

# FACING THE FUTURE

## Saturday Support Program Launched

The new monthly FFC-sponsored Saturday Drop-in Program for parents kicked off on September 22 with craniofacial nurse Dotty MacDonald, RN, addressing issues related to raising a child with a craniofacial difference from birth to age 5 and included prenatal screening. Ten parents, with children ranging in age from infants to teenagers, attended the event held at Boston Children's Hospital.

"It was a powerful two-hour session," says Mairi Fuller, FFC director. "Dotty gave pertinent information, but the core of the meeting was parents sharing stories and getting support from each other. There were tears and laughter."

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## Walking for the Children

A parade of hundreds of walkers wearing bright orange shirts circled Lake Quannapowitt under beautiful blue skies to support FFC. A record-breaking 600 family members, friends, and staff from Boston Children's Hospital turned out for the 16th annual FFC Walk and Family Picnic on September 23.

"We succeeded in our hopes of attracting new people," says walk co-chair Melina Fortin. "We had 63 teams register for the walk. It was a family-reunion type of gathering. Some families had relatives who came from far away."

Supporters raised more than \$60,000, which will further FFC's educational outreach through free publications, videos, and informational programs as well as the Foundation's website. The money will also be used to fund student scholarship awards.

"This event has grown enormously in the last two years thanks to the wonderful energy and enthusiasm of our amazing walk committee!" says Johanna (Joey) Smith, FFC president. "We are grateful to all the families who participated."

"It's fantastic to see our community grow and blossom each year," adds Mairi Fuller, FFC director. "I applaud the efforts of all the walkers and their supporters."

To accommodate the size of the crowd, this year's family picnic was held outside under a tent, rather than in the church hall as in previous years. Children's activities, including face painting, balloon creations by clowns, and

coloring, took place under the big top, too.

Also new this year, walkers who raised more than \$750 received special recognition as "Smile Striders." These individuals were honored and presented with red T-shirts and crystal paperweights on the day of the walk. Although not formally recognized, committee and board members also joined their ranks. Our deep gratitude goes to all of the following: Hailee Bergeron, Gina Brown, Katey Brown, Nicole Bussiere, Joseph Carroll, Olivia Chaves, Kerri Chatten, Kate Clark, Melissa Clericuzio, Ursula Costigan, Melina Fortin, Sheila Hatch, Kevin Hazel, Breann Hill, Elise Joyce, Jennie Keniston, Amanda MacKinnon, Cercie Miller, Adrienne Musto, Meera Oliva, Jared Popkin, Monir Sakha, Kate Shamon Rushford, Katie Remley, Monica Trivedi, Melanie VanderSande, Michael Yorba, and Shiyi Zan.

In addition, for the first time, the raffle, coordinated by Colleen Loughlin, featured "community baskets" filled with gift certificates valued more than \$200 from local businesses in Woburn, Wakefield, Stoneham, and Reading. A wide variety of other prizes were raffled off as well.

"We always want to improve the event," says Melina. "We want to create a positive experience to make people come back next year."

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## Finally, a Law to Make You Smile



On August 6, Governor Deval Patrick signed a law mandating insurance coverage for treatment of cleft lip and/or palate for children under the age of 18. A ceremonial signing, attended by supporters, was held at the State House on October 1.

Mass. State Rep. Louis Kafka (left) with parent advocates Tom Chappuis and Adrienne Musto

The legislation's passage was in large part due to the persistent grassroots organizing efforts of FFC board member Adrienne Musto, whose son Tony was born with a severe cleft in his lip and gum ridge, the bony structure that anchors the teeth. After facing her own frustrations with insurance denials, she took her fight for coverage to the Massachusetts State House.

She joined forces with Tom Chappuis, the parent of a child with cleft lip and palate, and approached Rep. Louis Kafka of Stoughton for his support. In May 2007, Rep. Kafka introduced a bill to guarantee insurance coverage for all medically necessary treatment for cleft lip and cleft palate. Adrienne then enlisted the support of FFC families, patients, and health care professionals at the Craniofacial Centre at Boston Children's Hospital, who testified in letters and

at the State House on behalf of the bill.

The new law, which will take effect January 1, 2013, provides benefits for all necessary medical, surgical, and dental care including speech therapy, audiology, nutrition services, orthodontics, and prosthetics (replacement of missing teeth). The long-sought legislation makes Massachusetts the 20th state in the country to enact a law requiring cleft lip and palate coverage.

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# Robin Sequence: More Than a Receding Chin

By John Mulliken, MD, Director, Craniofacial Centre, Boston Children's Hospital

Children born with Robin sequence (named for a early 20th century French physician; pronounced row-BAN) have a lower jaw that is smaller than normal (micrognathia) or set back from the upper jaw (retrognathia). This underdevelopment of the jaw causes the tongue to fall backward in the throat, resulting in feeding and breathing difficulties.

