

FACING THE FUTURE

Video Update

The American Cleft Palate-Craniofacial Association held its 61st annual meeting at the Holiday Inn Chicago Mart Plaza in Chicago, Illinois, March 15 through March 20, 2004. The Foundation for Faces of Children presented its Spanish-language version of its video "Understanding Cleft Lip and Palate: A Guide for New Parents" at the Videotape Forum provided for those who attended the meeting. Johanna Smith, FFC co-president, was there to discuss the project. The presentation generated considerable interest in both the English and Spanish versions of the video. The Foundation has since received several requests for copies of the video from meeting participants. Additional information about the ACPA can be found on their website at www.acpa-cpf.org.

Save the Date!
September 19, 2004
See inside for
Walk-a-Thon
info & materials

2004 Scholarship Awards

The Foundation for Faces of Children proudly announces the annual scholarship award recipients for 2004. Grants of \$1,000 each will assist these three extraordinary young people with post-secondary education expenses. In addition to recognizing their achievements, we applaud their ability to overcome challenges.

Matthew MacEachern of Wilmington, Massachusetts, graduated from Wilmington High School. An honor roll student, he competed on the varsity golf team throughout high school, including his freshman year. He also participated in math competitions and the Bread and Roses Club, which gathers and donates food for the town's food pantry.

Matthew has told us that he sees himself working in the field of communications in the future. He will be using his scholarship award for his studies at Curry College in Milton, Massachusetts.

Amelia Potvin of Hampden, Maine, is a graduate of Hampden Academy. An outstanding student, she was a National Honor Society member and a National Merit Scholarship semifinalist. Amelia received the Ironwoman Award for perfect attendance at practices and meets as an athlete on her school's cross country track team. She devoted much of her time to community service, including initiating a Job Shadow Program for student volunteers at the Eastern Maine Medical Center.

Apert Workshop A Success, by Cathy Noonan, PNP

On May 8, 2004, the Craniofacial Centre at Children's Hospital Boston organized a day-long workshop for families and children affected by Apert Syndrome. Nearly 80 adults and children gathered to meet each other and to hear staff physicians discuss current issues in the care of patients with Apert Syndrome. Speakers included Dr. John Mulliken, Director of the Craniofacial Centre, along with plastic surgeons Dr. Rogers and Dr. Upton; maxillofacial surgeons Dr. Padwa and Dr. Ferraro; Dr. Shusterman of Dentistry; Dr. Kimonis of Genetics; Dr. Proctor of Neurosurgery; and Elisa Bronfman PhD, Psychology. Two adults with Apert Syndrome led an inspirational discussion with families, while Dr. Bronfman explored the psychological impacts of this craniofacial disorder.

Foundation for Faces of Children, represented by co-president Jane McDaid and advisory board member, Paula Woodman, provided a small grant to help support the workshop. The event was organized by Elizabeth Leonard, Elizabeth Hanna, and Dotty MacDonald, RN, of the Craniofacial Centre, and Cathy Noonan, PNP, Plastic Surgery.

Apert Syndrome is a disorder involving craniofacial and limb abnormalities, with both genetic and sporadic etiologies, that occurs in about 15 of every one million births. To learn more about Apert Syndrome, visit www.facesofchildren.org



Amelia Potvin



Matthew MacEachern



Gina-Marie Scarpa

In addition to her academic talents, Amelia is skilled in the arts. Her artwork was selected for the traveling exhibition "Art in the Heart of Maine" and her poetry was published in our newsletter (Summer, 2003). Amelia plans to use her scholarship at Dartmouth College.

Gina-Marie Scarpa of Peabody, Massachusetts, attended Peabody Veterans Memorial High School. She will apply her scholarship toward her studies at Boston College. In high

school, she excelled academically despite a rigorous course schedule and participation in many extracurricular activities — even finding time to tutor a pair of twins. Other activities included National Honor Society and class treasurer. She represented her school at Girls' State and the National Honor Society's National Convention. Gina-Marie is clearly a leader among her peers, having served as prom committee chair, head of an American Red Cross blood drive, organ donation chairperson, science league captain and cancer relay team captain, as well as chairperson of "Mock Crash Disaster."

We congratulate all of this year's recipients for their achievements. We are confident that they will be successful in their future studies. For more information about our scholarship program, visit our web site at www.facesofchildren.org or call 617-355-8299.





In Their Own Words

David Rodriguez of Southborough, Massachusetts, is a 2004 graduate of Algonquin Regional High School. He plans to attend the University of Massachusetts at Amherst in the fall and the following essay was used for his college applications.



What Being Born with Cleft Lip and Palate Has Taught Me about Life

by David Rodriguez


I think I was in preschool the first time I remember answering the question, "What's wrong with your lip?" My parents had prepared me for this moment by always modeling a straightforward

response to this. Although I cannot remember the exact words I said, it was something like, "I was born with cleft lip and palate. I am going to Children's Hospital to have my clefts repaired and there's nothing wrong. Want to play with me?" I have answered that question hundreds of times since then and one thing has always been true: being born with cleft lip and palate has taught me many things about life.

