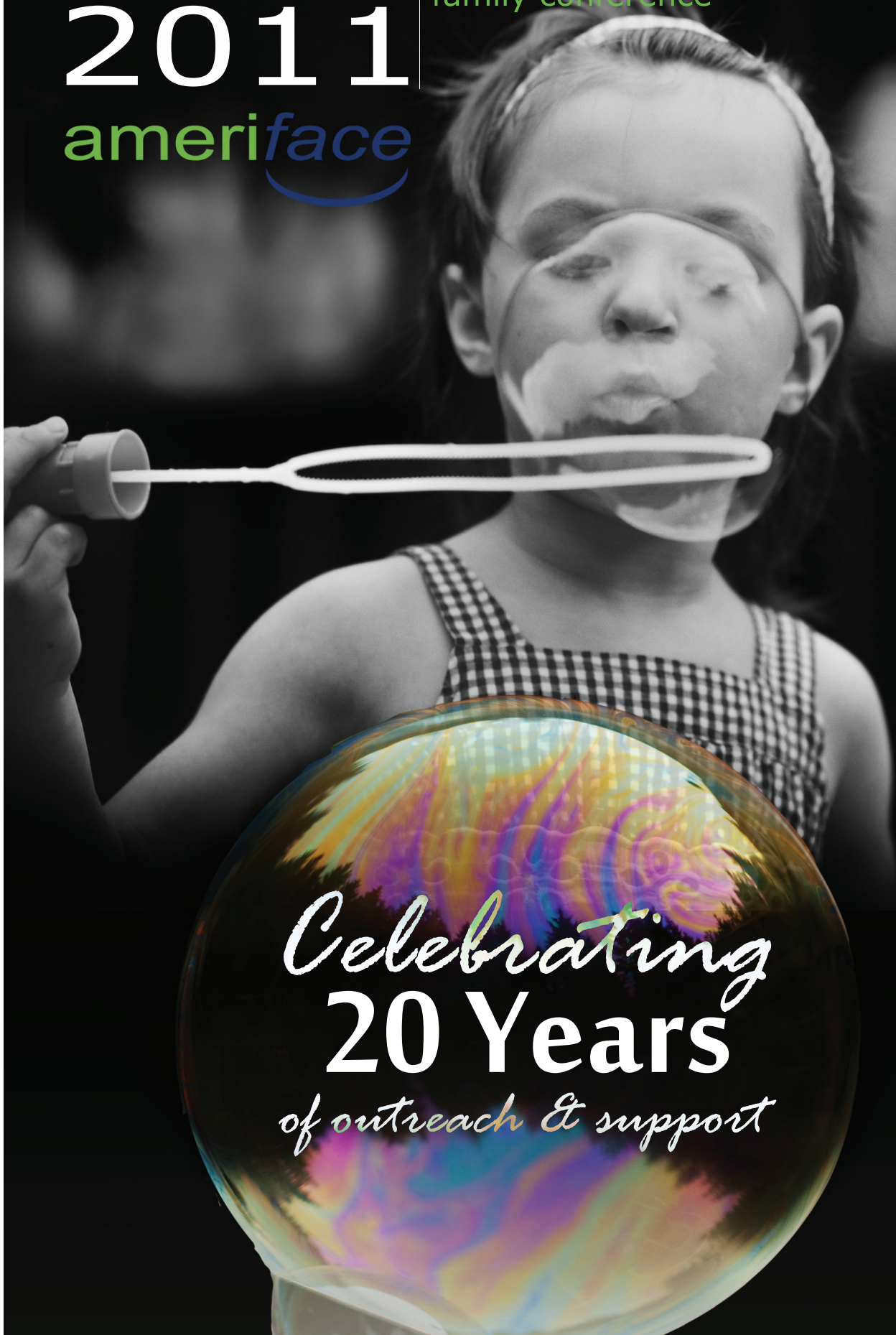



NACFC
2011
ameriface

north american
craniofacial
family conference



Celebrating
20 Years
of outreach & support

EDUCATE | INSPIRE | SERVE | LEAD



For 60 years, The National Foundation for Facial Reconstruction has supported the medical and emotional treatment of children with facial differences at the Institute of Reconstructive Plastic Surgery at NYU Langone Medical Center. The Institute treats 2,000 children per year, nearly 70% of whom are uninsured or receiving Medicaid.

