including a discussion of the different types and how often they occur, and an update on the search for genetic and environmental risk factors.

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.

## TUESDAY, JULY 21, 2009

■ **8:00 - 9:15 AM** **Workshop Modules**

### Florentine G

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

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

Congratulations! You have just been given an entire state to call your own! Now it's time to name the state and design the license plates. What will the plates look? What will they say about you and the state you own?

### Florentine E

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

### Module V – Teens (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!

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### Special Thanks to Channel 13 Action News!



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

# SCHEDULE

## TUESDAY, JULY 21, 2009

### ■ 9:30 - 10:30 AM Workshop Modules

#### Florentine E

#### 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*

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

#### Florentine C

#### Module II – Parents (ALT)

##### **Taking the Fear Out of Hospitalization**

*Sara Richins, CCLS  
Child Life Specialist  
University Medical Center  
Children's Services  
Las Vegas, NV*

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.

#### Rotunda

#### Module II – Parents (ALT)

##### **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 G

#### 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.

## TUESDAY, JULY 21, 2009

#### Florentine F

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

##### **The Worry Pot**

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

Toil, toil, boil and trouble! Sometimes our inner "worry pots" start boiling over. This workshop will utilize peer support to find real answers to your worries.

#### Florentine A

#### Module V – Teens (Ages 14-17)

##### **Video Project**

*Al Pedroza  
Videographer  
Digital Breakout*

Teens will interact in a casual group atmosphere, relating their experiences, thoughts and expectations to videographer Al Pedroza for the AmeriFace video project. Please review the project outline; parent permission is required for videotaping.

### ■ 10:30 AM Florentine D

#### Break

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



**Empowering Children for Success!**

[www.MyKidzMatter.com](http://www.MyKidzMatter.com)

# SCHEDULE

## TUESDAY, JULY 21, 2009

**11:00 – 11:45 AM**  
**Florentine C**

**Special Guest**  
**Louise Ashby**  
*Actress, Author, Life Coach*

**Skin Deep**  
**Getting Comfortable With**  
**Who I Am Inside and Out**

At the age of 22, Louise was a gorgeous young woman working in London as an actress and model, one of a small group of thespians that were on the cusp of stardom. In 1992, cut adrift by the loss of her mother, Louise took the plunge and moved thousands of miles away to Los Angeles.

Shortly thereafter, Louise was the victim of what city authorities described as the worst auto accident in the area in thirty years. A motorist driving on the wrong side of the road hit Louise's car head-on. Although wearing her seat belt, Louise hit the upper frame of the windshield with her face. The left side of her skull was crushed; her brain completely exposed.

To date, it has taken eighteen reconstructive surgeries to recreate her face. Louise will share her experiences and the challenges, both internal and external, that she had to overcome to keep her dream alive.

**Florentine G**

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

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

**Gimme a Break!**  
*AmeriFace Staff and Volunteers*

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

**Florentine E**

**Module V – Teens**  
*(Ages 14-17)*

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

Toil, toil, boil and trouble! Sometimes our inner "worry pots" start boiling over. This workshop will utilize peer support to find real answers to your worries.

## TUESDAY, JULY 21, 2009

■ **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.

■ **12:30 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 last afternoon session, scheduled to adjourn approximately 5:00 PM

**1:00 – 2:00 PM**  
**Florentine C**

**Special Guest**  
**Gina Butchin**  
*AmeriFace Pathfinder*

**Different is Divine**

Gina Butchin was born with a cleft lip and palate, and she believes there are really just three simple rules for surviving life with a facial difference. A devoted wife and mother, Gina will share her story of challenge and triumph and how it came to pass that she now serves the craniofacial community as a Pathfinder outreach volunteer.

■ **1:00 - 2:00 PM Workshop Modules**

**Florentine G**

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

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

**Module V – Teens**  
*(Ages 14-17)*

**Achieving Goals on the**  
**Road to Leadership**  
*Leland Brandon*  
*Master Instructor*  
*Kidz Matter*

This dynamic and interactive workshop will teach children and teens how to set and achieve goals and understand how to develop the skills required for Leadership.