One in every 600-700 babies is born with either a cleft lip or palate. In my case, being born with cleft lip and palate has really impacted my life and will continue to impact it. I think that being born with adversity has helped me learn to adapt to more difficult situations than most people have had to handle. I made about a dozen trips to the operating room at Children's Hospital, but that is not a defining characteristic of who I am or a hindrance to who I will become.

People react differently to strange or unusual things such as cleft lip and palate, but clear and complete information helps people overcome their initial fears and reactions. When I underwent a complex procedure called distraction osteogenesis that caused my mid-face and jaw to swell beyond recognition, I carefully described the procedure to my friends. Having extensive details about what was happening to me helped my friends become comfortable with my situation. In fact, it seemed like the more information I gave them, the more detailed questions they asked until their curiosity was satisfied and they could support me during my ordeal.

The image many people have of what is beautiful is only skin deep. What that has meant for me is that I need to work through any negative feelings about my birth defect and stay positive. When I went to the regional high school in ninth grade and met new people, I knew that I was getting weird looks or laughs from other kids who did not know me. I could have walked away thinking to myself that they were ignorant, but instead I did things like sitting with new people at lunch and inviting new people to my house. That way, people who did not know me too well saw that I am a good person and friend.

Looking forward to next year, I have dreams to pursue just like my peers. I often dream that I will become a craniofacial surgeon and help kids by sharing my story. It is not clear if that will happen, but I will go to college next year knowing many things about life that most kids do not, because I was born with cleft lip and palate. 

Please Join The Foundation for Faces of Children for its Eighth Annual Walk-a-Thon:

Miles for Smiles

Sunday, September 19, 2004
Registration begins at 11:00 am
Lake Quannapowitt,
Wakefield, Massachusetts

- Preregister at **617-355-8299** or **jsmith@facesofchildren.org** so we know how many participants to expect. Leave your name and phone number and the number of walkers in your group.
- Feel free to make as many copies of the sponsor sheet as needed for family members and friends who may wish to participate.
- Be sure to bring your sponsor sheet the day of the walk as well as any monies already collected. Remaining monies should be mailed **no later than November 14, 2004** to:
Foundation for Faces of Children
Miles for Smiles
258 Harvard Street, #367
Brookline, MA 02446
- Come meet the **Marc Brown character "Arthur™"**, courtesy of WGBH Boston.
- Refreshments will be provided.



Questions?

Call us at **617-355-8299** or visit our website at www.facesofchildren.org.

All proceeds will benefit the Foundation for Faces of Children, a New England-based organization that is dedicated to improving the lives of children with facial conditions, including cleft lip, cleft palate and other head and facial differences.

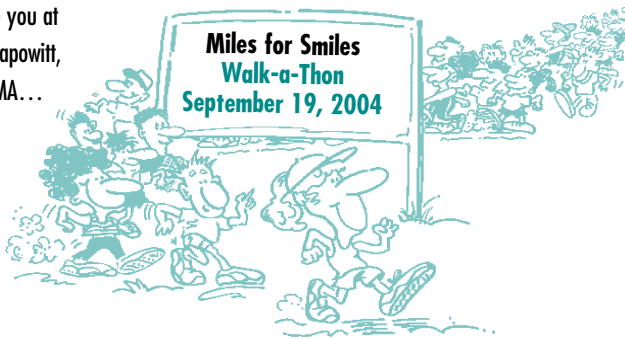
Directions To Lake Quannapowitt

From North or South—Take Route 93 to Exit 37 (128/95 North). Continue on Route 128/95 to Exit 40 (Route 129). The exit ramp puts you onto a rotary where you will follow signs for Route 129/Wakefield. Continue along Lake Quannapowitt for about a mile. There is limited parking along this side of the lake. We will be meeting on the common by the lights. Turn right onto Church Street at the lights. There is both on-street parking and a small lot behind the church to your right.

From Saugus and the East—Take Route 129 West to Wakefield Center. Turn right onto Main Street and go through the town till you reach the lake. Turn left onto Church Street at the lights at the head of the lake. There is both on-street parking and a small lot behind the church to your right.

From the West—Take Route 2, Route 90 or other preferred route to Route 128/95 North. Follow remainder of directions from second sentence of “From North or South,” above.

Hope to see you at
Lake Quannapowitt,
Wakefield, MA...



The **Foundation for Faces of Children** is dedicated to improving the lives of children with craniofacial conditions, including cleft lip, cleft palate, and other head and facial differences. We concentrate our efforts on education, training, family support systems, and the dissemination of accurate and timely information. We also fund targeted research about the causes, treatments, and outcomes of these congenital conditions. The goals and strategies of the Foundation for Faces of Children are to...

- Provide leadership and advocacy through research and education.
- Distribute accurate and timely information as quickly and widely as possible to children, families, medical professionals, and the community at large.
- Endorse the team approach to treatment of craniofacial conditions; we believe that the best outcomes result from collaborative treatment by an experienced group of specialists.
- Partner with organizations that have similar goals and values.

We are a 501(c)3 not-for-profit organization supported entirely by private donations, grants, and fund-raising initiatives. We receive no government funding. If you are interested in having a board member speak to your group about our organization, or if you wish to participate in or sponsor a fundraising event, please write to **Foundation for Faces of Children, 258 Harvard Street, #367, Brookline, MA 02446** or call us at **617-355-8299**.

(617) 355-8299 | www.facesofchildren.org

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