Formerly known as Pierre Robin syndrome, Robin sequence (RS) usually includes a cleft palate, an opening in the roof of the mouth that is wide and more U-shaped than that in more typical cleft palate. (See illustration.) The cleft is thought to be caused by the tongue being pushed upward by the lower jaw, blocking fusion of the palatal shelves during the first trimester of fetal development.

Many RS infants also have tongue-tie (ankyloglossia) in which the tip of the tongue is tethered to the floor of the mouth, making speaking and eating difficult.

Diagnostic imaging can help doctors predict RS before birth. Prenatal ultrasonography can detect a small jaw, and MRI can show a cleft palate.

RS is sometimes part of a syndrome—a group of associated anomalies—that may be inherited. The most common genetic causes for syndromic RS are Stickler syndrome (a disorder of the body's collagen) and velocardiofacial syndrome (a condition involving heart defects), but there are more than 30 other possible diagnoses.

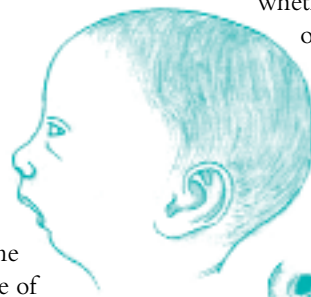
RS may be minor (Grade I), moderate (Grade II), or severe (Grade III). A baby with Grade I RS can eat and breathe well while lying on the back. A baby with Grade II breathes well but chokes when fed. A Grade III baby cannot eat or breathe without obstruction, resulting in low levels of oxygen in the blood.

## A range of treatments

Some hospitals rely on conservative measures, such as a feeding tube through the nose into the stomach, breathing tube in the nose, and prone positioning. Long-term use of a feeding tube, however, often leads to refusal to accept food by mouth. It may take months before the infant will eat normally.

Rarely, a tracheostomy, an operation in which a hole is made in the windpipe, is necessary to ensure the infant has enough oxygen. While effective, the procedure requires “around-the-clock” care.

For Grade III RS, the most aggressive approach is to cut the lower jaw on both sides and pull it forward using an appliance attached to the bone (distraction osteogenesis). At Boston Children's Hospital, we only consider distraction for syndromic RS infants whose lower jaw will not grow normally, for example, Treacher Collins syndrome, Nager syndrome, and bilateral hemifacial microsomia.



Infant with Robin sequence and intraoral view of U-shaped cleft palate.

Our first choice for infants with Grade III and some Grade II RS is a tongue-lip adhesion, a procedure that temporarily attaches the tip of the tongue to the inside of the lower lip to keep the tongue from blocking the airway. We use a grading system called GILLS that accurately predicts whether or not a tongue-lip adhesion operation is likely to be effective — which it usually is.

These infants use a feeding tube immediately after the operation and begin oral feeding by 10 days. They are discharged from hospital and monitored at home with a pulse oximeter — an oxygen-measuring device — for several weeks.

Cleft palate in infants with RS should be closed before age 1. The tongue and lip are detached at the time of the palate repair.

Remarkably, the lower jaw grows to almost a normal size during the first few years of life in children with non-syndromic RS. Speech outcomes in these children are similar to those in children with common cleft palate. In contrast, patients with syndromic RS are two times less likely to develop normal speech. Furthermore, children with syndromic RS usually require surgical advancement of the lower jaw. ■

## What You Need to Know

- The new law applies to all HMOs, PPOs, and health insurance providers in Massachusetts but not to self-insured companies, which pay employee claims directly.
- Parents with health insurance will still be responsible for co-pays and deductibles.
- Parents must still receive prior authorization for treatment if required by their insurance company. Treatment must be deemed “medically necessary.”
- The new law applies only to children under age 18.
- The guarantee of coverage starts on January 1, 2013 and is not retroactive.

## A Law to Make You Smile *continued from page one*

“The law will lift a huge financial burden from parents and alleviate many of the stresses placed on families,” says parent advocate Musto. “Every procedure is major for our kids. Eliminating the insurance battle will help parents focus on what is important, and that is their child.”

“By mandating coverage for all necessary treatment for cleft lip and palate between birth and age 18, the new law will help ensure that parents can afford to give their children the proper care,” adds Mairi Fuller, director of FFC and the mother of a child with cleft lip and palate.

Depending on the treatments required, the cost of surgical and dental care for children with cleft lip and/or palate can range from \$50,000 to \$200,000. The cost of the new law, calculated by the Division of Health Care Finance and Policy, will be two cents for each member insured per month or less than a quarter per year. Some state insurers, including Harvard Pilgrim Health Care,

Blue Cross and Blue Shield of Massachusetts, and MassHealth, have already begun to provide coverage for these services. ■





FFC supporters gather on the Wakefield Common before the start of the FFC Walk.