To find out more about us and how you can help, go to www.nffr.org



**National Foundation
For Facial Reconstruction**

Changing Faces, Transforming Lives

333 East 30th Street, Lobby Unit
New York, NY 10016

212-263-6656

www.nffr.org

Join us and get news, event updates and connect with other families



July 24, 2011

Dear Friends,

Welcome to our sixth annual North American Craniofacial Family Conference! It is always such a pleasure to host this great event but more so this year as AmeriFace is celebrating its 20th anniversary.

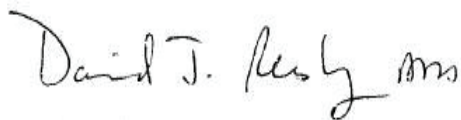
We have a great educational program with nationally recognized speakers, but also a lot of fun events to commemorate our birthday!

We certainly have gone through some changes since we started out; some more challenging than others. But it gives me such pride, as president, to boast about the great organization we have become. Many thanks to Executive Director 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 always like to say, please take the opportunity to renew old friendships, make new ones, share experiences, and enjoy being together.

Welcome to Las Vegas and AmeriFace's birthday party!

Sincerely,



David J. Reisberg, DDS
President

AmeriFace
Board of Directors

David J. Reisberg, DDS
President

Christina Corsiglia
Vice President

Teresa Grillo
Secretary/Treasurer

Board Members
Todd Beutler
Gerry Gedroic Lichterman
Kerry Mandulak, PhD, CCC-SLP
Erik Kabik

Debbie Oliver
Executive Director
Robin Remele
Program Director
Joyce Bentz
Action Team Coordinator



EDUCATE › INSPIRE › SERVE › LEAD



JULY IS NATIONAL
CLEFT &
CRANIOFACIAL
AWARENESS & PREVENTION MONTH

Organizations and individuals will recognize and celebrate NCCAPM by promoting awareness and prevention of cleft and craniofacial conditions. These conditions include orofacial birth defects as well as conditions acquired as a result of trauma, burns and disease. Materials will be made available for distribution.

Patients and families seeking information about these conditions, including causes, prevention, treatment and support, will find contact information for various participating organizations, medical teams and related supporting entities on the NCCAPM website.

The general public will be exposed to information regarding these conditions and the challenges facing patients and families.

The Alliance of NCCAPM members stand as partners in education and support.

Visit www.nccapm.org for additional information.



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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 24, 2011

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

Pick up your conference packet and the 2011 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 25, 2011

- **7:00 - 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 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) during the lunch break and immediately following the afternoon joint session, scheduled to adjourn approximately 5:00 PM.

- **9:00 AM** Getting to Know You
Florentine F Icebreakers!
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!

MONDAY, JULY 25, 2011

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

July is Cleft & Craniofacial Awareness & Prevention Month!

- **9:00 AM** Keynote
Florentine C Isabel Garcia, DDS, MPH
*Deputy Director
National Institute of Dental
and Craniofacial Research
(NIDCR)*

NIDCR and NIH Research and its Relevance to Persons with Facial Differences

Dr. Isabel Garcia will provide an overview of the NIH and NIDCR and describe NIDCR-funded projects in diverse areas of research such as craniofacial biology, genomic studies, and tissue engineering that are helping to determine the causes of various conditions and disorders that lead to facial differences. The presentation will also touch upon aspects of research and current research opportunities that may offer insights for more effective and efficient dental treatment of patients with complex diseases and disorders.

Dr. Garcia was appointed acting director of the NIDCR in August 2010. NIDCR is the federal government's largest funder of research and research training focusing on oral, dental and craniofacial diseases and disorders. As interim Director, she provided leadership for a team of ~500 scientists, administrators and support staff with an approximate annual budget of ~ \$409 million. Dr. Garcia is a career-officer with the U.S. Public Health Service and holds the rank of Rear Admiral - Lower Half. She has been NIDCR's Deputy Director since January 2007.

Dr. Garcia's experience spans 27 years of work in dental public health, research and administration at the local, state and national levels. Since joining the NIDCR in 1995 Dr. Garcia has held several positions within the Institute. She led NIDCR's science transfer efforts, directed the Institute's science planning, health policy, legislative, and evaluation programs and led the development of NIDCR's last two strategic plans. Prior to her career in the Public Health Service Dr. Garcia worked in the private sector as a clinician and later held health management positions in Virginia and Ohio.

