

AboutFace^{USA}

Leading the Way for People with Facial Differences

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Anaplastology _____ 2-3

Meet AboutFace
USA's new
president _____ 12

North American
Craniofacial
Family Conference
Materials _____ 5-11

"The Perfect Flaw"— An Interview

"The Perfect Flaw" is a new, multiple-award-winning documentary about David Roche, a humorist and public speaker from Mill Valley, Calif., who was born with a venous malformation and gets speaking engagements worldwide, including a performance at the White House. His condition is a benign tumor consisting of swollen blood vessels, and he uses a lifetime of public experiences regarding his face for much of his stage material. The film captures Roche offstage as well as on — with his wife, friends and storytelling students — and revisits the harrowing medical and social ordeals of his early years. It also lets him articulate the priceless spiritual perspective that his experiences unexpectedly gave him. The filmmaker, Mike Grundmann, is a Los Angeles Times editor who was born with a cleft lip and palate.



David Roche

Q: Wasn't your face a make-or-break proposition?

A: My struggle has not been a clear-cut one. I have to keep working at it. Baseball is called a game of failure because the best batters make an out 7 out of 10 times. Well, I would say I'm a .400 hitter in life, which is great, but that means I make an out more often than not. I have to walk back to the dugout of life (our apartment) and get my attitude together for the next at-bat. Luckily, I have learned to surround myself with good teammates (friends) and an excellent manager (Marlena).

Q: What's the most important lesson your face has taught you?

A: Like I say in my show, it has forced me to look inside for my strength.

Q: You and your wife, Marlena Blavin, make regular presentations in schools, titled "Love at Second Sight." How do the kids react?

Q (Grundmann): My strategy when growing up and being ridiculed at school was pretending it didn't bother me — even after I got home from school, even when there was blood on my shirt from being hit. What were your coping techniques? Did any of them work?

A (Roche): I had similar coping techniques. Lots of denial. I also used humor. And I adopted the techniques of the teasers and became feared for my mouth. Of course, I am ashamed of this now, but the truth is that it worked very well — though only in the short run.

See pages 6-11 for complete information about the NACFC conference including speakers, resort & registration information.

NACFC 2005

July 17-20, 2005

Las Vegas

ALEXIS
RESORT



NACFC
Conference Information
See pages 5-11.

Continued on Page 4

Anaplastology

Improving patients quality of life

Suzanne Verma, MAMS

Sharon Haggerty, MAMS

Anaplastology is the art and science of restoring a malformed or absent part of the human body through artificial means. By combining technical, medical, and artistic skills with patience and compassion, an anaplastologist can create custom-made, life-like prostheses that meet the needs of each patient.

Facial and somato (body) prosthetic devices serve an essential role in restoring the physical and psychological well being for patients with missing or disfigured anatomical structures due to congenital abnormalities, trauma, or disease such as cancer. Patients may be able to gain renewed function, appearance, and confidence after receiving a prosthetic ear, eye, nose, finger, or hand. Renewed self-image may help patients feel better about themselves, more accepted into society, and enable them to function as they had before their loss. This restoration of self-esteem is an invested accomplishment for both the patient and anaplastologist or facial prosthesis. The primary goal of prosthetic rehabilitation is to help patients improve their quality of life and uphold their self-image during their traumatic psychological adjustment. A truly successful prosthesis may go unnoticed in public, allowing patients to go about life without drawing attention to that aspect of their physical appearance.

Each prosthesis is unique in its design, makeup, and method of retention. For example, if a patient has adequate bone quality and is willing to adhere to a daily hygiene regime, they may be a candidate for an osseointegrated implant-retained prosthesis. Titanium craniofacial implants, similar to dental implants, are surgically placed in the bone and used to anchor the silicone prosthesis with bar and clip, or magnet retention. Those patients unable to utilize retention through osseointegration may require the use of traditional adhesives, or the prosthetic design may rely on the inherent retention characteristics of the patient's anatomy. Due to the uniqueness of each patient's needs, it is important that his or her treatment plan for reconstruction be defined with the expertise of various members of a multi-disciplinary Craniofacial or Maxillofacial Team.