Kevin Hazel and Julie O'Neil at the start of the walk

Daniel Rogers (left) and Charlie Gagnon welcome walkers.



Friends enjoying face painting and balloons.



Dr. John Mulliken of Children's with William Clark



Lunch under the big top



Crossing the finish line



Mairi Fuller, FFC director, and Joey Smith, FFC president, helped orchestrate the successful event.



Our top fundraisers—the "Smile Striders"

A huge lineup of raffle prizes



Photos: Sarah Santos, Cindy Shields

## 2012 Paces for Faces Walk and Family Picnic *continued from page one*

Congratulations to Melina and her co-chair Jennie Keniston for coordinating the walk for the second straight year and for rallying so many people to the cause. Many thanks to committee members Ursula Costigan, Kevin Hazel, Colleen Loughlin, Liz and Logan O'Keefe, Julie O'Neil, Meera Oliva, Monir Sakha, Cheryl Silveri, and Shiyi Zan for their tireless work on registration, food, raffle prizes, children's activities, and more. Thanks, too, to members of the FFC board of directors who worked alongside committee members on the day of the event to ensure it was a success.

FFC is grateful for the generous support of its Platinum Corporate Sponsors (donations of more than \$1,000)—the International Brotherhood of Electrical Workers Local 42 and the Synthes Corporation. Our gratitude also goes to major food contributor Whole Foods Market of Framingham, Mass.

Visit [www.pacesforfaces.com](http://www.pacesforfaces.com) for a complete list of list of sponsors, donors, and volunteers, along with walk photos and a link to WBZ's coverage of the FFC Walk on their segment "One Last Thing." 📺

# FFC is grateful to all who made the walk a success!



## Platinum Corporate Sponsors

(official donation of \$1,000)

International Brotherhood of Electrical Workers  
Local 42

Synthes Corporation

## Logistics Support

Peterson Party Center – tent, tables, and chairs

The Throne Depot – portable toilets

Boston Audio Rentals – sound equipment

Fannie Gilarde – T-shirts

Diana O'Keefe, Threads & Ink, Braintree, Mass.  
– merchandise, Smile Strider shirts

Big Y Foods, Inc., Springfield, Mass. – paper  
products for lunch

Sarah Santos, Cindy Shields, Gregg Skelly –  
photography

Waste Management Systems – recycling/  
waste bins

The Crystal Cave, Chicago, Ill. – Smile Strider  
gifts

Ludlow Community Center/Randall Boys and  
Girls Club – walkie talkies, cash boxes

First Congregational Church of Wakefield  
Town of Wakefield

## Food

Whole Foods Market, Framingham, Mass.

BJ's, Framingham, Mass.

North End Treats, Framingham, Mass.

Delicious Desserts, Burlington, Mass.

D'Amici's Bakery, Wakefield, Mass.

Something Sweet Without Wheat, Woburn,  
Mass.

Utz Quality Foods, Wilmington, Mass.

Papa's Bar and Grill, Malden, Mass.

Anthony's Roast Beef & Pizza, Reading, Mass.

Breezeland Orchards, W. Brookfield Mass.

Watermark Donut Co. (Erik Lania),  
South Boston, Mass.

## Raffle Prizes

Your IT Solutions

Trader Joe's

Lazer Craze

Canobie Lake Park/Screamfest

Boston Duck Tours

Metropolis Café, Boston

Bertucci's

YMCA

Lake Compounce

Sky Zone

Target, Framingham, Mass.

Outback Steakhouse

Panera Bread

Stellabella Toys

Santa's Village

Storyland

Boston Bruins

Boston Celtics

Boston Red Sox

New England Patriots

Jimmie Johnson

Colley Hill Candles

Six Flags

Imax Theatre

Body Mind Systems

Christmas Tree Shops

Sports Authority

Galeazzo's Hair Salon

Dunkin' Donuts

Breezeland Orchards

Tokyo Joe's Studios of

Self Defense

Legal Seafoods (Jeff Lipson)

Picaboo Photo

BJ's Wholesale Clubs

Elizabeth Grady

Nancy Heffernan

Adrienne Musto

Jean O'Connor

Mike Riley

## Town Baskets for Raffle

### Wakefield Basket

Avon Beauty Center

Gone to the Dogs

Greenwood Wine & Spirits

J'Adore

Paw Stops

Rada Boutique

Silver Clay Fabulous Gifts and

Jewelry

The Queen's Vault

Wakefield Chamber of Commerce

Zuzu's Café

### Stoneham Basket

Areille's Café & Pizza

Cost Cutters

Walt Curran & Sons

Body Mind Systems

JB Butcher Shop

Hago Harrington's Miniature Golf

Dunkin' Donuts

Stop & Shop

Gaetano's

La Fitness

### Woburn Basket

Uno

Panera Bread

Today's Fitness

The Restaurant

On The Border

Tre Monte Restaurant & Bar

Target

Gary's Automotive

Bay State Tee Shirt Supply, Inc.

