

FACING THE FUTURE

OVERCOMING INSURANCE OBSTACLES

Children's Hospital Boston

Join us for a discussion of how to get the best care and insurance coverage possible for your child on Saturday, November 13, from 10 am to 12:30 pm (followed by lunch). The FFC-sponsored event will take place at Children's Hospital Boston in the pavilion dining hall, located at the top of the main staircase, to the left. All parents of children with cleft lip/palate and other craniofacial differences are invited.

Learn how to successfully deal with insurance issues related to your child's medical and dental care. Hear an update on the Massachusetts legislation, dealing with health care coverage for cleft lip/palate and other craniofacial conditions. Guest speakers for the event will include Beth Dworetzky, Massachusetts Family-to-Family Health Information Center, and Leah Ledgewood, coordinator, Children's Department of Dentistry.

Please RSVP to Mairi Bleakie at mbleakie@facesofchildren.org or 781-875-1914. And let her know about your current concerns or past obstacles with insurance so the speakers can address those issues.



FFC Gets Checkered Flag — Wins \$10,000 Grant

Champion race car driver Jimmie Johnson has chosen FFC to receive a grant of \$10,000 to support its efforts to improve the lives of children with craniofacial differences. FFC's name has also been added to the Jimmie Johnson Foundation's Samsung Helmet of Hope—the helmet Johnson wore when he competed in the NASCAR Sprint Cup Series race at Auto Club Speedway in California on October 10.

Seth Livingstone, a sports reporter for *USA Today*, nominated FFC in honor of Dr. John Mulliken at Children's Hospital Boston. Dr. Mulliken provided care for his son Andrew when he developed a hemangioma, a bright red blood vessel growth, as an infant. (See "Treating Infant Hemangiomas" below.)

"When I heard of the Samsung Helmet of Hope, I immediately thought of our own family situation and how Dr. Mulliken and others like him help children regain a degree of normalcy in their lives," says Livingstone. "I can't think of a more worthy foundation, so I nominated the Foundation for Faces of Children.

And we were fortunate enough to have Jimmie select the Foundation."

Now in its third year, the Samsung Helmet of Hope program is sponsored by the Jimmie Johnson Foundation, Samsung, and Lowe's. Fans and media members nominate their favorite children's charity to be featured on Johnson's helmet and receive a \$10,000 grant. FFC is one of thirteen charities selected this year.

"We are thrilled to receive this grant," says Mairi Bleakie, FFC director. "The money will help fund a video on specialized feeding techniques, which we hope to premiere in the spring." ■



Champion race car driver and FFC benefactor Jimmie Johnson.

Treating Infant Hemangiomas

In 1989, Andrew Livingstone was born without a blemish, but two weeks later, a strawberry red growth began to bloom on his upper lip. At age three months, the mass enlarged quickly, extending up to his nose. It became an open sore, which would scab over, only to ulcerate again and again. Andrew's pediatrician diagnosed the condition as a hemangioma and referred his parents, Seth and Marcy, to renowned expert, plastic surgeon John Mulliken, MD, at Children's Hospital Boston.

A hemangioma is a tangled mass of poorly formed blood vessels typically found on the head or neck. This noncancerous growth is the most common tumor of infancy and childhood.

"Most of these vascular tumors are in the skin, but they can occur in any organ, including the liver and even the iris of the eye," says Dr. Mulliken, co-director of Children's Vascular Anomalies Center, the first interdisciplinary center of its kind in the country.

"About 20 percent of affected children have multiple hemangiomas."

Hemangiomas typically develop during early infancy, initially appearing as a pale red stain, bruise, or cluster of spidery blood vessels. During the first year of life, they grow

rapidly into a firm mound, and then over the next five years or so, shrink and fade away slowly in a process known as "involution." Some hemangiomas are present at birth at a nascent or early stage of development.

Although hemangiomas sometimes run in families, they are not strictly hereditary. Fair-skinned babies develop hemangiomas more often than babies with darker complexions. And girls are affected 3 to 5 times as often as boys. Hemangiomas are also more common in premature babies with low birth weight as well as in multiple births.

