Born with Marfan syndrome and dislocated lenses, Yamil Kouri spent most of his young life legally blind. The fog lifted when he got eyeglasses that worked for his complex refraction. He was finally able to ride a bike, try skiing and enjoy the activities of a normal 9 year old. His new lifestyle nearly came to a halt when doctors discovered that his retina had detached. Yamil was taken to Mass. Eye and Ear for emergency care.

Marfan syndrome is a multi-system disorder in which the body’s connective tissue is abnormal. It most often affects the connective tissue of the heart and blood vessels, eyes, bones, lungs and spinal cord covering. Complications are many, and they can be life- and sight-threatening.

“Yamil’s lenses had dislocated when he was 2, rendering him severely nearsighted and legally blind,” his mother, Suzanne Kouri, says. “This changed when he was 9, and we found Dr. Lois Smith at Children’s Hospital Boston who was able to prescribe eyeglasses to correct his vision. Yamil had a great year. You can imagine how alarmed we were when Dr. Smith discovered what she thought may be a detached retina during a routine eye exam.”

“Detached retina is one of the most acute and severe eye problems in Marfan syndrome,” said Dr. Shizuo Mukai, retina surgeon at Mass. Eye and Ear, who is one of the country’s few retina surgeons who specialize in pediatric patients and who sees a significant number continued on page 7
Dear Friend,

Some of you may have recently seen the story of Nicholas, an energetic and charming young boy whose parents adopted him in Russia. They realized on the plane ride home that Nicholas was hearing impaired. The care that Nicholas received from a team of specialists at Mass. Eye and Ear has brought him the gift of hearing and, therefore, the gift of speech.

It is stories like this that continuously motivate the patient care, research and teaching at Mass. Eye and Ear. In recent months, we have taken strides to expand our universe so that Mass. Eye and Ear care can reach more people.

You will see in the pages that follow that we have just broken ground on our new multi-ambulatory care center, which is now under construction at 800 Huntington Avenue in Boston’s Longwood/Mission Hill neighborhood. The center, with four ORs, spacious clinics and ancillary services, will provide state-of-the-art care in a convenient location for many of our patients.

In November, we opened an expansion to our Quincy suburban center: a new diagnostic center that includes a sleep center and an allergy clinic.

We have also recently opened newly renovated clinics on the 9th floor of our main campus, including a Sinus Center, and centers for Neuro-ophthalmology and Neurotology. And we have opened a new center for Pediatric Otology to offer kids like Nicholas the very best care with a multi-disciplinary approach.

Physical and programmatic expansion and renovation are not inexpensive and they take tremendous focus and work. But we believe they are the proper investment to ensure that our patients always receive the highest quality, world-class care, which Mass. Eye and Ear continues to offer at low cost to patients and payers.

Ultimately, we are planning for a future in which vision and hearing loss are eradicated. Putting ourselves out of business is the ultimate goal! Until we do, be assured that Mass. Eye and Ear’s scientists and surgeons, nurses and staff press forward to ensure that our patients enjoy the best quality of life possible.

Your generosity helps to push us closer to cures each day and allows us to continuously improve the quality of our care. As demonstrated by the $1.2 million raised at our Sense-ation! gala in October and by the $10 million raised during our last fiscal year, your support is stronger than ever. To you we offer our deepest thanks.

We wish you a very Happy New Year and look forward to exciting advancements in 2012.

Sincerely,

John Fernandez
President and CEO

To see Nicholas’ story, including the moment that he hears his very first sound, visit us on YouTube: www.youtube.com/MassEyeAndEar

Follow us on Twitter:
http://twitter.com/MassEyeAndEar

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Groundbreaking Held for Longwood Area Mass. Eye and Ear Center

A little rain did not dampen spirits at the official groundbreaking for Mass. Eye and Ear’s multi-specialty ambulatory care center to open fall 2012 in Boston’s Longwood/Mission Hill neighborhood.

Mayor Thomas M. Menino, Mass. State Representative Jeffrey Sanchez and Boston City Councilor Michael Ross joined Mass. Eye and Ear Chairman Wyc Grousbeck, President & CEO John Fernandez, Beal Company executives and others in celebrating the start of construction at 800 Huntington Avenue. The new location will include a state-of-the-art surgical center, eye and ENT clinics, physician offices, an optical shop, a hearing aid center, and a coffee shop. The building, which is owned by the Beal Company, is being designed by Tsoi/Kobus Associates and built by Suffolk Construction.

“Today is about care, community, collaboration and creating,” declared John Fernandez. “By that we mean creating both construction jobs and long term healthcare jobs.”

“This project shows how communities can work with institutions,” Mayor Menino said. “A year from now we will celebrate the grand opening right here on Huntington Avenue. This opens up a whole new world for Mass. Eye and Ear.”

