

# FACING THE FUTURE

## FFC IS GOING GREEN!

In keeping with the times, *Facing the Future* is converting from a print to an electronic publication. This switch will help save trees as well as printing and mailing costs. It will also allow for a shorter production schedule, increasing our ability to include timely news. Plus, we hope to encourage interactivity with you, our readers.

Online publishing will allow us to take a new approach to content and design, including links to other online resources for readers who want more information. (A limited number of printed copies will still be available upon request.)

Our e-newsletter will continue to be published free of cost, three times a year — in March, July, and November. If you would like to be sent e-mail alerts when the newsletter is posted, please go to the home page and click on:

### Join our e-mail list

Be assured that your address will be kept confidential and not shared with any other parties.

## FFC Celebrates 25 Years

November 25 of this year marks the 25th anniversary of the Foundation for Faces of Children (FFC), dedicated to improving the lives of children with cleft lip and palate, and other head and facial differences. Thanks to our generous supporters, FFC has continued to grow through the years and add to its list of accomplishments.

The Foundation was started by plastic surgeon John B. Mulliken, MD, and a handful of parents whose children were receiving treatment at the Craniofacial Centre at Children's Hospital Boston. Organizers included Norman and Rita Bartczak, Fred and Polly Frawley, and Robert and Priscilla Bradway. With the assistance and support of Children's Hospital nurse Dotty MacDonald, RN, and coordinator Kathryn (Kit) Mount, initial efforts focused on developing funding for teaching materials and information for parents.



Dr. Mulliken, one of the founders of FFC, in 1986.

Today, the Foundation's mission has expanded to address not only medical concerns but also psychosocial, financial, and educational issues related to craniofacial conditions. To achieve this, FFC collaborates with leading specialists to provide accurate, up-to-date information for patients and parents, regionally, nationally, and internationally.

"FFC is now using technology to reach out through our website, Facebook, and e-mail communications," says Mairi Bleakie, FFC director.

She points with pride to FFC accomplishments during the quarter century including:

- publishing *Facing the Future* for 22 years
- awarding 27 student scholarships since the program's inception in 1999

- distributing the video *Understanding Cleft Lip & Palate: Guide for New Parents* free of charge to more than 2,000 families in the US and many other countries worldwide.
- creating a website containing medically reviewed information about craniofacial conditions.

### Facing the Future

Still much remains to be done in the future. "We plan to increase the number of informational workshops and other events for families and young adults," says Johanna (Joey) Smith, FFC president. "We also plan to continue to improve our website in response to the needs of our families. And we are excited about the gala we are planning for early 2012 to celebrate all of our accomplishments during the first 25 years."

"Our focus has always been the families of affected children living in New England," adds Mairi. "But in the future, with help from our supporters, we hope to broaden our efforts here, and elsewhere through the website. We want to educate new families as a complement to the craniofacial team they have chosen and to develop meaningful resources for families by ourselves and in partnership with other like-minded organizations."

In addition, in collaboration with board member Dotty MacDonald, FFC is planning the production of a teaching video, *Feeding the Cleft Lip and Palate Infant—The First Year of Life*, for use by pediatricians and nurses as well as new parents nationwide.

"Our immediate priority is finding funding for this teaching video," says Joey. "If you are interested in providing financial support for this important project, please [donate online](#) or mail a check to the Foundation of Faces of Children [258 Harvard Street, #367, Brookline, MA 02446]."



Organizes as a New England-based not-for-profit foundation

Is featured on Oprah and Sally Jessy Raphael TV talk shows

Awards first student scholarship

Selects co-presidents Jane McDaid and Johanna Smith

Produces Spanish version of cleft lip and palate video

Sponsors first teen and young adult forum and produces video of presentations

Launches Facebook page  
Partners with support group Prescription Parents

*Facing the Future* goes online!

1986

1989

1996

1999

2000

2001

2003

2004

2008

2009

2010

2011

Designs logo and publishes first issue of *Facing the Future*

Holds first annual FFC Walk fundraiser

Produces video *Understanding Cleft Lip & Palate: Guide for New Parents*

Launches website [www.facesofchildren.org](http://www.facesofchildren.org)

Publishes online dental brochure

Awards first Annual Jane McDaid Scholarship in honor of its long-time president, who died in 2009

Offers parent workshops on overcoming insurance obstacles to care

Appoints first director of operations, Mairi Bleakie

## In Your Own Words

### “Elan’s Wide Smile,” By Meera Oliva

*Editor’s note: Meera Oliva wrote this account of her experiences last year. Elan’s palate repair was completed in July and Meera is happy to report that he’s making plenty of sounds, eating all sorts of new foods, and walking.*



Six months ago, we welcomed our little boy into the world, a perfect

little bundle with one major imperfection — a cleft lip and palate. Next week, Elan will undergo the third surgery of his short life, the one where the doctors will cosmetically repair his lip. It has made me think a lot about the last year and what our expectations were for Elan and how different things have turned out to be. Of course, we will still have one more operation to endure to repair his palate, but this one — the lip repair — feels like the big one, the one that we’ve been waiting for since the first day we heard the words “cleft lip,” and now that it’s here, I can’t believe how bittersweet it feels.

