



ameriFace

Educate|Inspire|Serve|Lead

Making a world of difference in a world of facial differences

AmeriFace addresses the diverse medical, financial, psychosocial and educational needs of the cleft/craniofacial community.

## AmeriFace – Just the Facts

- AmeriFace is extremely fortunate to have a network of dedicated volunteers throughout the country, including volunteer staff at headquarters. AmeriFace delivers more than 92% of every dollar donated directly to programs.
- AmeriFace is a national non-profit organization headquartered in Nevada.
- 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. 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.
- AmeriFace hosts the North American Craniofacial Family Conference (NACFC), an annual event focused primarily on the needs of patients and families. Offering unique education and networking opportunities, the NACFC attracts highly-qualified professionals from around the country as presenters and facilitators, representing the medical, education and community support sectors.
- AmeriFace programs and volunteers have been recognized and honored by:
  - American Cleft Palate-Craniofacial Association (ACPA)
  - Cleft Palate Foundation (CPF)
  - Jefferson Awards for Public Service
  - Oprah's Big Give
  - VOICES - One voice can lead to a chorus for change® campaign (featured on the Montel Williams Show)
- Our support programs include:
  - Pathfinder Outreach Network
  - cleftAdvocate
  - Goldenhar Syndrome Support Network
  - Crouzon Support Network
  - Treacher Collins Connection
- AmeriFace partners with like-minded professional and support organizations to enhance and expand services benefitting the cleft/craniofacial community.
- Logging more than 2 million hits to its program websites, AmeriFace has also delivered more than 11 million pieces of correspondence to patients and families in the last four years alone.

Learn more at our website: [www.AmeriFace.org](http://www.AmeriFace.org) or call (888) 486-1209.

**The premier support organization for the cleft/craniofacial community**  
AmeriFace | PO Box 751112 | Las Vegas, NV 89136 | Phone (888) 486-1209 | Fax (702) 341-5351

## The Statistics of Facial Differences

*A facial difference is any condition that alters facial appearance, whether that condition is present at birth or is acquired through trauma, illness, burns or disease.*

- Cleft lip and/or palate is the most common birth defect in the United States according to the Centers for Disease Control and Prevention (CDC).

### **One in every 600 infants is born with an orofacial cleft.**

- Interdisciplinary team care is critical in the treatment of orofacial clefts and complex craniofacial conditions such as Crouzon, Apert, Goldenhar and Treacher Collins syndromes, as well as in the treatment of acquired facial differences.
- Team specialties include:
  - Plastic Surgery
  - Neurosurgery
  - Psychology
  - Genetics
  - Speech/Language
  - Maxillofacial Surgery
  - Pediatric Dentistry
  - Orthodontics
  - Prosthodontics
  - Feeding/Nutrition
  - Otolaryngology
  - Audiology
  - Psychology
  - Social Work
  - Case Management
- The financial burden of medical care can exceed \$100,000 for patients born with a cleft lip and/or palate, and many times more for patients born with complex craniofacial conditions; however, insurance and managed care companies often deem surgery and treatment as cosmetic procedures when they are, in fact, reconstructive in nature.
- Multi-staged treatment and surgery can continue for a lifetime.
- Craniosynostosis, a complex craniofacial condition, occurs in approximately one in every 2,000 births and has been associated with more than 100 syndromes.
- Oral cavity/pharynx cancer cases alone totaled nearly 38,000 from 1975-2005.
- Facial differences caused by trauma, burns, and animal attacks account for thousands more facial injuries each year.