Cover Art by Heather Brincko

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International Studio
*Portrait, Wedding,
and Plain ol' Life Photographer*

hpbphoto.com

SCHEDULE

MONDAY, JULY 25, 2011

Dr. Garcia is a Diplomate of the American Board of Dental Public Health. She has served as an officer in the American Association of Public Health Dentistry's Executive Council, the Oral Health Section of the American Public Health Association and the American Board of Dental Public Health. In addition to her duties as Deputy and Acting Director, Dr. Garcia directs NIDCR's Residency Program in Dental Public Health and serves as her Institutes' coordinator for International Health. She In addition to numerous honors and awards Dr. Garcia has been recognized for her role in a Presidential and Secretarial health diplomacy mission which provided health care to people in 12 countries in Latin America. She received her undergraduate degree in Chemistry from the University of Mary of Michigan where she also completed a Residency in Dental Public Health.

■ **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**

Pisa **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, FACP
Maxillofacial Prosthetics
The Craniofacial Center
University of Illinois
Medical Center at Chicago

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

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

MONDAY, JULY 25, 2011

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!

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 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.

Florentine E **Module V – Teens**
(Ages 14-17)

NetSmartz™ Internet Safety
Margarita Hughes
Educational Outreach
Nevada Child Seekers

It's important to be alert and safe when surfing the internet. Nevada Child Seekers has been successful in implementing this Internet Safety program for students, parents and school administrators, developed by law enforcement and the National Center for Missing & Exploited Children.

The Wells Fargo
Foundation
Supports the NACFC!

WELLS
FARGO

SCHEDULE

MONDAY, JULY 25, 2011

■ 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 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 last afternoon session, scheduled to adjourn approximately 5:00 PM.

■ 1:15 PM General Session Florentine C

Cynthia H. Cassell, PhD
*Birth Defects Branch
Division of Birth Defects and
Developmental Disabilities
National Center on Birth Defects
and Developmental Disabilities
Centers for Disease Control
and Prevention (CDC)*

The Hows and Whys of Tracking Craniofacial Defects

The Centers for Disease Control and Prevention (CDC) helps support state-based birth defects surveillance systems to track birth defects, including craniofacial defects. Many states in the U.S. have birth defects surveillance programs that capture infants and children born with craniofacial defects.

This presentation will include an overview of the hows and whys of birth defects surveillance programs with a focus on craniofacial defects. The following topics will be addressed: the importance of obtaining information on craniofacial defects, the types of data sources used, and the types of data collected. This presentation also will briefly discuss what has been learned about children with craniofacial defects from CDC-sponsored activities.

Cynthia Cassell, PhD, is an epidemiologist with the National Center on Birth Defects and Developmental Disabilities at the Centers for Disease Control and Prevention (CDC). Her research focuses on health service use, costs, access to care, and long-term outcomes and consequences of children with birth defects, with a primary focus on cleft and craniofacial defects. She is also an Adjunct Assistant Professor with the University of North Carolina Craniofacial Center.

MONDAY, JULY 25, 2011

Before coming to CDC, Dr. Cassell was an Assistant Professor at the University of North Carolina at Charlotte and was a recipient of the 2010 March of Dimes Basil O'Connor Starter Scholar Research Award for her work on health service use, cost, and access to care for children with birth defects. Prior to her appointment at the University of North Carolina at Charlotte, Dr. Cassell was a statistician with the North Carolina birth defects registry for almost five years. In that position, she was the project manager for two craniofacial supplemental grants associated with the National Birth Defects Prevention Study. These grants examined health service use, cost, and barriers to care, and parental perspectives on outcomes and quality of life among children with orofacial clefts in North Carolina.

■ 1:15 - 2:15 PM Workshop Modules

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

NetSmartz™ Internet Safety
*Margarita Hughes
Educational Outreach
Nevada Child Seekers*

It's important to be alert and safe when surfing the internet. Nevada Child Seekers has been successful in implementing this Internet Safety program for students, parents and school administrators, developed by law enforcement and the National Center for Missing & Exploited Children.

Florentine F 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!

Special thanks to
Corey Wyman
for her unending commitment
to the patients and families
of AmeriFace and the NACFC!

SCHEDULE

MONDAY, JULY 25, 2011

■ 2:30 - 3:30 PM Workshop Modules

Florentine C Module I – Adults

Dental Management for the Adult Cleft/Craniofacial Patient

*David J. Reisberg, DDS, FACP
Maxillofacial Prosthetics
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 G Module II – Parents

Pathfinder Outreach Workshop

*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.