The founders of Kidz Matter are experts in child development training. With over 40 years of combined experience, they have developed and implemented programs that have impacted the lives of thousands of children. Their programs focus on the development of physical, mental, and character-building skills, which contribute to life-long success. Learn more about Empowering

# SCHEDULE

## TUESDAY, JULY 21, 2009

### ■ 2:15 - 3:15 AM Workshop Modules

**Florentine E**

**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.

**Florentine G**

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

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

**Nia**

*Karen Alexander*

Nia's approach to fitness and working out addresses the whole person, placing attention on integration, play, and sensory awareness. Participants will experience movement that will engage the body, mind, emotion and spirit, used to recognize personal power, foster self-healing and expand each person's potential.

Karen Alexander began her dance career at the age of five. She has studied with the Boston Ballet, the International Ballet School in Yugoslavia and the American Society of Russian Style Ballet in Boston. In 1978 Karen met and studied extensively with Madame Anna-Roje, protégé and only assistant to the great Russian teacher Nicolas Legat. Karen completed a three-year program from the Dance Teacher's Club of Boston and is a certified dance instructor. She has taught ballet in studios on the South Shore and Boston. In 2004 Karen found Nia and fell in love with it, becoming a white belt certified teacher in November 2008. Karen brings the Joy of Nia to the studio where she has taught ballet for so many years. For more information, contact [www.nianow.com](http://www.nianow.com) or call 1-800-762-5762.

## TUESDAY, JULY 21, 2009

**Rotunda**

**Module V – Teens  
(Ages 14-17)**

**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 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!

### ■ 3:15 PM Break Florentine D

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

### ■ 3:45 - 4:45 AM Workshop Modules

**Florentine C**

**Module I – Adults**

**Module II – Parents**

**MetDESK®**

**MetLife's Division of Estate  
Planning for Special Kids**

*Glenn Merryman, LUTCF, CLTC  
MetDESK® Specialist*

*Andre Thornton*

*Financial Services  
Representative*

MetDESK® was created to serve families with children and/or dependents of all ages with disabilities. This workshop will address critical areas of concern for a dependent with special health care needs, such as government benefit eligibility for SSI and Medicaid, a review of guardian, conservatorship, and client self-determination and advocacy issues, and determining appropriate funding vehicles, such as life insurance, to help assure not only lifetime care, but quality of life.

# SCHEDULE

## TUESDAY, JULY 21, 2009

### Florentine G

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

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

**Module V – Teens**  
(Ages 14-17)

**Totally Awesome  
Talented Kids!**

*Shannon Osborne  
Wee Can Sign*

*Joelle Jenson  
Singer/Songwriter  
Lead Magic Assistant to  
Lance Burton*

**Part B** - Young stars will have the chance to sing and dance away some energy during this workshop. We will learn some songs, some sign language and some dance moves...and we'll be performing at the Celebration Dinner for all conference participants!

### ■ 6:00 - 10:00 PM 5th Anniversary Florentine D Celebration Dinner

Join us for an evening of fun and frolic! A brief program will be presented during dinner and dessert, including entertainment provided by Totally Awesome Talented Kids, a production by the children and teens attending the 2009 NACFC. More music and entertainment by Mariah's Sound Occasions!

## WEDNESDAY, JULY 22, 2009

### ■ 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)

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 4:30 PM.

## WEDNESDAY, JULY 22, 2009

### 9:00 – 10:00 AM Florentine C

### General Session

**Drew Schnitt, MD**  
*Plastic Surgeon  
Craniofacial Specialist  
Diplomate, American Board  
of Plastic Surgery*

### Medical Missions Abroad

As a surgeon and an education coordinator for cleft/craniofacial surgical missions, Dr. Schnitt has traveled with volunteer medical teams to Venezuela, Bolivia, Russia, Kenya, Thailand, China and several other countries. Today he shares his personal photographs and stories of hope from around the world.

### ■ 9:00 - 10:00 AM Workshop Modules

#### Florentine G

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

#### Storytime

*AmeriFace Staff & Volunteers*

Many of our favorite storytime friends have to visit the doctor and the hospital just like we do. Do we have any advice to offer them? Do they have any advice for us?