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## Supporting Documentation

### [Frequency of Birth Defects](#)

#### [Orofacial clefts are the most common birth defects in the United States](#)

*Center for Disease Control and Prevention (CDC)*

*January 5, 2006*

### [National Prevalence Estimates for 18 Selected Major Birth Defects \(Table\)](#)

*Center for Disease Control and Prevention (CDC)*

*January 5, 2006*

### [Priorities for Future Public Health Research in Orofacial Clefts](#)

#### [CDC identifies gaps in knowledge](#)

*Cleft Palate Craniofacial Journal, 2007*

### [Recurrence Risk for Cleft Lip \(with or without Cleft Palate\)](#)

Risks in siblings and children of persons with the anomaly

*Tolarova & Oh, 2006*

### [Recurrence Risk for Cleft Palate Only](#)

Risks in siblings and children of persons with the anomaly

*Tolarova & Oh, 2006*

### [Parameters for Evaluation and Treatment of Patients with](#)

#### [Cleft Lip/Palate or Other Craniofacial Anomalies](#)

*American Cleft Palate-Craniofacial Association, 2007*

### [Priorities for Public Health Research on Craniosynostosis](#)

*American Journal of Medical Genetics, 2007*

### [2007 Reconstructive Surgery Procedures](#)

Includes cleft lip/palate, maxillofacial surgery

*American Society of Plastic Surgeons, 2007*

### [Cancer of the Oral Cavity and Pharynx](#)

*SEER Cancer Statistics Review, National Cancer Institute, 2007*

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For additional information about AmeriFace programs, please visit our websites and our [Press Room](#).

# cleftAdvocate



ameri**face**

pathfinderoutreach

network ::

ameri**face**  
THE FACE  
OF Change

HOP  
SKIP  
JUMP  
SMILE!

ameri**face** presents

NACFC

north american  
craniofacial  
family conference



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**NACFC** | north american  
craniofacial  
family conference

AmeriFace brings to the craniofacial community a unique opportunity to explore and exchange resources, learn from experts, and network with individuals and families from around the country!

**Keynote and General Sessions will be enhanced with Specialty Workshops for all participants.**

#### **Parents of Children w/Facial Differences**

Workshops are designed to answer the most pressing questions for parents with children of all ages. Topics will include speech and language, genetics, early intervention and other education services, a guide to managing healthcare information, how to best interface with your insurance company, family and couples relationships, and more.

#### **Adults w/Facial Differences**

Sessions will focus on issues important to adults with facial differences, such as secondary surgery and treatment, tackling insurance hurdles, social and behavioral skills, and employment and ADA law. Focus groups for those interested in outreach are scheduled.

#### **Teens (Ages 14-17)**

With a focus on goal-setting and developing social and behavioral skills, get ready for fun-filled workshops that will help you communicate with parents, siblings, peers, and adults like doctors and teachers. Great information for students in high school as well as recent graduates who will be going to college or entering the workforce. Siblings are included in all activities.

**Sponsorship Opportunities Available!**  
**Contact AmeriFace for details!**

#### **Pre-Teens (Ages 11-13)**

The middle school years are a time of transition. Workshops are designed to help pre-teens recognize and maximize their potential in school and the community, and learn how to best communicate their ideas and opinions about friends, family, school and their healthcare. Siblings are included in all activities.

#### **Explorers' Club (Ages 7-10)**

Games and activities with both education and fun in mind! Sessions will help children understand their trip to the doctor and develop their social skills so they can answer questions about their facial difference when parents aren't around. Siblings are included in all activities.

#### **Kids' Camp (Ages 0-6)**

Childcare for the little ones will be provided for your convenience. Plenty of fun close-by so parents can benefit from workshop activities, and know their little ones are safe and sound. Activities, games, videos, and more! Siblings are included in all activities.

**Professionals are welcome at all conference events, of course!**

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## LAS VEGAS SUN

### Mother fights to help those with cleft palates

**Malia Spencer, Las Vegas Sun  
Tue, Jun 24, 2003**

In 2001, Debbie Oliver, a Las Vegas mother of six, fought for four months for just one of the facial surgeries her daughter Erin needed to help her eat, breath and swallow.

While struggling through the six pounds of paperwork and the uphill battle to get her health insurance provider to approve the surgery to correct her daughter's cleft lip and cleft palate, Oliver vowed to do everything she could to try to help the many other parents whose children have birth anomalies similar to Erin's.

Clefts are the fourth most common birth defect in the United States and occur in one of every 700 births.

From her northwest Las Vegas home, Oliver's advocacy website has grown into Cleft Advocate Inc., a national organization. And on Wednesday Oliver will be in the nation's capital urging lawmakers to support legislation that would require insurance companies and HMOs to unconditionally cover the surgeries needed by people with cleft palates, cleft lips and other craniofacial problems.

Some states have laws that force coverage of clefts and other craniofacial abnormalities, but many others, including Nevada, do not, Oliver said.

Insurance companies sometimes do not cover cleft surgeries because they are seen as cosmetic and dental in nature, but in fact the surgeries are necessary for these children to function normally, Oliver said.

Many children with a cleft lip or palate are treated by an interdisciplinary medical team consisting of a reconstructive surgeon, an oral maxillofacial surgeon, speech therapists, and an audiologist.