What causes hemangiomas? Using samples of infantile hemangioma provided by Dr. Mulliken, Joyce Bischoff, PhD, and her colleagues in Children's Vascular

Hemangiomas

continued from page 1

Biology Program have shown that the answer is an abnormality in a primitive stem cell that divides and develops into specialized tissues, including blood vessels.



Multiple hemangiomas on the head of an infant.

ing facial features," says Dr. Mulliken. "Drug therapy is often required for large hemangiomas in the liver, which can cause congestive heart failure, and even hypothyroidism.

"While deep lesions regress to relatively normal skin," adds Dr. Mulliken, "superficial lesions can result in tiny red capillaries, sagging, thin skin, fibrofatty tissue, and scarring—particularly if ulceration has occurred. Even small hemangiomas stretch the skin and may leave behind a bulging, fatty lump that requires treatment."

When and How to Treat

In 9 out of 10 cases, diagnosis of a vascular tumor can be made based on patient history and a physical examination. But magnetic resonance imaging (MRI) and ultrasonography may also be needed to confirm the diagnosis or determine the extent of a large lesion in the airway or brain.

While many hemangiomas disappear without lasting effects, some require treatment. "Surgical resection is indicated when a hemangioma obstructs breathing or vision, or is ulcerated, bleeding, or deform-

Dr. Mulliken recommends that all infants or children with problematic hemangiomas be seen at a vascular anomaly center at a major teaching hospital. At Children's Hospital Boston, an interdisciplinary team,

composed of surgeons, dermatologists, interventional radiologists, neuroradiologists, pathologists, nurse practitioners, and other specialists, meets weekly to discuss treatment plans for patients with hemangiomas and other vascular anomalies.

The most common medical treatment for infant hemangiomas involves daily oral corticosteroid, decreasing over a 10-month period. However, during the past two years, some doctors have begun using an alternative for shrinking lesions—a beta-blocker called propranolol. French doctors accidentally discovered this new therapy when using the drug to treat two infants with heart problems, who also happened to have hemangiomas. Some doctors believe propranolol, which has fewer side effects than steroids, should be the first-line treatment for this tumor.

Surgical intervention may be needed for larger hemangiomas. "Operations may be undertaken during the proliferative,

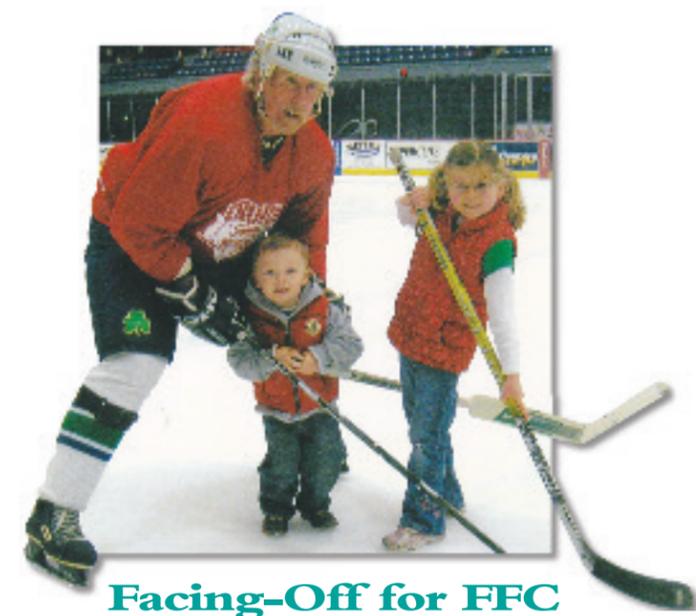
involuting—year 2 to 5 or so—and involuted stages," says Dr. Mulliken. "But it is important to go to a surgeon who has experience handling hemangiomas at these different phases. Operating on something that's downsizing is not like working on a sculpture of stone. Each hemangioma is unique—some can be trimmed in one operation, while others require a series of operations.

"Laser treatment is not indicated during infancy," he adds. "When the child is older and the lesion is involuted, it plays an important role and can be used to fade tiny residual capillaries."

