

FACING THE FUTURE

FFC Website has a New Design!

FACESOFCHILDREN.ORG

Over the last several months, FFC has been working on re-designing our website and we are pleased to announce that it launched on January 7.

To see the new look, visit www.facesofchildren.org. You will find the latest news and upcoming events on the bottom of the home page at **"What's Happening @FFC."** Read details about each event by expanding its highlighted link.

Under **News & Events**, you'll see information about our upcoming events, as well as our Paces for Faces website, and the Newsletter Archives.

Our Scholarship program continues to thrive and allows FFC an opportunity to support deserving applicants. On our website, we're proud to showcase each scholarship recipient with a photo and short bio from their application.

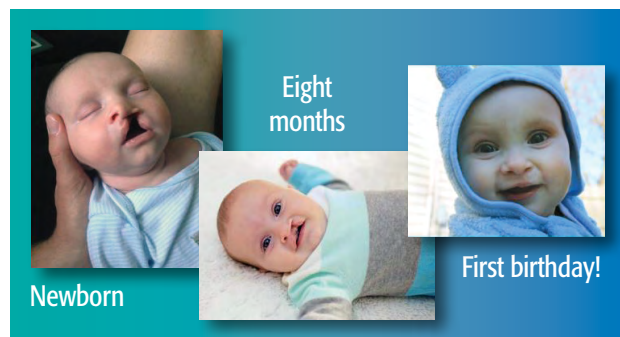
Narratives have been added to the **Personal Stories** and **Teens and Young Adults** pages. Finally, we've refined the **Conditions** page to include updated information on craniofacial conditions along with a glossary of medical terms.

We hope you like it!

The Latham Video is here!

The Cleft Team at Boston Children's Hospital understands that preparation for the insertion of the pre-surgical Latham device in infants with complete cleft lip and palate is a very stressful period of time for parents. Not only is it the first experience for the baby and parents in the operating room, but the ensuing 5-8 weeks of adaptation to the appliance, feeding difficulties, and structural changes around the mouth and nose are very challenging. The Cleft Team sought to ease parents through this time by providing explanation, demonstration and hands-on, always-available support.

The Team worked with talented videographers to create a resource to enable parents to understand Latham device treatment in the repair of cleft lip and palate. Drs. Shusterman and Ross, along with Craniofacial Centre nurse Olivia Oppel, skillfully illustrated the protocol. Latham-type devices have been employed at BCH for nearly 30 years and finally our parents and expectant parents can access detailed information about the process any time or place they choose.



If you have already been through the early stages of your child's cleft repair, this video will give you perspective on how far your child has come. If you are just beginning the process, the video will help you understand and prepare for procedures to come in the next few months. Finally, if you are expecting your child, these images will not only help you prepare, but also give you a glimpse of the amazing future transformation your baby will experience.

Join us for the premiere screening of the video at the scholarship awards in June. And tell others about the video — other parents, families and professionals will be deeply gratified to see how far these children progress.

The Foundation is grateful for the generous support of our community and family members who made this project possible. 🎬



Prototype for a New Latham-style Device

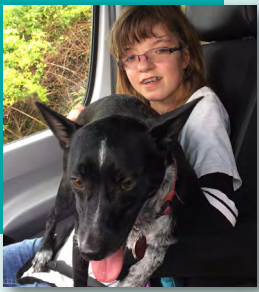


Boston Children's Hospital faculty member James MacLaine, BDS, is an innovator with world-wide dental experience. Here in Boston, he has turned his sights toward creating an improved Latham-type device.

Dr. MacLaine grew up in Northern Ireland before moving to Scotland for dental studies at the University of Dundee. Since qualifying as a dentist, he has undertaken positions in Scotland, Australia, Hong Kong — where he undertook his Orthodontic Residency — and England. Occasional exposure to Cleft and Craniofacial treatments during these years piqued his interest. Wanting to learn more, he applied to BCH's renowned Fellowship in Cleft and Craniofacial Orthodontics, headed by Drs. Stephen Shusterman, Rich Bruun and Liz Ross.

After beginning his BCH Fellowship in 2013, Dr. MacLaine's penchant for innovation was encouraged by his mentor, Dr. Shusterman. He started working on designs for a new type of appliance for unilateral cleft infants that would overcome some of the mechanical limitations of the Latham device. Upon return to BCH as Faculty in 2015, Dr. MacLaine resumed this project and shortly afterward was awarded a competitive hospital grant to continue developing the new device. The Foundation for Faces of Children provided additional funding.