My husband, Raul, and I went for our 20-week ultrasound last March. Like most expectant parents we were just excited to see our first baby on the monitor and were not too focused on anything being wrong. At the end of the ultrasound, the radiologist said she never got a good look at the baby’s face and wanted me to come back again.

Since Raul had already missed a lot of work for my appointments, we decided I would go back by myself. That day another doctor conducted my ultrasound. When he finished, he said he’d back in a minute to talk about “some things.” I’ll never forget the way my heart dropped out of my chest at that moment.

When he came back, he said, “Your baby has a cleft lip.” And then he continued on about how plastic surgery these days is excellent but that this could be a warning sign of other problems, and he wanted me to have an amniocentesis and meet with a genetic counselor later that day. He was all business, and I was not processing any of it. I held up my hand to stop him and said, “I’m going to cry.” His demeanor instantly changed, and he said, “Well, that’s why we keep a box of tissues right here.”

I called Raul the second I got home, but when he asked me what was wrong, I could barely speak. All that came out was crying. He dropped everything at work and

drove the 45 minutes home, while I tried to pull it together enough to just get out the words “cleft lip.” At the time, we knew so little about what that meant. All I had in my head were the pictures of kids in Operation Smile ads, and I felt crushed.

I immediately started Googling more images, which made everything worse. I just remember feeling so bad for this baby and thinking about whether he or she would get teased at school and wondering if something else would be wrong. Raul and I went back to the doctor’s office that afternoon. The doctor we saw spent a lot of time with us, trying to get a good picture of the baby’s face.

“From the moment we saw Elan, we were absolutely in love with him, and with his cleft in particular...”

After a while, I asked if she thought the baby had a cleft palate, too. I barely knew what that meant but had read enough earlier in the afternoon to know that the two often go hand in hand. She went quiet and finally said that she couldn’t get a great image of it, but she was fairly certain there was a cleft palate.

I sat up on the table and started crying again. She put her hands on my outstretched legs and said, “We are going to help you. I know some people who are very, very good at this sort of thing, and I’ll talk to them, and we will help you.” And then she wiped tears from her eyes. I thought things must be really bad if even the doctor is crying.

They sent us to the waiting room to wait to see the genetic counselor. We felt terrible sitting in that room with all the other parents-to-be. My face was so red from crying, and I felt like people were watching and wondering what happened to us and feeling thankful that whatever it was hadn’t happened to them. At some point,

the receptionist called me to the desk. I assumed we were ready to be seen, but instead she told me they were going to waive my parking fee since I had been at their office most of the day, and she handed me a validated parking ticket. I laughed a little and thought to myself, “Something’s wrong with your baby, but it’s not a complete loss, because you do get free parking!”

The next three or four weeks were a real roller coaster. During this time, we learned about a world-class cleft surgeon, Dr. John Mulliken, at Children’s Hospital Boston and made an appointment to see him. We had many more ultrasounds and two fetal MRIs in those weeks. We got varying opinions from people about whether other things were wrong with the baby. And we learned a lot about the treatment and special feeding considerations for babies with cleft lips and palates.

At some point, we decided we had done all the preparation and worrying and crying that we could do, and we just wanted to get back to being excited about having a baby. We did a pretty good job of it too, though a fear of all the things we didn’t know was always in the back of our minds. How bad would the cleft be? What would it be like to see it for the first time? How hard would it be to feed him and go through the multiple surgeries? What would other people say when they saw him?

I read repeatedly on blogs and message boards that all of these questions and worries would disappear the moment the baby arrived. I didn’t believe that for a second, and then it turned out to be completely true. From the moment we saw Elan, we were absolutely in love with him, and with his cleft in particular, and suddenly all of the things to come like surgeries, arm restraints, and special feeding bottles seemed much more manageable.

So here we are ... a little less than a year from that difficult day and just a few days away from having Elan’s lip fixed, and everything feels completely different now.

*continued on page 3*



## Elan's Wide Smile, continued from page 2

In many ways I think this journey has enriched our lives. Of course we have our struggles, and certainly sending this happy little baby in for surgery every few months has not been easy. But becoming a part of the Children's Hospital and cleft lip-palate communities has been a real blessing. I have spoken to many other mothers of babies with clefts, and they are always so eager to offer support or a bit of advice on how to keep food from coming out your baby's nose. It has helped me see how kind and helpful and compassionate complete strangers can be.

We participated in a fund-raising walk in October [2009] for the Foundation for Faces of Children, and we felt so loved and supported by all of the people who contributed to our efforts.



Elan and his parents Raul and Meera Oliva shared the festivities with Dr. Mulliken at the 2010 "Paces for Faces" Walk and Family Picnic.

Elan's cleft feels like a part of who he is, and yet if Dr. Mulliken does his job right, Elan will grow up and never feel like his cleft defines him.

But it's hard to imagine. For now, we feel a little sad to be saying goodbye to this wide smile that we have loved so much these last six months. So we will enjoy it as much as we can the next few days, and then we'll get to work on loving his new smile just as much. I'm guessing that won't be too hard. 🍷

We are in awe of Dr. Mulliken every time we see him, knowing how many people's lives he has made immeasurably better, including our little Elan's.