#### Florentine E

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

**Module V – Teens**  
(Ages 14-17)

**Leaving Pediatric  
Healthcare and Entering the  
World of Adult Medicine  
(Youth Perspective)**

*Nicole Schomberg  
Project Director  
Family TIES of Nevada*

*Melissa Krutsinger  
Training Coordinator  
Family TIES of Nevada*

**Part A** – As adolescents grow older, they leave pediatric health care and enter the world of adult medicine. For some, this is an easy transition. For those with special health care needs including craniofacial conditions, it can be complex and scary. For this reason it is important that youth with special health care needs know how to manage their own health care and work with appropriate professionals as partners in their care.

Youth will learn the information and supports they need to be more in charge of their own health care, including how to communicate more effectively with their health care providers; how to manage appointments; and how to develop a health transition timeline.

# SCHEDULE

## WEDNESDAY, JULY 22, 2009

### ■ 10:00 AM Break Florentine D

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

### ■ 10:30 - 11:30 AM Workshop Modules

#### Rotunda 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.

#### Florentine C Module II – Parents

##### **An Overview of Children’s Friendship Training** *Nicole Ann Cavenagh, PhD Clinical Director Pediatric Neuropsychology Touro University Nevada Center for Autism and Developmental Disabilities*

*Kathy Patten, MPA, OTR/L  
Occupational Therapist  
Touro University  
Nevada Center for Autism and Developmental Disabilities*

Parents will be provided with a brief overview of Children’s Friendship Training, an evidence-based social skills intervention that is administered in a group format and is parent-assisted. Children’s Friendship Training was developed at UCLA’s David Geffen School of Medicine. This program covers such social skills as having a two-way conversation, joining in with a group of children already at play, being a good sport, being a good host/guest, and coping with bullying and teasing.

Parents will experience the module that is designed to address coping with teasing during this session. They will be taught strategies that they can apply at home to help their child better deal with being teased. Parents will receive handouts that outline the key points addressed during this session.

## WEDNESDAY, JULY 22, 2009

### Florentine G Module III – Explorers’ Club (Ages 7-10)

#### **Gimme a Break!** *AmeriFace Staff and Volunteers*

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

### Florentine E Module IV – Pre-Teens (Ages 11-13)

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

##### **Leaving Pediatric Healthcare and Entering the World of Adult Medicine (Youth Perspective)** *Nicole Schomberg Project Director Family TIES of Nevada*

*Melissa Krutsinger  
Training Coordinator  
Family TIES of Nevada*

**Part B** – As adolescents grow older, they leave pediatric health care and enter the world of adult medicine. For some, this is an easy transition. For those with special health care needs including craniofacial conditions, it can be complex and scary. For this reason it is important that youth with special health care needs know how to manage their own health care and work with appropriate professionals as partners in their care.

Youth will learn the information and supports they need to be more in charge of their own health care, including how to communicate more effectively with their health care providers; how to manage appointments; and how to develop a health transition timeline.

### ■ 11:30 AM Buffet Lunch Florentine D

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.

# SCHEDULE

## WEDNESDAY, JULY 22, 2009

### ■ 12:30 PM 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) immediately following the afternoon joint session, scheduled to end approximately 4:30 PM. Families will be together for tasty treats, raffle prizes, gift bags and final farewells at a reception in Florentine D.

### ■ 1:00 - 2:00 PM 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

**Leaving Pediatric Healthcare and Entering the World of Adult Medicine (Parent Perspective)**  
*Nicole Schomberg*  
Project Director  
Family TIES of Nevada

*Melissa Krutsinger*  
Training Coordinator  
Family TIES of Nevada

**Part A** – As adolescents grow older, they leave pediatric health care and enter the world of adult medicine. For some, this is an easy transition. For those with special health care needs including craniofacial conditions, it can be complex and scary. For this reason it is important that youth with special health care needs know how to manage their own health care and work with appropriate professionals as partners in their care.

Parents will learn the information and supports they need to help their child be more in charge of their own health care, including how to develop a health transition timeline with their child; how to involve youth in decision-making; and health insurance options for children over age 18.

## WEDNESDAY, JULY 22, 2009

### Florentine E

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

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

### Module V – Teens (Ages 14-17)

### Children's Friendship Training Tease the Tease

*Nicole Ann Cavenagh, PhD*  
Clinical Director  
Pediatric Neuropsychology  
Touro University  
Nevada Center for Autism and  
Developmental Disabilities

*Kathy Patten, MPA, OTR/L*  
Occupational Therapist  
Touro University  
Nevada Center for Autism and  
Developmental Disabilities

**Part A** – Children will participate in the Children's Friendship Training module that addresses coping with being teased. Children will learn real-life strategies that can be employed to cope with, and reduce the chances of future, teasing. This module is called "Tease the Tease." By the end of the session, children will be able to identify which strategies work to reduce the frequency and intensity of teasing that they experience.