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

NetSmartz™ Internet Safety

*Margarita Hughes
Educational Outreach
Nevada Child Seekers*

It's important to be alert and safe when surfing the internet and interacting with friends and strangers. Nevada Child Seekers has been successful in implementing this Internet Safety program for students, parents and school administrators, developed by law enforcement and the National Center for Missing & Exploited Children.

MONDAY, JULY 25, 2011

■ 2:30 - 3:30 PM Workshop Modules

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

Beyond High School

*Dionnie Martin
College Preparation Specialist*

Are you preparing to attend a four-year college or university? Have you given much thought to the types of classes you're taking in high school to prepare for your higher education? Explore the possibilities and map your success starting today, because it's never too early!

■ 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

Pisa Module I – Adults

Employment/ADA Law

Nevada Equal Rights Commission

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

Speech & Language Development and the Cleft/Craniofacial Child

*Mark S. James, MS, CCC-SLP
Managing Director
Therapy Management Group*

In this workshop we will discuss the definitions of speech and language, typical developmental milestones, and the diverse reasons why a child with a cleft/craniofacial issue may not progress as rapidly as his/her peers.

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

SCHEDULE

MONDAY, JULY 25, 2011

- **4:00 - 5:00 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)
- Totally Awesome Talented Kids!**
Shannon Osborne
Wee Can Sign
- Amy Oberg*
Author/Singer/Songwriter
Freelance Producer

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.

Amy Oberg is an author, as well as an accomplished singer/songwriter. A freelance producer at Joshua Tree Global and a devout Christian, Amy routinely serves in the Women's Ministry at Canyon Ridge Christian Church in Las Vegas, NV.

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 Tuscany 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). Thank you!

TUESDAY, JULY 26, 2011

- **7:00 - 8:30 AM** **NACFC Registration**
Florentine Foyer
- Florentine D** **Breakfast with Exhibitors**
- **8:30 AM** **Kids' Camp Child Care**
Siena *(Ages 0-6)*

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

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.

- **9:00 - 10:00 AM** **Workshop Modules**
- Pisa** **Module I – Adults**
- Relationship Roundtable**
A Time to Share

Adults with facial differences will have a candid roundtable discussion about the different types of relationships we experience (family, workplace, personal), and how the way we feel about ourselves and our facial difference can affect those relationships.

- Florentine C** **Module II – Parents**
- An Overview of Children's Friendship Training**
Elizabeth A. Baca, MS, CCC-SLP
Touro University
Nevada Center for Autism and Developmental Disabilities
- Rachel Davis, MA*
Advanced Doctoral Student
Clinical Psychology, UNLV

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.

SCHEDULE

TUESDAY, JULY 26, 2011

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.

Florentine F

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

Module IV – Pre-Teens
(Ages 11-13)

License Plate to Drive
Kristina Huddleston Wolfs
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 V – Teens
(Ages 14-17)

Accepting the Gray of Adolescence
Samantha Jennings, MSW
Director of Family Services
Cleft Palate Foundation

Life is not always black and white. It would be difficult to live in a world of extremist standards where everything is ‘yes or no’, ‘right or wrong’, ‘always or never’. In the gray area of life we may find uncertainty and insecurities about all aspects of life. Learning how to accept this gray area will allow you to be flexible, open to change, and consider all options and perspectives in a life stage that is filled with numerous choices, pressures, and layered responsibilities. This workshop will present ways to use your creativity and critical thinking to challenge a black and white perspective. ‘Accepting the Gray’ means being content with yourself and embracing uncertainty in adolescence with confidence and assurance.

Special Thanks to Channel 13 Action News!



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

TUESDAY, JULY 26, 2011

Samantha Jennings, MSW is the Director of Family Services for the Cleft Palate Foundation. Sam received her bachelor’s and master’s degrees of Social Work at Appalachian State University. She has provided direct services to children and families through the North Carolina Autism Society since 2008. As a member of the Watauga County Autism Initiative Task Force, Samantha co-developed and facilitated numerous services for families affected by Autism in Western North Carolina, including a weekend respite camp, a social skills group for young adults with Asperger’s syndrome, and parent support groups. She continues to volunteer with the Autism Society camp programs throughout the year and co-teaches social skills groups for young children with Autism Spectrum Disorders.

PLEASE NOTE - The following youth workshop will begin immediately, so quickly grab a beverage and let’s get started...thank you!