Oliver's daughter, Erin, was born without an upper lip or roof of her mouth and has needed more than 12 reconstructive surgeries, Oliver said. Among other things, Erin had to have her jaw broken from her cheekbones to her tear ducts in order to grow about half and inch of bone, her mother said.

Since Erin's birth Oliver has been battling with her health insurance companies to cover the expensive surgeries which can range from \$20,000 to \$40,000 each.

Jeff Moxley, Erin's oral maxillofacial surgeon, said children with a cleft lip or palate may require five to six surgeries and face difficulties in speech, eating, hearing and affected facial growth. Moxley's experience with health insurers has varied greatly, he said.

"Some will cover everything, no questions asked; others don't seem to care," Moxley said.

He recalled one conversation that took half an hour in which he had to convince the insurer that the surgery was not cosmetic or dental.

"Cosmetic and dental issues are just a component of the overall problem," Moxley said.

*(more)*

Armed with her frustration and knowledge of how the insurance company will deal with a cleft surgery Oliver began [www.cleftadvocate.org](http://www.cleftadvocate.org) to aid other Las Vegas families, she said. Her site supplied a sample appeal letter and instructions on how to present to an insurance grievance committee.

Oliver soon began receiving e-mails and phone calls from people across the country.

"That's when I realized it's not an isolated incident, to one insurer or geographic region," Oliver said.

The small website soon became an organization whose "mission is to educate and empower families, and provide the tools they need to secure timely insurance approvals and payments," Oliver said.

Her organization, Cleft Advocate, has teamed up with the Children's Craniofacial Association and will present at a Congressional Panel Wednesday in order to find support for the Reconstructive Surgery Act of 2003 (HR 1499). Authored by Congressman Mike Ross, D-Ark., the act will require health insurers and HMOs to cover all cleft and craniofacial surgeries, Oliver said in a statement.

Advocates of the HR 1499 are looking for a national standard for this type of health coverage, Oliver said. Thirteen states other than Nevada currently have some sort of laws regarding cleft coverage but they are haphazard, Oliver said.

Reconstructive surgeries are typically staged by age, Moxley said. Dealing with insurance company red tape can hinder a child's progress, Oliver added.

"HMOs and insurers are standing in the way of proper care," Oliver said.

This is not the first time legislation of this type has been before Congress, Oliver said. Sen. Harry Reid, D-Nev., previously co-sponsored a similar Senate bill but it never made it to the floor for a vote.

"(Sen. Reid) feels it's disgraceful for insurance companies to think these procedures are only cosmetic," Reid's press secretary Tessa Hafen said.

This time around advocates are trying to gain enough support to "keep the issue in the limelight" she added.

While in Washington, Oliver is to meet with U.S. Rep. Shelly Berkley, D-Nev., and Sen. John Ensign, R.-Nev., to urge them to support the legislation. As a member of the Senate Committee on Health, Education, Labor and Pensions, Ensign could play a key role in pushing forward the Senate version, the Treatment of Children's Deformities Act, S977, which would cover speech therapy, hearing aids and pre-surgery orthodontics in addition to surgery.

Ensign's press secretary Jack Finn said he could not comment yet on whether or not the Ensign will support S977 because Ensign has not yet fully reviewed the legislation but he will discuss it with Oliver.

David Cherry, Berkley's spokesman, said this morning that Berkley's name will be added to the list of nine co-sponsors for HR 1499.

Cherry said the bill still has a long way to go but there is "a strong case to be made" in favor of the bill.

"You can see the need for it at a national level," Cherry said.

When they return from the capital, Erin will undergo two more surgeries, a lip reconstruction in July and a nose reconstruction in August, but both have yet to be approved by Oliver's insurance company, she said.

In the meantime, Oliver, who is a stay-at-home mom, has turned her advocacy work into a 40-hour-a-week job, keeping up the website and speaking to other families. She sees the long road ahead and hopes Wednesday's meeting will round up some more support for her fight.

"We're not professional lobbyists," she said. "We're just folks."

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## LAS VEGAS SUN

### **cleftAdvocate gets recognition**

(cleftAdvocate is a program of AmeriFace)

**Ed Koch, Las Vegas Sun**  
**Tue, Nov 29, 2005**

When Erin Scott was born in 1987 without the roof of her mouth or an upper lip, her mother, Debbie Oliver, was determined to shelter the child from the staring, teasing and other forms of cruelty that facially deformed children endure.