To see a video about the groundbreaking, visit Mass. Eye and Ear’s YouTube channel: www.youtube.com/MassEyeAndEar.

Above: An artist’s rendering of the new Mass. Eye and Ear multi-specialty ambulatory care center. Below: Officially breaking ground on the new facility were Stephen Faber (Senior Vice President, The Beal Companies), Peter Spellios (Senior Vice President, The Beal Companies), Jeff Sanchez (Massachusetts State Representative), Bruce Beal (Chairman, The Beal Companies), John Fernandez (President and CEO, Mass. Eye and Ear) Boston Mayor Thomas M. Menino, Wyc Grousbeck (Mass. Eye and Ear Board Chair), Robert Beal (President, The Beal Companies) and Mike Ross (Boston City Councilor).

Contact
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Please write to the Development Office, Massachusetts Eye and Ear Infirmary, 243 Charles Street, Boston, MA 02114 if you wish to have your name removed from the list of people who receive fundraising requests from the Mass. Eye and Ear in the future. In the event that you write to us with this request, all reasonable efforts will be taken to ensure that you will not receive any fundraising communications from us.
Breathing Easier and Thriving

Francisca Fetuga didn’t get a good night’s sleep for the first two years of her son’s life. She would listen to her son’s labored breathing while he slept and worry. His sleep apnea, periods during sleep where he would stop breathing altogether, was alarming. Two-year-old Adekanmi wasn’t able to eat solid food, or speak, either. Francisca expressed her concerns to her local pediatrician, but her fears were brushed aside.

Adekanmi’s issues became so dire that in October 2010, he was brought to the emergency department at Mass General Hospital, where he was soon referred to Dr. Christopher Hartnick, Mass. Eye and Ear Director of Pediatric Otolaryngology.

After performing a direct laryngoscopy, Dr. Hartnick and his team immediately spotted the problem. They could see that Adekanmi’s tonsils and adenoids were so swollen that they were blocking his airway. Dr. Hartnick performed an immediate adenotonsillectomy — removal of the adenoids and tonsils that were preventing him from eating, and breathing normally.

After surgery, Adekanmi recovered in Mass General’s pediatric intensive care unit, where clinicians closely monitored his respiration and oxygen saturation, and watched closely for any other possible post-surgical complications.

Days after his operation, Adekanmi began eating solid food. Soon he was starting to speak. Today Adekanmi is doing well. “Now he sleeps with ease,” says Francisca. “He is making such good progress. He is so much happier — and making so much noise!” she says.

Play Golf for a Good Cause

Daniel Deschler, M.D., was promoted to Professor of Otology and Laryngology at Harvard Medical School this year. Dr. Deschler chairs the Head and Neck Surgery Committee for the American Academy of Otolaryngology — Head and Neck Surgery, which was recently named a “model committee” by the Academy. Dr. Deschler also served as 2011 Visiting Professor at the University of Nebraska Medical Center.

Mass. Eye and Ear was awarded an $11 million grant from the National Institute of Allergy and Infectious Diseases to fund the Harvard-wide Project on Antibiotic Resistance.

Michael Gilmore, Ph.D., the Sir William Osler Professor of Ophthalmology at Harvard Medical School, will lead a team of investigators from across Harvard University, the Broad Institute and industry to further the development of new treatments for bacterial and other multi-drug resistant infections.

Why I raised $10,000 for the Neurotology Fellowship

By Terry Zimmerman, Team Eye and Ear

In March of 2010 my husband, Brad, was diagnosed with a large vestibular schwannoma (acoustic neuroma) brain tumor. Surgical removal was the only viable option. This is an extremely delicate operation. At best, Brad would lose the hearing in his right ear and his right vestibular (balance) nerve. Our goal was to find the best surgical team available to increase the odds of a successful result.

During our search for a suitable physician, our neighbor and friend in the Bahamas heard of Brad’s problem and contacted us. He told us about his successful cancer treatment by Dr. Daniel Deschler at Mass. Eye and Ear and suggested we speak with him. Dr. Deschler recommended his colleague Dr. Michael McKenna for the procedure. Brad and I were impressed with the humility, compassion and dedication of these two men. On May 28, 2010, Brad underwent a 12-hour surgery, and the tumor was successfully removed. We credit Dr. McKenna and his dedicated team for the successful outcome.

Brad’s medical problem impressed upon me the need for properly trained and experienced surgeons to replace the Dr. McKennas of the world in the future. I decided to raise funds for the Neurotology Fellowship at Mass. Eye and Ear so others like my husband will have the benefit of highly trained physicians and the best possible surgical outcomes in the years to come. In April 2011 I ran with Team Eye and Ear, Mass. Eye and Ear’s Boston Marathon Team, and raised $10,000 to help with a Neurotology Fellowship. Brad is running with Team Eye and Ear in 2012. You can join him.