■ 10:15 - 12:00 PM Workshop Modules

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

Elizabeth A. Baca, MS, CCC-SLP
Touro University
Nevada Center for Autism and
Developmental Disabilities

Rachel Davis, MA
Doctoral Student
Clinical Psychology, UNLV

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.

■ 10:15 AM Florentine D

Break

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

SCHEDULE

TUESDAY, JULY 26, 2011

■ 10:45 - 11:45 AM Workshop Modules

Pisa

Module I – Adults

Adult Focus Group
Samantha Jennings, MSW
Director of Family Services
Cleft Palate Foundation

The Cleft Palate Foundation has recently developed an adult task force team consisting of medical professionals and adults affected by craniofacial differences. Through our CLEFTLINE services, online information requests, and professional relationships, CPF is aware of a lack of resources for adults. We hope to conduct a needs assessment to identify specific gaps in information and care. Please join us as we discuss common issues, concerns, and victories for adults affected by craniofacial disorders.

Florentine C

Module II – Parents (ALT)

Your Early Childhood Rights and Responsibilities
Amy M. Zadorozny
Developmental Specialist IV
Nevada Early Intervention Svcs.

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.

Florentine F

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!

AmeriFace Action Team
Robin Remele - Program Director
Joyce Bentz - Action Team Coordinator

Kristi Branstetter • Kiku Collins • Sandi Daniels
Milli Davis • Roisin Delaney • Adele Liu
Robert Oliver • Patricia Bacon Smith
Heather Wilson • Amanda Veazey

TUESDAY, JULY 26, 2011

■ 12:00 – 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 last afternoon session, scheduled to adjourn approximately 5:00 PM.

■ 1:15 1 2:15 PM General Session

Florentine C

Module I – Adults
Module II – Parents

Cynthia H. Cassell, PhD
Birth Defects Branch
Division of Birth Defects and
Developmental Disabilities
National Center on Birth Defects
and Developmental Disabilities
Centers for Disease Control
and Prevention (CDC)

Timeliness of Services Among Children with Orofacial Clefts

Orofacial clefts are relatively common birth defects in the U.S. and include cleft palate alone and cleft lip with or without cleft palate. These birth defects affect about 7,000 infants each year. Children with orofacial clefts can often have problems with feeding, speech, ear infections, hearing loss, and teeth development. They frequently need specialized services to improve their health outcomes and overall quality of life.

Recommended services and treatment for children with orofacial clefts were originally outlined in the "Parameters for Evaluation and Treatment of Patients with Cleft Lip/Palate or Other Craniofacial Anomalies" by the American Cleft Palate Craniofacial Association (ACPA) in 1993 and were amended in 2000, 2004 and 2009. There is little research on adherence to these standards of care. This presentation will discuss the few studies on timeliness of services for children with orofacial clefts, using the North Carolina and Florida birth defect registries.

SCHEDULE

TUESDAY, JULY 26, 2011

■ 1:15 – 2:15 PM Workshop Modules

Florentine E

Module III – Explorers' Club

(Ages 7-10)

Module IV – Pre-Teens

(Ages 11-13)

Module V – Teens

(Ages 14-17)

Be Kind!

*Drew Stevens, Founder
Josh Stevens Foundation*

We believe in "catching" kids in the act of being genuinely kind. Josh Stevens left a legacy of kindness that lives on, as the Foundation named in his honor carries out its mission to recognize acts of kindness by children everywhere with the Kindness Card. Learn more about how you can be Kind Like Josh!

■ 2:30 – 3:30 PM Workshop Modules

Florentine C

Module I – Adults

Module II – Parents

Be Kind!

*Drew Stevens, Founder
Josh Stevens Foundation*

We believe in "catching" kids in the act of being genuinely kind. Josh Stevens left a legacy of kindness that lives on, as the Foundation named in his honor carries out its mission to recognize acts of kindness by children everywhere with the Kindness Card. Learn more about how you can be Kind Like Josh and about the social education module shared with NACFC youth this afternoon.

Florentine G

Module III – Explorers' Club

(Ages 7-10)

Module IV – Pre-Teens

(Ages 11-13)

Module V – Teens

(Ages 14-17)

Gimme a Break!

AmeriFace Staff and Volunteers

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

TUESDAY, JULY 26, 2011

■ 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

*Special Guest Ben Kjar
NCAA All-American Wrestler*

Everyone has a story to tell, a message to bring, based on their personal experience. Special guest Ben Kjar became Utah Valley University's first-ever wrestling All-American after placing fourth at the 2011 NCAA Wrestling Division I Championships. Born with Crouzon Syndrome, Ben will share his story and will challenge you to do the same.