A multi-disciplinary team approach to craniofacial reconstruction offers numerous advantages. By utilizing various specialists, patients can receive optimal treatment in an appropriate sequence. There are many individuals who play an important role in rehabilitating craniofacial patients,

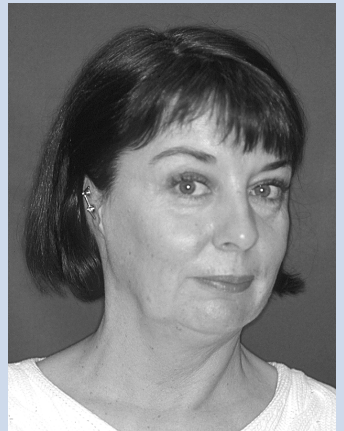
ranging from medical and surgical professionals, to rehabilitative and support groups. The most important "team member", of course is the patient! A team approach to patient treatment may also facilitate the incorporation of advanced technologies into the planning and fabrication process of creating a prosthesis. Numerous technologies can be utilized, such as rapid prototyped medical models made from CT scans, CNC milling, and Computerized Color Formulation software to name a few. The Anaplastologist creating the prosthesis has a wealth of resources available, as well as the creative freedom to formulate patient specific solutions. These technologies help health care professionals in diagnosis, surgical and prosthetic planning, and fabrication of the final prosthesis.

The fabrication process of creating the prosthesis entails a series of appointments with the anaplastologist. A sculpture made to look like the missing anatomy is made out of wax. The final prosthesis is made out of medical grade silicone to simulate the texture and appearance of skin. The silicone is colored to match the patient's various skin tones, including small details such as blood vessels and freckles. Unfortunately,



The gold bar attached to two titanium implants will be used to retain the prosthesis through bar and clip retention.

Anaplastologist: S. Verma, COMPRU, 2002



Patient without auricular (ear) prosthesis.

Anaplastologist: S. Verma, COMPRU, 2002



Patient post-treatment with implant retained auricular (ear) prosthesis in place.

Anaplastologist: S. Verma, COMPRU, 2002

Anaplastology—

Continued from Page 2

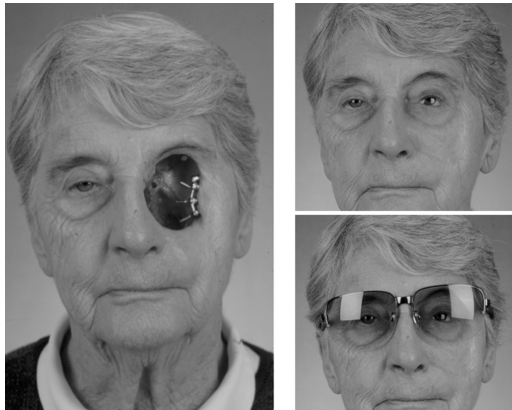
present-day silicone materials and coloring components remain durable for only a short period of time. With proper care, a prosthesis can last as long as 3-5 years.

Silicone prostheses may lose their color, flexibility, texture, and possibly tear along the margins due to environmental factors encountered by the patient. Changes in the appearance and function of a prosthesis may require repair or replacement of the prosthesis, which can be an inconvenience to the patient. The quest to find a method to stabilize the color of silicone is a shared vision among many disciplines involved in prosthetic rehabilitation. To help make the process of wearing a prosthesis easier for patients, anaplastologists and material scientists continue to put forth research efforts to find ways to improve the materials used in the fabrication of prostheses.

The field of anaplastology functions within the larger medical community, in which cross-disciplinary communication and cooperation is essential in order to provide patients with successful prosthetic restorations and a positive treatment experience.

Although a prosthesis is created to mimic the form and color of the missing or deformed anatomy as much as possible, there are still limitations. Current technologies, materials, and research provide valuable tools for professionals in the field.

Anaplastology is an evolving discipline, where high-tech tools are often utilized, but a traditional goal remains: to provide honest, competent and compassionate treatment to those patients who seek our services.



Patient with implant-retained orbital (eye) prosthesis.

(Anaplastologist: R. Seelaus, COMPRU;
Ocularist: J. Koroscil: LeGrand Northwest Ocularists, Inc.
Edmonton, Alberta, Canada, 2002)



The American Anaplastology Association (AAA) serves as an "Information Center," uniting specialists involved in anatomical restorations, and encouraging understanding and acceptance of facial and somato (body) prosthetic treatment among healthcare specialists worldwide.