Andrew Livingstone is now 20, and his hemangioma is a thing of the past. He is thriving as a third-year student at Cornell University, majoring in Industrial and Labor Relations.

Starting at age 4, he underwent several operations to remove excess skin left as the hemangioma receded. Later, he had laser treatments to fade remaining discoloration.

"Dealing with his own physical imperfections has enabled Andrew to develop a sensitivity that does not come automatically," says his father. "He's very attuned to others. In high school, he was the student founder of the athlete-to-athlete club, which organized and paired special needs kids with varsity athletes. He sees people for what they are, not just skin-deep." ■



Facing-Off for FFC

The Parks family and the Syracuse Crunch Hockey team continue to support FFC by organizing an annual charity hockey game. This year's game raised \$1,500, which was donated in honor of six-year-old Madison Parks, who was born with unilateral craniosynostosis.

Here Madison takes to the ice with her little brother Gavin and their grandfather. Unfortunately, her father, John, was on the injured list after breaking his leg playing goalie in a game two weeks earlier.

Our special thanks to John and Teri Parks and to the whole staff and team of the Syracuse Crunch Hockey organization. ■

Walking for a Good Cause

Nearly 200 FFC supporters laced up their sneakers to join the "Paces for Faces" walk around Lake Quannapowitt in Wakefield on September 26. Now in its 14th year, this was the most successful FFC Walk and Family Picnic yet.

"Our fall fundraising event helps make possible FFC's free publications, videos, and website as well as our annual presentation of student scholarships," says Mairi Bleakie, FFC director.

Among the walkers were friends and family members, including grandparents and babies in strollers. Joining the cause was a team of seven 12-year-olds, organized by Erica King, who wore T-shirts with the message "If not you, who?"

After the three-mile walk, participants were treated to pizza and more, catered by Bellino's Trattoria. During lunch, "Mister Twister" (aka Bill Campbell) created fun balloon hats and animals for the kids, and "Dora the Explorer" and "Elmo" stopped by for a visit.

Later, FFC president Johanna (Joey) Smith recognized teams organized by Meera Oliva and Melina Fortin as the top fundraisers, and board member Jack Condon awarded raffle prizes to winners.

continued on back page



◀ Page 1: John Loughlin with daughters Molly (left) and Megan enjoying Mister Twister's balloon handiwork.

A huge turnout for the start of the walk! ▶



The 14th Annual "Paces for Faces" Walk and Family Picnic

Raul and Meera Oliva with Elan ▶



▶ Monir Sakha and her daughter Diba Jalalzadeh prepare to roll out.

▶ Brandon Kiley and his dad Todd



▶ Kevin Elmendorf and Julie Tarris Powers with Tyler

◀ Left to right, FFC director Mairi Bleakie with board members Anne-Marie Gagnon, Dotty MacDonald, Joey Smith, and Kara Jackman



▶ A winning team: Melina and Carter Fortin with Dr. John Mulliken

◀ The "If Not You, Who?" team with organizer Erica King at right

Paces for Faces, continued from page 2

Hats off to the many walkers, volunteers, and sponsors who made the day a success. Special thanks to Joe Carroll of the FFC Advisory Board for providing the colorful T-shirts and beverages, Erik Lania of Watermark Donuts for the coffee and donuts that got the day started, Sean Kane Party Rentals for the tents, and the Synthes Corporation for furnishing the delicious lunch. Also thanks to Fotos by Mimi, Ganz, Highlights for Children, Colleen Loughlin, Christine Pizzi, Picaboo, Magic Beans in Brookline, and Avon Basket by Diana Cavanaugh for supplying prizes. And, as always, our appreciation goes to the First Parish Church of Wakefield and the town of Wakefield for hosting this event.

For a link to our online photo album, please e-mail Mairi at mbleakie@facesofchildren.org. 

Wearing apparel with the FFC logo is a great way to show your support. Visit www.facesofchildren.org to learn how you can purchase FFC merchandise.

Go Green! Help save the environment and reduce our printing and mailing costs by receiving your newsletter by e-mail. To join our electronic mailing list, please send your name and e-mail address to us at info@facesofchildren.org. **Thanks!**



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:

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Brookline, MA 02446

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