



In Your Own Words

By Lacey Clericuzio, age 13

On June 19, 2000, I was born with a birth defect which made everyone think that I would be weak and dying. But they were wrong; except one thing, I do have a birth defect. It makes me a very special and gifted child. I am a brave, smart, and charming deaf and low-vision girl

Right before my first birthday, my parents learned that I was deaf. I am so lucky to be a deaf girl because I don't hear horrible noises — like IV pumps alarm beeping. I can talk with my hands.

At age four, I had an operation to insert a plastic nose on my face. My new, sparkly red glasses finally had something to sit on! Around that time when I could see better, I started to communicate. My mother says I haven't stopped talking (and arguing) since!

I started elementary school with my class. Sometimes kids make fun of me but I think positive.

When I was 12 years old, I had another operation to extract eight teeth. This year, I had another operation to take bone from my skull to form a "real" nose and insert a forehead implant.

I would like to thank everyone for their support that I have needed and will need in the future. I will have many more operations. When I am an adult, I want to be a doctor to give back help to other children. Now, I am a pretty teenage girl. I am very special. ■

Think positive whoever you are!

who's gone through so many operations.

It is hard for my sweet family to see me in my hospital bed with tubes and bandages or stitches on me. Luckily, my parents met with Dr. John Mulliken; he is the best doctor ever! He said I have a cleft face. We all stay positive throughout our life. When I was one week old, I had my first major operation. A month later, I had an even bigger operation to fix my eyes and insert wires, screws, and a plate to correct my eyes. I wore a brace-like helmet for it. I lived in the NICU and Children's Hospital for most of my first year of life. Over a dozen surgeries in about two years!

Newsletter of the Foundation for Faces of Children

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Save the Date for the 18th Annual Paces for Faces Walk and Family Picnic on Saturday, September 13, 2014!

Whether you are a veteran of the annual Walk or new to the FFC family, we hope you will consider joining us for the 2014 event. The 3-mile walk around Lake Quannapowitt in Wakefield, Mass. and family picnic and activities immediately following, provides a great opportunity to meet new friends and catch up with old. Registration and further details about the Walk will be forthcoming so keep your eyes open for information.

To receive information by email, sign up for our "Fundraising" e-list at www.facesofchildren.org or to receive information by mail, send your name and mailing address to info@facesofchildren.org.

To volunteer to help organize this year's Walk, send your name and contact information to info@facesofchildren.org or call us at 617-355-8299 and someone will follow up with you!



2014 FFC SCHOLARSHIP AWARD PROGRAM: Expanded to Honor Four Leaders

Now in its 16th year, the FFC Scholarship Award Program has distributed 44 scholarships totaling \$54,000. Established in 1999, the Program recognizes promising students born with a facial difference by annually awarding post-secondary educational scholarships (college or vocational/technical school). High school graduates or college students who are residents of New England (Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, and Vermont) are eligible to apply. The Foundation selects award recipients based on their academic performance, extracurricular activities and community service. Mary Lania has served for ten years as the FFC Scholarship Committee Chair. She observes "I am always amazed at the caliber of the applicants. They are exceptional, creative students who give back to their community and persevere through unbelievable obstacles to emerge as amazing young adults. Each spring when the scholarships are awarded, it is truly an honor to learn of their accomplishments and play a small part in seeing their dreams coming true as they pursue their college education."

In recent years, many scholarship recipients have returned to serve as FFC volunteers; helping at events, offering support to younger generations and establishing themselves as mentors and role-models.

FFC works to build a robust scholarship program in order to give back to the craniofacial community, and it has grown to be more successful each year. At the Program's inception, FFC awarded a single \$1,000 scholarship. Increased interest and funding soon enabled FFC to award three annual scholarships. In commemoration of our 25th anniversary year in 2012, the awards were increased to \$2,000 each. This year has seen yet another milestone with the establishment of scholarships named to honor extraordinary people who have made their mark not only within FFC, but throughout the entire craniofacial community. The four scholarship awards are:

MEMORIAL SCHOLARSHIPS



The Jane C. McDaid Memorial Scholarship

Awarded to the applicant who shows evidence of strong community service, this scholarship honors Jane McDaid, past president and board member of the Foundation for Faces of Children.