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*

*Amy Oberg
Author/Singer/Songwriter
Freelance Producer*

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!

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.

Amy Oberg is an author, as well as an accomplished singer/songwriter. A freelance producer at Joshua Tree Global and a devout Christian, Amy routinely serves in the Women's Ministry at Canyon Ridge Christian Church in Las Vegas, NV.

SCHEDULE

TUESDAY, JULY 26, 2011

■ 6:00 - 10:00 PM 20th 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 2011 NACFC. More music and entertainment by Mariah's Sound Occasions!

WEDNESDAY, JULY 27, 2011

■ 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 3:30 PM.

■ 9:00 General Session

Florentine C

Cynthia H. Cassell, PhD
*Birth Defects Branch
Division of Birth Defects and
Developmental Disabilities
National Center on Birth Defects
and Developmental Disabilities
Centers for Disease Control
and Prevention (CDC)*

Barriers to Care Among Children with Craniofacial Defects

Barriers to care among children with craniofacial defects were recently identified as an important public health research priority by convened expert panels sponsored by the CDC. Some examples of perceived barriers to care include: geographical factors, financial limitations, family health beliefs, perceptions of need, lack of appropriate referrals, experiences with stigmatization, and concerns about confidentiality. Such factors can impede health service use and affect the receipt of timely services among children with craniofacial defects.

WEDNESDAY, JULY 27, 2011

This presentation will include a discussion of the few past and current studies that examine access to care for children with craniofacial defects. This presentation will focus on the results from a study examining parental perspectives on barriers to care among children with orofacial clefts, using a state-wide, population-based birth defects registry.

Florentine E

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

Module IV – Pre-Teens *(Ages 11-13)*

Module V – Teens *(Ages 14-17)*

Can I Get Your Autograph? *AmeriFace Staff & Volunteers*

You've made lots of new friends, and we want to help you stay in touch!

■ 10:15 AM Break Florentine D

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

■ 10:45 General Session

Florentine C

Planning for the Future
*Robert R. Froehlich
Financial Advisor
Morgan Stanley Smith Barney*

Learn how to best plan for your child's future education needs, providing the greatest opportunities for their academic growth regardless of the medical challenges they may face in their young life. We will discuss 529 college savings plans, as well as the value of long term financial planning and special needs trusts.



Empowering Children for Success!
www.MyKidzMatter.com

SCHEDULE

WEDNESDAY, JULY 27, 2011

■ 10:45 - 11:45 AM 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 Children for Success at www.mykidzmatter.com.

■ 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.

■ 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 4:30 PM. Families will be together for tasty treats, raffle prizes, gift bags and final farewells at a reception in Florentine D.

WEDNESDAY, JULY 27, 2011

■ 1:15

General Session

Florentine C

Sensory-Cognitive Processing and Its Impact on Reading and Comprehension

Monica Daggs, MA, JD
Center Director

Lindamood-Bell Learning Processes
Las Vegas, NV

This presentation will discuss some of the causes of and solutions for learning challenges - including the symptoms of dyslexia, hyperlexia, ADD/ADHD, and autism spectrum disorders. The presentation will also discuss how Lindamood-Bell® instruction develops the specific mental processes that underlie reading, comprehension, and math.

Lindamood-Bell is an internationally recognized leader in the research and development of programs for language and literacy development. Their Learning Centers specialize in one-to-one instruction based on the individual's learning needs; through diagnostic evaluation, specific strengths and weaknesses can be identified and remediated. Lindamood-Bell also collaborates with hundreds of schools to provide innovative instructional programs, professional development, and consulting. Lindamood-Bell has received national recognition from CNN, Newsweek, Time, US News and World Report and the neuroscience journal *Neuron*, along with being featured on the PBS special *The Secret Life of the Brain*. More information on Lindamood-Bell is available online at www.lindamoodbell.com.