### ■ 2:15 - 3:15 PM Workshop Modules

#### Rotunda

#### Module I – Adults

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

It is sometimes necessary to revise previous reconstructive surgery or complete treatment during adulthood. Often the needs and challenges of adult patients differ greatly from those of pediatric patients. This workshop will consist of an open Q&A session.

# SCHEDULE

## WEDNESDAY, JULY 22, 2009

### Florentine C

### Module II – Parents

#### Leaving Pediatric Healthcare and Entering the World of Adult Medicine (Parent Perspective)

*Nicole Schomberg  
Project Director  
Family TIES of Nevada*

*Melissa Krutsinger  
Training Coordinator  
Family TIES of Nevada*

**Part B** – As adolescents grow older, they leave pediatric health care and enter the world of adult medicine. For some, this is an easy transition. For those with special health care needs including craniofacial conditions, it can be complex and scary. For this reason it is important that youth with special health care needs know how to manage their own health care and work with appropriate professionals as partners in their care.

Parents will learn the information and supports they need to help their child be more in charge of their own health care, including how to develop a health transition timeline with their child; how to involve youth in decision-making; and health insurance options for children over age 18.

### Florentine E

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

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

### Module V – Teens (Ages 14-17)

### Children's Friendship Training Tease the Tease

*Nicole Ann Cavenagh, PhD  
Clinical Director  
Pediatric Neuropsychology  
Touro University  
Nevada Center for Autism and  
Developmental Disabilities*

*Kathy Patten, MPA, OTR/L  
Occupational Therapist  
Touro University  
Nevada Center for Autism and  
Developmental Disabilities*

**Part B** – Children will participate in the Children's Friendship Training module that addresses coping with being teased. Children will learn real-life strategies that can be employed to cope with, and reduce the chances of future, teasing. This module is called "Tease the Tease." By the end of the session, children will be able to identify which strategies work to reduce the frequency and intensity of teasing that they experience.

## WEDNESDAY, JULY 22, 2009

### ■ 3:30 - 4:30 PM

### General Session

### Florentine C

### 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 (Ages 14-17)

**Let's get this party started!** While the adults are attending the last educational session of the conference, we have something planned for our fabulous children and teens as a kick-off to the Farewell Reception!

### ■ 4:30 PM

### Farewell Reception

We'll wrap up the 2009 North American Craniofacial Family Conference with farewells, a raffle and lots of great surprises! Oh, and some sweet treats for the road!

## THURSDAY, JULY 23, 2009 (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!

**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.

**This program is subject to change.**

# MORE INFO

**FREE Family Portraits!** During our 5th Anniversary Celebration Dinner on Tuesday night, be sure to redeem your certificate for free portraits, courtesy of BK Photography. Family sittings, couples, individuals...it's up to you! After the conference you will receive digital files of your photos; print them yourself or have the wonderful folks at BK Photography professionally print them for you at a deep discount. There is no obligation to purchase prints. Many thanks to Kenneth and Barbara Gunn and family!

**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!

**Watch Your Valuables!** It's very easy to be distracted with all the great things going on at the NACFC, but don't forget to secure your valuables. While we have security personnel on-site, AmeriFace is not responsible for lost or stolen articles.

**AmeriFace Video Project** AmeriFace has teamed up with Al Pedroza and Digital Breakout to produce a video that will inspire others to look past our differences and think deeper about what true beauty really is. We couldn't think of a better place to start the videotaping than here at the 5th Anniversary NACFC, where families are gathered in a pleasant and uplifting atmosphere; where experiences are shared and stories are told and life-long friendships begin.