The Barbara Seltzer Memorial Scholarship

Awarded solely to an applicant with cleft lip/palate who will be pursuing a career in the arts, this scholarship honors Prescription Parents co-founder Barbara Seltzer.

HONORARY SCHOLARSHIPS

The Dorothy MacDonald Scholarship

Awarded to an applicant who will be pursuing a career in a health profession, this scholarship honors Dorothy B. MacDonald, RN, who has dedicated her career to caring for children with craniofacial differences.



The Dr. John B. Mulliken Scholarship

Awarded to an applicant who demonstrates excellence in academic scholarship and leadership, this scholarship honors Dr. John B. Mulliken, founder of the Foundation for Faces of Children. He is passionately devoted to working with and improving the lives of children born with craniofacial differences.



For information on the FFC Scholarship Award Program, go to www.facesofchildren.org to find the scholarship application link, or call Mary Lania, Scholarship Committee Chair, evenings or weekends at 781-255-8931. ■



FOUNDATION FOR Faces of Children

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Connect Online



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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Finding Genes that Cause Vascular Malformations with Overgrowth

by Reid A Maclellan MD, MMSc, Research Fellow, Department of Plastic and Oral Surgery, Boston Children's Hospital



Using a technique called "massively parallel sequencing," the Vascular Anomalies Center at Boston Children's Hospital has discovered somatic mutations for non-inheritable vascular malformations associated with overgrowth of soft tissue. The genetics team has determined that a mutation in the gene *PIK3CA* is the likely cause for CLOVES

syndrome (congenital lipomatous overgrowth, vascular, epidermal, and skeletal anomalies), infiltrating lipomatosis in the face, FAVA (fibro-adipose vascular anomaly), KTS (Klippel-Trenaunay syndrome), and LM (lymphatic malformation).

Each cell in the human body contains two copies of parental DNA which are composed of 20,000 genes. Genes tell the cells how to build the baby's body. Vascular malformations occur when there are mistakes in information of veins, arteries, or lymphatics during embryonic development. Vascular malformations affect 0.5% of newborns; they are most commonly located in the head and neck, but can arise anywhere in the body. A mutation is a permanent change in part of DNA that may be inherited from a parent or may occur spontaneously. Mutations

that occur in a sperm or egg are inheritable, meaning they can be passed to the next generation. Somatic mutations that occur after fertilization are not inherited.

Several genes are already known to cause inheritable vascular malformations. To identify disease-causing mutations in vascular malformations, we prepare genetic libraries by extracting DNA from affected tissue. We place the DNA libraries on a computer chip that is custom designed with genes thought to play a role in the disease under study and then use computer software to detect mutations in these libraries.

A *PIK3CA* mutation has been found in nearly all patients with a vascular malformation and overgrowth tested so far. Similar *PIK3CA* mutations have been discovered in certain cancers and are known to cause cell overgrowth. A *PIK3CA* mutation may be a reason why these vascular malformations enlarge over time. Several drug inhibitors are currently being studied in clinical trials for treatments of cancers caused by *PIK3CA* mutations. These drugs block this mutation from overacting and they may have a therapeutic role in patients with expanding or recurring vascular malformations. ■

2014 FALMOUTH ROAD RACE: JOIN THE FFC TEAM



The New Balance Falmouth Road Race celebrates its 42nd running this year and the spirit which made the first race so special is still present today. More than 12,000 runners will gather in Woods Hole, Massachusetts for the 2014 renewal, including many of the world's elite, though the essence of the event remains a fun run. Back-of-the-pack joggers share the road with the best, forming a tapestry of colors from the start on Water Street to the finish at the beach in Falmouth Heights.



Following last year's success, the Foundation for Faces of Children is excited to return to the race with a team of its own! Are you an avid runner? Consider joining Team FFC for this year's Falmouth Road Race on Sunday, August 17.