The funding kick-started the ongoing prototyping process and Dr. MacLaine hopes to have clinic-ready devices in the near future. Watch this space! 🎬



In Your Own Words

My name is Joyelle. I am 15 years old and live in Maine. I was born with Apert Syndrome, which is basically that my bones didn't form properly so I look a bit unusual. Two summers ago, I had a mid-face advancement to move the bones in my face forward so I could see and breathe better. I worked very closely with the team Psychologist, Dr. Elise Bronfman. She followed me through the whole procedure then afterward nominated me for a "Dream" with the Dream Factory of Maine.

My dream was to volunteer at Best Friends Animal Sanctuary in Kanab, Utah. It is the largest no-kill sanctuary in the U.S. and a model for other animal shelters. I heard about Best Friends when I bought a book on its history at a silent auction for Puppy Love, a local dog rescue in Maine. For some reason my heart told me to go there someday, so I always had it on my radar. I was thrilled that my dream was going to come true. To have a dream come true after going through a big operation was truly the best part to end a painful procedure. I have never experienced a vacation that could beat this one. It was the best "Dream" ever.

I volunteered during my week at Best Friends with dogs, horses, cats and pigs. My favorite section in the sanctuary was Dog Town. I enjoyed playing with the puppies in puppy socialization class, hand-feeding very shy dogs, doing obedience and agility training, changing bedding, scooping poop, and being with the world's most snuggly pit bull, a male named Bomber. He loved me so much that he climbed and kissed me all over. I did not know that pit bulls were so sweet and lovable — I have finally found a favorite breed. I also met some of my heroes from the Dog Town series and the Champions film: Rescuers and lead trainers who rehabilitated the pit bulls rescued from Michael Vick's dog fighting ring.

My love for animals started when I was nine years old, volunteering for Puppy Love. Every month a transport of dogs from high-kill shelters would come to Maine. My job was to help unload them, comfort them and settle them in before they met their forever families. Around the age of ten, I met the owners of Mahoosuc Guide Service, who take clients on overnight dog-sledding trips. I went on one and loved it. Now I volunteer with off-season chores caring for huskies. I also attended rallies and became involved with Maine Citizens Against Puppy Mills. There I learned how much dogs were mistreated and wanted more than anything to stop these puppy mills.

At age twelve, I became a volunteer for the Coastal Humane Society and have been with them since. On weekly shifts, I perform enrichment with shy and frightened dogs, unload and settle rescue dogs and even go on rescue transport! I love holding puppies and chatting with my favorite staff! I hope to continue learning and working with animals in the future. My parents and I are grateful for the surgeons and caregivers at Boston Children's Hospital, who brought me through many surgeries. I am especially grateful to Dr. Bronfman for nominating me for the "Dream" trip and for all the opportunities that life has opened up for me.

To all the wonderful animals and the people who love them. — Joyelle 🐾



MAY 5 MOTHER'S DAY BRUNCH "Lessons Learned"

Embassy Suites Hotel, 550 Winter Street, Waltham, Mass.

There is free parking directly off of Rt. 128

Save
the date!

The Foundation for Faces of Children is sponsoring a special day to honor mothers of children with Cranio and Facial conditions. Please Join us to celebrate "YOU" mothers. Share and learn "lessons" from other moms. **Dr. Elisa Bronfman**, psychologist at BCH, will deliver comments. The program will be hosted by **Dotty MacDonald** (retired) and **Olivia Oppel**, craniofacial and plastic surgery nurses.

THE EVENT IS FOR MOTHERS ONLY (no children or spouses please)

Registration: 9:30 am | Program: 10 am (sharp) to 2 pm

Please register ASAP at programs@facesofchildren.org or 617-355-8299.

Provide your name, phone number and age of your child.



JOIN US FOR FREE PROGRAMS IN 2018!

MEN'S HOCKEY!

Saturday, March 11
3:00 pm to 6:00 pm
SNHU Arena, Manchester, N.H.