Ms. Daggs began working with young adults while attending the University of North Carolina at Chapel Hill. In addition to her numerous volunteer activities, she worked as Program Manager for the non-profit organization, Sisterhood Agenda, Inc., where she implemented its acclaimed self-development program for at-risk adolescent girls titled, "A Journey Toward Womanhood." Upon earning her M.A. in Psychology from North Carolina Central University, she moved to Baltimore, MD, where she worked as a school psychologist for the city's public school system. After working for six years in youth development, she attended Duke University School of Law and began a career as an attorney focused on labor and employment law. She soon realized she missed working with children and young adults. Lindamood-Bell Learning Processes allowed Ms. Daggs become a member of the education community once again. She has served as the Center Director for Lindamood-Bell's Las Vegas, NV Learning Center since it opened in 2007 and established the Henderson, NV Seasonal Intensive Learning Center in 2010.

SCHEDULE

WEDNESDAY, JULY 27, 2011

■ 1:15 - 2:15 AM Workshop Modules

Florentine E **Module III – Explorers’ Club**
(Ages 7-10)

Module IV – Pre-Teens
(Ages 11-13)

Module V – Teens
(Ages 14-17)

Storytelling Workshop
Special Guest Ben Kjar
NCAA All-American Wrestler

Everyone has a story to tell, a message to bring, based on their personal experience. Special guest Ben Kjar became Utah Valley University’s first-ever wrestling All-American after placing fourth at the 2011 NCAA Wrestling Division I Championships. Born with Crouzon Syndrome, Ben will share his story and will challenge you to do the same.

■ 2:30 - 3:30 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!

■ 3:30 PM Farewell Reception

We’ll wrap up the 2011 North American Craniofacial Family Conference with farewells, a raffle and lots of great surprises! Oh, and some sweet treats for the road!

THURSDAY, JULY 28, 2011 (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 without notice.

Family Portraits! During our 20th Anniversary Celebration Dinner on Tuesday night, be sure to have your portrait taken, courtesy of Witzel Photography. Family sittings, couples, individuals...it’s up to you! After the conference, you will receive one complimentary digital file from your photo session, and prints can be purchased directly from Witzel Photography. For more information, go to www.witzelphotography.com or call at (702) 375-3733. Many thanks to the lovely and talented Ms. Diane Witzel!

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 thanks **Diane Witzel**
of **Witzel Photography** for her
support of the NACFC!
www.witzelphotography.com

NOTES

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S U P P O R T

There are many ways you can support AmeriFace and its family of programs!

Donate - Your financial support is always appreciated! It's easy to make a one-time or recurring monthly donation on-line at our website. Visit www.ameriface.org/donate.html to initiate your secure transaction. If you prefer to make a donation by mail or by phone using your Visa or Mastercard, see our contact page at www.ameriface.org/contact.html.

Sponsor - There are a variety of opportunities to sponsor specific AmeriFace programs and events. Call our office at toll-free (888) 486-1209 or write to Executive Director Debbie Oliver at debbie@ameriface.org for an overview of these opportunities.

Become a Pathfinder - Join our family of volunteers across the country and around the world at the Pathfinder Outreach Network! Visit <http://pathfinders.ameriface.org> for more information on the largest, most active support program for the cleft/craniofacial community and how you can join the team.

Time-sensitive support opportunities include:

The Vivint Gives Back Project is granting \$250,000 and \$100,000 to five worthy charities, based on your votes. Vote for AmeriFace each and every day through August 27, 2011 at the **Vivint Gives Back** website at www.vivint.com/givesbackproject/charity/147.

vivint.givesback
PROJECT



Macy's Shop for a Cause shopping passes are available here at the NACFC and on-line at www.ameriface.org/macys.html for a minimum donation of \$5.00. Your **Macy's Shop for a Cause** pass is good at ANY Macy's store and on-line at Macys.com for 25% off ALL DAY on regular, sale & clearance items, and 10% off furniture, electronics and more on August 27, 2011!!

Thank You

The Family-to-Family Connection listserv is hosted by



Genetic Alliance

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

Mission

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

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Thank You!

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

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"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 • faces@faces-cranio.org • 800-3FACES3



Danya would like to thank
cleftAdvocate for supporting
the Facing Cleft project.

Funded by the National Institute of Dental and Craniofacial Research, Danya is developing **Facing Cleft**, a resource guide designed to support parents of children with cleft lip and palate from infancy through adolescence. Danya is currently recruiting parents of children born with a cleft lip and/or palate to participate in evaluations of this program throughout this summer. Please contact us at facingcleft@danya.com or visit the cleftAdvocate website for more information.

For more information, please contact:

Christine Zhang
Research Assistant
facingcleft@danya.com
301.960.1674

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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
vickimc@iland.net



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.

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