An additional consent form is required to participate in the videotaped interviews. Parents/guardians must consent for minor children to participate. See complete project information in the handout included with your conference packet.



ameriface • po box 751112 • las vegas, nv 89136 888.486.1209

## 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](http://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.*

# PARTNERS

## Thank You! We couldn't have done it without you...

*AmeriFace Board of Directors*  
*AmeriFace Action Team*  
*American Cleft Palate-Craniofacial Association*  
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*Cleft Palate Foundation*  
*Cathy Coleman, BS, CCLS*  
*Kiku Collins*  
*Robert O. Cooley, DDS, MS*  
*Elizabeth Crosby, MS*  
*Sandi Daniels*  
*Danya International*  
*Karen Gavin-Evans, PhD*  
*Milli Davis*

*Carl Dennison*  
*Digital Breakout*  
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*Family TIES of Nevada*  
*Genetic Alliance*  
*Lisa K. Gist, MA*  
*Give Me A Break (GAB), Inc.*  
*Tina Gordon*  
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*Kelly Luckey*  
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*Gina Matson*  
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*Glenn Merryman*  
*MetDesk®*  
*Rhonda Millican*  
*Moebius Syndrome Foundation*  
*Jeff E. Moxley, DDS, PC*  
*Nevada Early Intervention Services*  
*Nevada Governor's Office for Consumer Health Assistance*  
*Nevada State Health Division*  
*Debra Wagler*  
*Darko & Zorana Nikolich*  
*Frank Nolimal*  
*Amanda Oliver*  
*Debbie Oliver*  
*Jeffrey Oliver*  
*Robert Oliver*  
*Russell Oliver*

*Operation Respect*  
*Don't Laugh at Me*  
*Shannon Osborne*  
*Kathy Patten, MPA, OTR/L*  
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# THE NATIONAL CRANIOFACIAL FACES ASSOCIATION

Networking • Newsletters • Research Information • Travel Assistance  
Information Packets • Craniofacial Center Information

"We love reading your newsletter and hearing from the other parents the positive stories of their special children."

*E. West, Kansas*

"Our deepest gratitude to all the fine people at FACES that have time and again put themselves out to facilitate our son's medical treatments and arrangements. You have made us feel a part of your extended family!"

*R. Marshall, Missouri*

"We are teaching the girls to say their prayers and we include our friends at FACES every night."

*J. Adams, Pennsylvania*

PO Box 11082 • Chattanooga, Tennessee 37401  
[www.faces-cranio.org](http://www.faces-cranio.org) • [faces@faces-cranio.org](mailto:faces@faces-cranio.org) • 800-3FACES3



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](mailto:kgavin-evans@danya.com)

240-645-1759

**Danya's mission is to impact global public health and education through the development and implementation of innovative health communication, research, and technology programs.**

8737 COLESVILLE ROAD, SUITE 1100  
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Craniofacial Family Conference!*

**[www.henryschein.com](http://www.henryschein.com)**

## **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](http://www.moebius syndrome.com)



Moebius Syndrome Foundation, PO Box 147, Pilot Grove, MO 65276  
[vickimc@iland.net](mailto:vickimc@iland.net)

# CMF Medicine is more than expert science.

It is hope and promise  
and, to some, the  
miracle of a normal life.

Stryker CMF supports Cleft Advocate and the  
2008 North American Craniofacial Family Conference.

For more information contact  
your local Sales Representative:

**James Pell**

**P: 702.513.4344**

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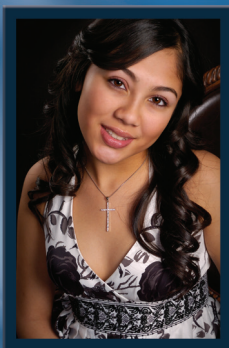
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The Organization with One Message:

## 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!**  
Send me a Membership brochure & application!

### 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.

Name: \_\_\_\_\_

☐ Mr. ☐ Ms. ☐ Mrs. ☐ Dr. Title: \_\_\_\_\_

Organization: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_ State: \_\_\_\_\_ Zip: \_\_\_\_\_

Phone: \_\_\_\_\_ Fax: \_\_\_\_\_

Email Address: \_\_\_\_\_

Web Address: \_\_\_\_\_

Please MAIL this form to: FNIDCR, 1901 Pennsylvania Avenue, NW, Suite 607, Washington, DC 20006 Or FAX to: (202) 463-1257

For More Information, CALL: (202) 223-0667 Or VISIT: [www.fnidcr.org](http://www.fnidcr.org)

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