A limited number of bibs are available. To learn more, call us at **617-355-8299** or email us at info@facesofchildren.org. Each team member must commit to raising \$1,000 — with the support of the Foundation — through online fundraising efforts.



YOUR DONATION DOLLARS AT WORK

PROGRAMS AND EVENTS FFC HAS PLANNED FOR YOU IN 2014!

Parent Support Gatherings

Wednesday evening gatherings take place at the Newton Senior Center, 345 Walnut St, Newton, Mass. from 7:00 to 9:30 pm. Dates for 2014 are:

March 19	May 21	September 17	November 19
April 16	June 18	October 15	December 17

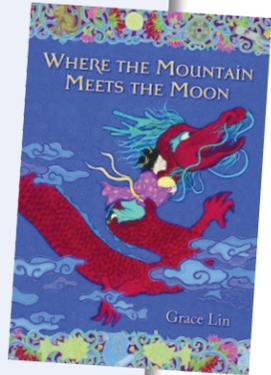
Come share your experiences and develop a sense of community in an environment where parents of older children are able to offer support and insight to parents of younger children and newborns. These relaxed, low-key gatherings provide an opportunity for parents to meet in a non-clinical setting and provide both support and encouragement to one another. During these small gatherings, parents explore available resources and share personal stories, needs and concerns. Common themes for discussion include caring and feeding issues of younger children; preparing for surgeries; dealing with insurance issues; and coping with teasing. Our hope is that by participating, parents will feel better supported through the difficulties and uncertainties they may face each day. While registration is not required, it is certainly helpful for planning. Please email parentsupport@facesofchildren.org, providing your name(s), your child's information (name, age and craniofacial condition), and the date(s) you will be attending.



Event at Wheelock Family Theatre, Boston

FFC has reserved tickets for the WFT's performance of "Where the Mountain Meets the Moon," Saturday, April 12 at 3:00 pm. Inspired by her father's stories of the Jade Dragon and the Old Man of the Moon, young Minli sets off on an extraordinary journey to change her family's fortune. She encounters magical creatures along the way, including a dragon that accompanies her on her quest, and finds her questions answered in unexpected ways. WFT proudly presents the East Coast premiere of Grace Lin's Newbery honored novel.

Discounted ticket price is \$15 per person by March 22. Seating is limited and will be assigned on a first-come, first-served basis. Limited ADA seating available so indicate need. Order tickets by phone at **617-355-8299** or via PayPal on our website www.facesofchildren.org.



Batter Up!

Plan to join us for a baseball game: Pawtucket Red Sox vs. Scranton/Wilkes-Barre RailRiders at McCoy Stadium in Rhode Island on Sunday, May 18. Event includes running the bases following the game. Last year, ten FFC families showed up for a great time together at a PawSox game.

Or, join us on Father's Day, Sunday, June 15 at LeLacheur Park for a Lowell Spinners game against the Vermont Lake Monsters (Peanut-free Day).

If you are interested in either of these games, email programs@facesofchildren.org. Specify which event you plan to attend, number of adults and children, and children's ages.



Regional Conference Held December 6, 2013

FFC in partnership with BCH hosted a regional one-day day education conference in Waltham for more than 70 medical professionals. "Caring for the Newborn with Cleft Lip-Cleft Palate" provided training, resources and networking opportunities for clinicians and others interested in the care of young children with cleft lip and/or cleft palate. Attendees learned the newest evidence-based care approaches. The conference began with a screening of FFC's new feeding video "Caring for the Newborn." Keynote speaker was Patricia Daly Chibbaro, RN, MS, CPN, from New York. The conference culminated with a parent panel which was one of the highlights for the participants.

Receive notifications about these and other events organized by the Foundation for Faces of Children by visiting www.facesofchildren.org and clicking on the "Sign Up for Email Updates" button.

WINTER BOWL!

Family Bowling Event Held December 30, 2013

On a cold winter's day during school break, six families came together at Boston Bowl in Dorchester to enjoy an afternoon of bowling, pizza and networking. One dedicated family drove from New Hampshire, bringing their own bowling shoes. One 5-year-old girl joined us to bowl for the very first time, her face beaming with joy and delight!