While an American association, the AAA has a diverse membership made up of professionals and students from 21 countries. International experts coming from the fields of anaplastology, maxillofacial prosthetics, medical illustration, ocularistry, prosthetics and orthotics, dental laboratory technology, prosthodontics, materials research, clinical cosmetology, biomechanical engineering, medicine, psychology, and other allied fields participate in the multidisciplinary task of improving patient treatment outcomes through research and information exchange.

The AAA's professional development activities are designed to respond to the professional and educational interests of its members. The AAA annual conference and publications offer timely topics on various aspects of the restorative prosthetic devices, as well as workshops on new and innovative developments in biomaterials, advanced technologies in craniofacial reconstruction, and techniques and approaches in prosthetic fabrication. Since the first meeting, over 1300 people have attended the annual conference.

For questions regarding membership or the organization please contact the AAA Administration Office, or visit the web site at: www.anaplastology.org

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Suzanne Verma, MAMS, is an anaplastologist at the Center for Maxillofacial Prosthetics, Baylor College of Dentistry, in Dallas, Texas. Sharon Haggerty, MAMS is the director and anaplastologist at Custom Prosthetic, Ltd., in Seattle, Washington.

The Perfect Flaw—Continued from front page

A: 4-5 year olds: “Are you a monster? Do you know Freddy Kreuger?” **6-8 year olds:** “Does your face hurt? How many operations did you have? How do you eat?” **9-10 year old boys:** “Did you play sports?” **11-13 year olds:** “Did other kids tease you a lot? How did you stop them? Did you have a girlfriend?” **11-13 year olds (to Marlena):** “What did your parents say?” **14-18 year olds:** “Cool!”

Q: Because you get speaking/performing gigs all over the world, you travel a lot, which puts you among crowds of strangers all the time. Does that take courage, even still?

A: Yes, it does. There is anonymity in a big city, which I like. But there is also permission to stare, which is a normal human activity, though unpleasant for the receiver. When I can perform for those strangers, it's a good thing. I'm writing this from New York City, where I have been with Marlena for a few days now. I love New Yorkers. They seem to be very much themselves. Old people look really old, obese people look really obese, Jewish people look very Jewish, African people look African. I realized with a shock that I may not be facially different enough by New York standards.

Q: Have you ever had the fantasy, like I have, that everyone was blind, and thus they could judge you based only on who you really are rather than what you look like?

A: Not really. But it is a nice fantasy. Can I borrow it for a while? Sometimes blind people want to feel my face. Their hands are really gentle. One person said that the raised blood vessels were sort of like Chinese Braille.

Q: Perhaps the human face is a test, as in “don't take it too seriously” or “don't confuse it with its owner.”

A: Well, don't take TV and movies and magazine faces too seriously. They are not faces; they are marketing concepts. Or you can see them as works of art. Actually, the right side of my face deserves a little attention. It has done just as much work as the left, but nobody is that interested in it. Do you see the right side of my face listed in the credits of “The Perfect Flaw”? No.

Q: How hard was it quitting your day job several years back, to devote yourself to performance because that's what you decided is most important? And how well is it going?

A: Hard, hard, hard. Harder than that. Fear. Much fear. Early on, I self-produced a show figuring I could make up to \$5,000. But I failed to note that I would be competing with the World Series and Mill Valley Film Festival. I drew a small crowd and lost almost \$1,000. I did the show feeling sick at heart. But in the middle of that show, I had an epiphany: I realized how good my show is and how good a performer I am. And that feeling has never left me. I was raised working-class, to get up in the morning, go to work, sit down and do what I was told, and expect a check every two weeks. My life doesn't work that way now. But I'm doing well and have never looked back. I pay the bills and am able to save some. I'm doing creative work that I love all the time.

Q: If you were born without a facial difference, would you still be funny?

A: Absolutely. I am totally confident about my sense of humor. Although, like most comedians, I would probably be telling jokes about airline food.

Q: Our readers, undoubtedly inspired by your success, may now try something new, which can also mean scary. What's your advice on dealing with the fear? What has worked for you, and what hasn't?