The most shocking thing of all to both of us is how bittersweet it feels to have Elan's lip fixed. To us, his face doesn't need any fixing. His smile is so sweet and part of what makes it so cute is its imperfection. His



## FFC Student Scholarships

The Foundation for Faces of Children will once again offer scholarships to young adults born with a craniofacial difference who wish to pursue post-high school education.

High school students or graduates living in New England (Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, or Vermont) are eligible to apply for the \$1,000 scholarships to a college or vocational/technical school. This year's application deadline is April 1.

For scholarship applications and instructions, visit our website [www.facesofchildren.org](http://www.facesofchildren.org) and click on [For Patients and Families](#) at the top of the page. Or, call Mary Lania, Scholarship Committee Chair, at 781-255-8931 (evenings or weekends).



Board members and staff turn out for FFC's "Paces for Faces" Walk and Family Picnic. Those pictured here (from left to right) include Ron Parkinson, Mairi Bleakie, Joey Smith, Mary Lania, Kara Jackman and Katherine Murphy.

**Save the Date!**  
**Walk Family Picnic**  
**September 25, 2011**

## Introducing...

The 2010-2011 craniofacial fellow at Children's Hospital Boston is Kamlesh B. Patel, MD. Before coming to Children's, Dr. Patel completed a two-year plastic surgery residency and a three-year general surgery residency at the UC Davis Medical Center in Sacramento, California.

A native of England, Dr. Patel moved to the US with his family at the age of 18. After graduating with a degree in biology from the University of Missouri - Kansas City, he went on to earn his medical doctorate from the University of Arizona College of Medicine.



Dr. Patel, who received an award for compassionate care in 2009, is an active researcher as well as a skilled surgeon. At Children's, he's conducting research with John Mulliken, MD, on better ways to fix cleft nasal deformities. He's also studying speech outcomes following cleft palate repair for Robin Sequence (a genetic condition marked by a small or out-of-place jaw). In addition, he is evaluating the results of fronto-orbital advancement for metopic synostosis (the premature closing of the two bones of the forehead).

Dr. Patel is married and the father of a 1 1/2-year-old son. He fluently speaks Gujarati, the language originating from northwestern India, and in his spare time, he enjoys soccer and cricket.

After finishing his fellowship, Dr. Patel hopes to find a position as a pediatric plastic surgeon. 🍷

## Renewed Effort for Passage of Bills

Advocates for families of children affected by cleft lip and palate and other craniofacial conditions are once again pushing for insurance coverage of necessary treatments. On Beacon Hill, Massachusetts Representatives Lou Kafka and John Scibak have re-introduced bills guaranteeing coverage for medical needs, such as craniofacial and dental surgeries, nutrition supplies, feeding supplies, speech therapy, and orthodontics. The bills, now known as Bill H02065 (cleft lip and palate) and H00321 (craniofacial conditions), are currently under review by the Joint Committee on Financial Services.

“The net cost of these bills is negligible, only adding 2¢ per month, or 24¢ per year for each person covered by private insurance,” says parent advocate Adrienne Musto. “In contrast, many of our parents now incur astronomical out-of-pocket expenses to provide their children with craniofacial and cleft repair services.”

During the past year, the Joint Committee on Financial Services heard testimony from our community of parents and doctors and passed the bills (formerly known as Bills H932 and H1034) with favorable votes. However, at the conclusion of the session, the bills did not make it to the desk of Governor Patrick.

This year bill advocates believe they can navigate successfully through the legislation process and get the bills through both the Finance and Healthcare Committees. In addition to asking for support from state representatives, they plan to arrange a legislative day to interact with staffers and key representatives. 📍

## A Fond Farewell

Our sincere thanks to James (Jim) O’Sullivan, who recently stepped down from the FFC Board of Directors. Jim first joined FFC as an advisor in 2007 and a year later, became a member of the Board. During his years of service, Jim helped guide FFC and was instrumental in the search for its first director. Last year, he custom made a table to display the “smile” tiles created by Solomon Schechter Day School students for the waiting room of the Craniofacial Clinic at Children’s Hospital. We wish Jim the best of luck as he pursues his new ventures. 📍



**The Foundation for Faces of Children** is dedicated to improving the lives of children with craniofacial differences, including cleft lip, cleft palate, and other head and facial conditions.

Our mission is to:

- Provide patients and families with the most accurate, up-to-date, and accessible information about facial differences.
- Advocate for the best care possible for children with facial differences.

We achieve this by:

- Collaborating with leading specialists.
- Endorsing the team approach to care.
- Partnering with individuals and organizations with similar goals.

We are a not-for-profit organization entirely supported by private donations, grants, and fund-raising initiatives. If you would like to participate in or sponsor a fundraising event, please contact us at:

Mail: **Foundation for Faces of Children**  
**258 Harvard Street, #367**  
**Brookline, MA 02446**

Telephone: **617-355-8299**

E-mail: **info@facesofchildren.org**

Website: **www.facesofchildren.org**

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