"I did not want her to be bullied or to have people ask me if she had been in a car accident and things like that," Debbie Oliver said. Looks aside, she added, such physical deformities are potentially life-threatening because they often restrict the child's ability to chew, swallow and breathe.

"I had Erin's first 20 years all planned out -- send her to private school and do everything else I could think of to protect her," Oliver, 45, said.

But prior to what would be Erin's first of two dozen surgeries over 18 years -- operations that would cost more than \$100,000 -- Oliver, a mother of six, decided that giving her daughter a sense of normalcy was far more productive than hiding her away.

After years of assisting parents of facially deformed children, Oliver in 2002 founded Cleft Advocate Inc., which now is affiliated with the AboutFace USA nonprofit group. Cleft Advocate rapidly grew from a mom-and-pop Internet operation to a leading international voice on craniofacial abnormalities.

Oliver's hard work has paid off. She and her organization have been selected to receive a \$20,000 Voices Grant from Charming Shoppes Inc., a company that includes the Lane Bryant and Catherine's Plus Sizes stores.

She received the grant on the nationally syndicated "Montel Williams Show." The program is scheduled to air at 10 a.m. Thursday on KVBC Channel 3.

"I never dreamed that putting up a Web site ([cleftadvocate.org](http://cleftadvocate.org)) with the intention to help a few other Nevadans would become as big as it has," Oliver said. "We now get 26,000 hits a month."

Operating out of her northwest Las Vegas home on a shoestring budget, Oliver has helped thousands with emotional support and education and by providing families with baby bottles designed for deformed mouths.

She also has helped parents navigate through mounds of insurance company red tape. (A single 2001 operation for Erin, Oliver noted, required her to fill out 6 pounds of paperwork.)

"Insurance companies sometimes do not cover cleft surgeries because they are seen as being cosmetic, while in fact the surgeries are necessary for children to function normally and even survive," Oliver said.

*(more)*



About a dozen states have laws that force insurance companies to cover clefts and other such abnormalities. Nevada, though, is not one of them, Oliver said, noting that she is concentrating her efforts on changing federal laws.

She went to Washington two years ago to testify before Congress on a bill that would require insurance companies and HMOs to unconditionally cover surgeries needed to correct craniofacial problems. The bill, however, never made it to the floor for a vote.

Lawmakers will get another shot at the measure, though, because the issue recently was reintroduced.

Cleft palates occur in one of every 700 births, Cleft Advocate says.

"When Erin was 18 months old, her doctor called to my attention that she was not babbling as much as she should have been at that point in her development," Oliver said. "He asked how she relates that she is hungry, and I told him she pounds on the fridge and screams. He said that is unacceptable.

"That one word, unacceptable, got me moving. I got Erin into speech therapy. I no longer wanted to hide her away. That was unacceptable. I was determined that Erin was going to be treated like other kids -- that she would have normalcy."

Erin, who had her first surgery at age 10 weeks, endured the type of bullying in junior high school that her mother feared, but her outgoing nature that she says she inherited from Oliver, gave Erin the strength to cope with it.

"My mother definitely made the right decision," said Erin, a Cheyenne High graduate who works as a runner for Becker Enterprises and attends the Community College of Southern Nevada, where she is studying to be a pharmacist.

"Yes, I got teased and came home crying. And yes I knew I was different. But I didn't care, and I still don't care because I am happy with who I am. I never wanted anyone's sympathy. I don't need it."

The apparel company grant money represents half of what the Oliver family lives on in a single year.

Oliver's 38-year-old husband, Robert Oliver, Erin's stepfather, is a security company account executive. Debbie Oliver is a stay-at-home mom who takes no salary from her nonprofit organization.

She plans to use some of the grant money to help host the North American Craniofacial Family Conference next July in Las Vegas to further raise awareness of the nation's fourth most common birth defect.

"Ms. Oliver serves as an inspiration to women across the country, showing them one voice can make a difference," Dorrit Bern, chief executive officer of Charming Shoppes, said in a news release.

Erin agrees, saying her mother has instilled in her great confidence.

"I walk into a room with my head held up, not down -- it has worked for me," Erin said. "If I were to give advice to other kids (with cleft palates) it would be to feel good about yourself."

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