For more information, call (617) 573-3345 or visit www.MassEyeAndEar.org/teameyeandear.
Generous friends raised more than $1.2 million to benefit the Curing Kids Fund at the Sense-ation! gala on Oct. 18. Among special guests were NKOTB’s Joey McIntyre and his wife, Barrett, who brought their three children, including their 2-year-old son Rhys who was born with hearing loss. Helping Joey harmonize during his performance were two members of the Perkins School for the Blind chorus.

The evening offered even more inspiration in the form of another special guest: Nicholas, a Mass. Eye and Ear pediatric patient who was born with hearing loss and can now hear, thanks to a hearing aid, cochlear implants and rehabilitative therapy in our Audiology Department. His surgeon, Dr. Leila Mankarious, gave the audience insight into the challenges investigators face with reduced research funding.

Before the end of the evening, host Ayla Brown revealed her own personal connection to Mass. Eye and Ear, noting that she suffered hearing loss as a result of otosclerosis, and while on stage, she offered her heartfelt appreciation to the hospital’s researchers and physicians for their work toward finding better treatments and cures.

For more information, visit MassEyeAndEar.org/Sense_ation
of patients with Marfan syndrome. “In addition to dislocated lenses and the need for complicated glasses, other problems include early onset glaucoma (high pressure in the eye) and cataracts (the eye’s lens becoming cloudy).”

Dr. Mukai confirmed Yamil’s diagnosis, both by physical examination and by high-tech equipment including ultrasonography and optical coherence tomography (OCT). OCT is effectively an ‘optical ultrasound,’ providing high-resolution, cross-sectional images of the retina, the light-sensitive tissue that lines the inner surface of the eye. OCT was developed in collaboration between Mass. Eye and Ear and Massachusetts Institute of Technology.

Repair of detached retina in children poses special challenges. One of two repair methods is usually employed: scleral buckling or vitrectomy. “Scleral buckling is usually a better procedure for children,” Dr. Mukai explains. “Scleral buckling involves putting a ‘belt’ around the eye to support the retina from outside the eye. When it works well, there is very little complication, even long term, with the exception of perhaps changing your eyeglass prescription.”

With a vitrectomy, either gas or oil is placed into the eye to support the retina from inside the eye. This requires positioning as part of the recovery where the patient may have to lie still in a certain position for days or weeks. A cataract often develops as a complication. In Yamil’s case, the scleral buckle was the right choice.

The technique of scleral buckling is going out of favor since in adults vitrectomy works very well. Because of this, scleral buckling is not used as frequently. Many young surgeons have little experience with it and therefore will not recommend it. “It is a dying art, but still needed,” says Dr. Mukai. “Surgeons at Mass. Eye and Ear are adamant about teaching their retina fellows how to do this procedure so they have the skill to use it when most appropriate.”

Yamil had his surgery on August 27, which was a Friday. School started the next Monday, and he was able to go to class on Tuesday. Today, Yamil’s vision is 20/70 in his affected eye and 20/20 in the other. He doesn’t need to follow up with Dr. Mukai frequently any more, but he has a huge affection for his surgeon. “Yamil framed the letter that Dr. Mukai wrote giving him permission to resume normal activities and has it hanging his room,” Suzanne says. “After his surgery, at his next birthday, Yamil wanted no gifts; instead he asked his friends to support retina research at Mass. Eye and Ear.” Yamil’s support is helping Dr. Mukai and his collaborators at the Schepens Eye Research Institute improve retinal surgery outcomes. (For more information about this work, visit www.MassEyeAndEar.org.)

“The second I knew Yamil might have a retinal detachment, I reached out to the Marfan community. All of the children had the vitrectomy, and all had subsequent surgery because the retina was not re-attaching,” Suzanne says. “We, by the grace of God, ended up in the hands of Dr. Mukai.”

Yamil Kouri, III, enjoys the wonder of nature with his grandfather, Dr. Yamil Kouri, Sr.
Run the 2012 Boston Marathon with Mass. Eye and Ear!

You will bring new hope and a healthier future to people everywhere who suffer from debilitating conditions affecting sight, hearing, voice, balance, taste and smell, and cancers of the eye, head and neck.

Visit MassEyeAndEar.org/TeamEyeAndEar or call (617) 573-6364.

Since 2006, Mass. Eye and Ear’s marathon team, Team Eye and Ear, has raised over $1.4 million for research and patient care at Mass. Eye and Ear. In 2012, we aim to raise more than $350,000. All team members will be required to raise a minimum of $5,000.