## Reading Basket

Everything But the Dog

Café Capri

Haven Sea Food

The Green Tomato

Beauty Nail & Spa

Meineke Car Care Center

Reading Visor

Jenny Boston Boutique

Direct Jewellery

Aines Boutique

Christopher's Restaurant

Grumpy Doyle's

## Activities

Clowns – Bill Blodgett, "KuKu"; Mason

Harper, "Wheelie"; and Phil Sirois,

"Boba" (Aleppo Shriners)

Face painting – Jenna Caggiano, Colleen

Connor, Christine Connor, Erin Connor,

Felicia Lamarch, Katie Nugent, Whitney

VanLoon, Natalie Watson

Coloring pages – FFC/Paces original

artwork by Michelle Gregoire

Karate demonstration by Randy Allen,

Tokyo Joe's Studios of Self- Defense

## Volunteers

### Raffles

Christine Pizzi, Carolyn Heffernan,

Meredith Miller, Cindy Cambria, Diana

Cavanaugh

### Lunch

Board and committee members (service)

John Loughlin (transport)

### Face Painting

Christine Connor, Erin Connor, Colleen

Connor, Felicia Lamarch, Whitney

VanLoon, Katie Nugent, Natalie Watson,

Jenna Caggiano

### Logistics

Table and chairs set up and take down,  
trash removal

Garrett Fortin, Joshua Hills, Naomi Hills,

Christopher Gregoire, Michelle Gregoire,

Dominic DeSantis, Sergio Figueiredo,

John Loughlin, Jared Popkin, Matthew

Wolfman, Casey Costigan, Eric Kachel

### Registration

Board and committee members

## Planning Committee Members

Committee Co-Chairs: Melina Fortin &  
Jennie Keniston

Logistics: Mairi Fuller

Registration and Fundraising: Ursula

Costigan, Meera Oliva

Raffle: Colleen Loughlin

Food: Monir Sahka

Merchandise: Liz and Logan O'Keefe

PR/Corporate Sponsorship: Cheryl Silveri

Activities: Shiyi Zan

Volunteer Logistical Support: Kevin Hazel,

Julie O'Neil



Clowns KuKu (left)  
and Wheelie



## Saturday Support Program

*continued from page one*

The October 13 meeting focused on the development of speech and potential speech issues from infancy through early childhood. The featured speaker was Katie Engstler, MA, speech-language pathologist at Children's.

The Saturday sessions run from 10 am until noon and are held in meeting rooms A and B on the first floor of the Enders Building at Boston Children's Hospital. All parents are welcome at any session.

Upcoming programs will be held on November 17 and December 1, 2012. For more information and to preregister, please contact Mairi Fuller at 617-355-8299.



## Introducing...

Carolyn Rogers, MD, this year's craniofacial fellow at Boston Children's Hospital, always knew she wanted to work with children and considered a career as a pediatrician. But she also discovered a love of plastic surgery and found that she could combine the two by caring for children born with facial differences.

"Craniofacial surgery gives me a unique opportunity to help kids," says Dr. Rogers. "I'm passionate about patient care. Taking care of patients is what drives me every day."

After growing up in Columbia, Maryland, Dr. Rogers attended the University of Maryland. She then graduated from the University of Pittsburgh School of Medicine, where she spent time researching the genetics of cleft lip and palate and facial nerve dysfunction. She completed her residency training at the University of Wisconsin School of Medicine and Public Health.

While attracted to all aspects of plastic surgery, she was particularly drawn to craniofacial surgery. "Each procedure is tailored to the specific needs of the patient," she says, "and requires creativity and an artistic eye."

To further develop her expertise in craniofacial surgery, she began a fellowship at Children's in July. In addition to patient care, she conducts research. One of her studies focuses on predicting Robin sequence prenatally. Working with plastic surgeon John Mulliken, MD, and radiologist Judy Estroff, MD, she uses fetal imaging to evaluate small jaws and the likelihood of developing this condition.

In her spare time, Dr. Rogers enjoys hiking, camping, and backpacking with her significant other, Jon. A dog lover, she has a little chihuahua-pug mix named "Bruiser." 🐕



Dr. Carolyn Rogers (second from right) joined the Children's Hospital team at the 2012 FFC "Paces for Faces" Walk. From left are: Kelly Wood, Dotty MacDonald, Drs. Portia Chiou and John Mulliken with their daughter Olivia, Dr. David Kim, Dr. Rogers, and Jon Vizena holding "Bruiser."



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. Please contact us if you would like to participate in or sponsor a fundraising event.

### Foundation for Faces of Children

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

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