VS



Saturday May 5, 2018
10 am – 2 pm

MOTHER'S DAY BRUNCH

"Lessons Learned"

A discussion over brunch about bringing up a child with facial differences from infancy to adulthood – what mothers have learned and wish they had known. RSVP by Monday, April 30. FOR MOTHERS ONLY. Lunch will be served. (see page 2)

makingfaces.ca



Making Faces Workshop
with Michael Williams-Stark

Saturday April 7, 2018
10 am – 3 pm

Embassy Suites Hotel,
550 Winter Street, Waltham, Mass.



Using acting and improv games this workshop will build on important life skills that build self-confidence. This event is for the entire family! Michael has worked extensively with About Face of Canada providing workshops to the craniofacial community. He was born with a bilateral cleft lip and palate and went on to become a theatre major and later a professional voice actor. RSVP by Monday, April 2. Lunch will be served.

LATHAM VIDEO PREMIERE AND 2018 SCHOLARSHIP AWARDS PRESENTATION

Friday, June 22 (date subject to change)
6:00 pm

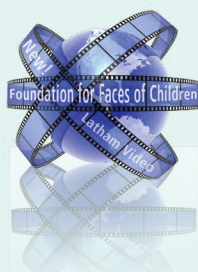
Embassy Suites Hotel, 550 Winter Street,
Waltham, Mass.

FFC invites you to join us for hors d'oeuvres and cocktails to celebrate the premiere of our Latham Video release and to recognize this year's scholarship award recipients.

Since its inception in 1999, the FFC Scholarship Award Program has distributed

58 scholarships for a total of \$104,000. The

Program recognizes promising students born with a facial difference by annually awarding post-secondary educational scholarships (college or vocational/technical school). Please RSVP by Friday, June 16.



PAWTUCKET RED SOX!
Sunday July 8, 2018
1:35 pm



McCoy Stadium, Pawtucket, R.I.

If you are interested in reserving seats for any of these events, email us at **programs@facesofchildren.org**.

Please list all of the programs you wish to attend and include the names of all those who will be attending along with the ages of those under 18. 📧

A Discussion of *Wonder* with Chelsea Middle School Fifth Graders

FFC Board members Dotty MacDonald, RN, and Jennifer Dodwell visited the Joseph A. Browne and Clark Avenue Middle Schools in Chelsea, Massachusetts to speak with fifth graders about R.J. Palacio's *Wonder*, a book the students were reading in class. Loosely based on the experiences of a young boy born with Treacher-Collins Syndrome, the book is about a fictional character, Auggie, a 10-year-old, also born with a craniofacial difference.

FFC was first invited to speak at Browne Middle School in December, then subsequently asked to make the same presentation in January at Chelsea's Clark Avenue Middle School. Ann-Marie Rogers from the FFC Board was able to join Dotty and Jennifer on their visit to Browne Middle School.

Dotty opened the sessions by introducing the Foundation and the important services it provides to its community of children and families. She followed this with a presentation about craniofacial differences, including genetic and environmental causes, specific types of craniofacial differences, detection methods, and likelihood of occurrence. Along the way, Dotty answered students' questions and made connections between real-life craniofacial differences and Auggie's condition as described in the book. Dotty concluded by introducing the students to a range of careers they might consider someday in the healthcare field.

Jennifer followed Dotty by sharing her personal experiences growing up with Hemifacial Microsomia. She explained the many ways in which she was similar to Auggie, as well as ways in which she was different. Jennifer's goal was to emphasize that while we as people have much in common, we are also individuals with differences to be celebrated. She also described several of her surgeries and answered a number of questions from the students. Toward the end of her presentation, she shared some of the life lessons she'd learned along the way.

The FFC thanks all the students and staff they met during their two visits to the Chelsea schools. They are most grateful for the opportunities to speak, as well as for the incredibly warm welcome they received from wonderful audiences. 📷

FFC HAS BEEN BUSY THIS WINTER!

Since our last newsletter, FFC has sponsored family outings to a hockey game, basketball game and bowling. We're happy to have welcomed more than 50 people for one or more events. The Merrimack Warriors hockey game was really exciting and ended in a TIE score. There was a holiday skate with the players, hot chocolate and Santa. It was a great way to end 2017! We watched the BU Women's Basketball game and had so much fun bowling at PiNZ together. These FREE events are a great way to meet new friends and catch up with others. FFC looks forward to seeing you at one soon! 📷



FOUNDATION FOR Faces of Children

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617-355-8299
info@facesofchildren.org
www.facesofchildren.org

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.

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