A: Fear is just part of the deal. How could I not be afraid? Everybody is afraid. I'm just more open about it. I think the way to courage is through fear; the way to faith is through doubt. My advice: Never try to repress negative feelings. Live with them. They go away after a while and actually can be the source of much creativity. Find your spiritual sweet spots and go there often. For me: nature, relationship, my own creativity. These are three areas I have to pay attention to regularly to feel strong and sane. Be physical. Use your body in whatever way you can, including to get pleasure. Surround yourself with supportive people.

Q: Readers, information on the film is at www.mikegrundmann.com. Dave, where's everything we've ever wanted to know about you?

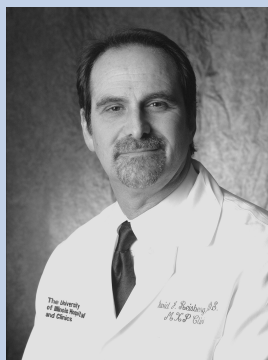
A: Thank you, Jay, it's great to be on the “Tonight Show” again. Try www.davidroche.com.

David Roche will be a Special Guest Speaker at the NACFC. Topic – My Face – A Gift

JOIN US! - cleftAdvocate / Pathfinder Program

The Pathfinder Outreach Network continues to make a difference in the lives of families across the United States and beyond. At the Family-to-Family Connection (www.cleftadvocate.org/ffc.html), the network hosts one of the most active and successful support listservs for the craniofacial community. Addressing feeding difficulties, social issues, speech therapy, early intervention, post-operative care and more, caregivers and patients come together to offer insight to others traveling a road of uncertainty. Additionally, Pathfinders reach out in their communities to provide support for families, and interface with cleft/craniofacial teams and other professionals. To become a Pathfinder, or for support and educational materials, contact Debbie Oliver at (702) 769-9264, via e-mail at debbie@aboutfaceusa.org, or visit our website at www.cleftadvocate.org. Directors and members of all craniofacial organizations are encouraged to participate.

Dr. David Reisberg President, AboutFace USA



David J. Reisberg, DDS

Dr. Reisberg received his dental degree from Case Western Reserve University in 1977. He went on to complete a Residency in Hospital Dentistry at Michael Reese Hospital and Medical Center in Chicago. He received a specialty certificate in Prosthodontics from Tufts University in Boston in 1980 and one in Maxillofacial Prosthetics from The University of Chicago in 1981. Since then, he has been Director of the Maxillofacial Prosthetics Clinic at The University of Illinois Medical Center in Chicago (UIC). In 1998, he was named Medical Director of The Craniofacial Center there. Dr. Reisberg is a professor in the Department of Surgery in the UIC College of Medicine and the Department of Restorative Dentistry in the UIC College of Dentistry.

Dr. Reisberg specializes in the care of pediatric and adult patients born with cleft lip and palate and other craniofacial birth conditions. He also treats patients who have suffered facial trauma or have had cancer surgery of the mouth or face. At the UIC Craniofacial Center, he works with a team of medical and dental specialists and allied health professionals to provide functional, cosmetic, and psychological normalcy for his patients.

In addition to his clinical practice, Dr. Reisberg has contributed to many scientific journals and textbooks and has lectured extensively in the United States and abroad. He is certified by the American Board of Prosthodontics.

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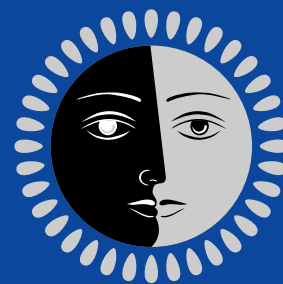
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OUR VISION — At AboutFace USA, our vision is to foster acceptance of people with facial differences so they may participate fully in society with self-worth and dignity. Everyone wants to be valued for who they are as individuals — for our talents, our interests, our personalities, our strengths. Sometimes it seems society, in general, values people largely based on their appearance. At AboutFace USA, we look beyond the physical appearance and see the person inside. Recognizing the challenges and contributes of individuals with facial differences is an important part of what we do. Seeing and sharing the endless possibilities is one of the many strengths of AboutFace USA



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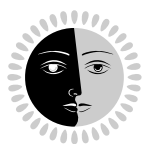
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