

# FACING THE FUTURE

## SAVE

## THE DATE!

The Seventh Annual "Miles for Smiles" Walkathon will take place on Sunday, **October 19, 2003**, beginning at 11:00 a.m. at Lake Quannapowitt in Wakefield, Massachusetts. Watch for registration materials in the next newsletter, or call the Foundation at 617-355-8299 for more information.

## Special Recital Benefits the Foundation

On April 27, 2003, friends of the Foundation for Faces of Children were treated to a stellar performance by Dr. Stephanie Kwei on violin and Dr. June Wu on piano at M. Steinert & Sons Company on Boylston Street in Boston. They performed Cesar Franck's Sonata in A Major and Sonata No. 3 in d minor by Johannes Brahms. These two talented young doctors approached the Foundation last year and volunteered to arrange the performance for the benefit of the Foundation. Stephanie Kwei is a general surgery resident at the New England Medical Center, Tufts University, and a research fellow in the laboratory of Dr. M. Judah Folkman at Children's Hospital, Boston. She began playing the violin at the age of four. June Wu is a craniofacial fellow with Dr. John Mulliken at Children's Hospital, Boston. She completed her training in Reconstructive and Plastic Surgery at the Albert Einstein College of Medicine in New York.



Dr. John Mulliken, Dr. June Wu, Dr. Stephanie Kwei, Joey Smith, FFC co-president, Jane C. McDaid, FFC co-president, and Dotty MacDonald gather with Jerome F. Murphy of M. Steinert & Sons after the concert.

June started playing piano at the age of four.

During a brief intermission between the two pieces of music, three scholarship awards were presented by Co-President Johanna (Joey) Smith. These scholarships are awarded annually to outstanding young adults to help fund post-secondary education. This year's recipients are Elizabeth Berry, Chantal Dewey and Jesse Dylan Kristin (see article below for more about these impressive young people).

We are grateful to June and Stephanie for so generously donating their time and their talents. Their support is greatly appreciated. Also, many thanks to Jerome F. Murphy and the staff at M. Steinert & Sons Company for providing the outstanding venue for this special event.

Thank you to all who attended and/or supported the recital; together you contributed \$2,000 to the Foundation. We appreciate your continuing support!

See more photos from the recital inside

### Contents

In Their Own Words .....2  
Interview with Craniofacial Coordinator .....3  
Benefit Recital Photos.....3  
Who We Are .....4

## 2003 Scholarship Awards

The Foundation proudly announced the recipients of its annual scholarship awards on April 27, 2003. Elizabeth Berry, Chantal Dewey and Jesse Dylan Kristin each received a \$1,000 grant to assist with post-secondary education. These scholarships assist extraordinary young people



Elizabeth Berry

with higher education and recognize and applaud achievement and the ability to overcome challenges. Elizabeth (Liz) Berry of Bedford, Massachusetts, attends the Cambridge School of Weston. She is a hardworking, extremely motivated student. She excels in math and science and has expressed an

interest in following a pre-med program in college. Liz volunteered in the Craniofacial Centre at Children's Hospital, Boston. During the school year, she held down a part-time job while maintaining a demanding academic schedule. Liz has told us that she is determined to

use her education to its full potential. She will be using her scholarship award for her studies at Hampshire College. Chantal Dewey of Concord, Massachusetts, attends Concord-Carlisle High School. A National Honor society student and a student athlete, she plays high



Chantal Dewey

continued on page 2

## 2003 Scholarship Awards

continued from page 1

school varsity field hockey and placed second in the Commonwealth in fencing. In addition to her academic talents, Chantal has won honors for her artistic talents. She plays violin.

Chantal has also devoted considerable time and effort to volunteer activities. She participated in a work retreat in Haiti, then helped to raise money for a surgical unit for the Center of Health there. She also raised money to enable a young Haitian boy in need of cleft palate surgery to come to the US for the procedure.

One of her English teachers wrote that Chantal "will fast become a treasured asset" at any college that admits her. She hopes to apply her scholarship award toward her studies at Smith College or Brandeis University.

Jesse Dylan Kristin of Winthrop, Massachusetts, attends Boston College High School. He excels academically in spite of a rigorous course schedule, and even tutors others. He has also been an assistant teacher at Head Start.

His extracurricular activities include National Honor Society, serving as a representative on his high school's Honor Code Committee, Key Society and Wellness Committee.

His artwork has been published in the school newspaper and displayed in art shows. In addition, he plays drums and guitar in two musical groups.

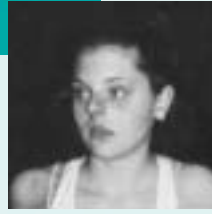
Jesse's Algebra II teacher tells us that he is a "likable, thoughtful, generous and mature young man...[who] will continue to excel at the next level of his education." Jesse plans to use the scholarship award at George Washington University. 🐾



Jesse Dylan Kristin



## In Their Own Words



*My name is Amelia Potvin and I am a patient of Dr. John Mulliken. I am 16 years old and I was born with an oral-ocular cleft. I wrote a poem last year about the experience of having surgery the day after my fifteenth birthday. I wanted to share it with you.*

### Boston's Two Faces

On the road map  
Of my face  
A scar connects  
Left eye to lip  
Like the highway  
Connects our house  
In small-town Maine  
To Boston

My parents drive  
The 250 miles  
Four hours  
South on I-95  
For me  
While I nap  
In the back seat  
Dreaming  
Of spending  
My birthday  
In the city  
My subconscious  
Denying the approach  
Of my 14th operation

I wake up  
Trees have turned to buildings  
We speed through the suburbs  
In our rugged SUV  
Traffic floods the freeway  
Glinting cars flash by  
Like Paparazzi cameras

Through sleepy eyes  
I see the sign  
For Storrow Drive  
And think of  
Anesthesia

A sharp turn in the road  
Whips us past  
The shimmering Charles  
With all its ivory-white  
sailboats  
  
And finally –  
We're in the  
Sparkling city  
Boston

I'm mesmerized  
By all the sights  
The adventures that await me  
My parents take me  
To the Omni Theater  
We sit in awe  
Beneath its glowing dome  
  
It's not so spectacular  
Really  
Imagine the art  
Doctors have molded  
From flesh of face  
In just fifteen years

We stay in a hotel  
In Copley Square  
Sleep in beds  
Made for kings  
Wearing silky pajamas  
I try not to imagine  
The coming night  
Waking to beeps  
At 3 a.m.  
A coarse nightgown  
And wooden mattress

For tonight  
At least  
We strut the streets  
Pretending we're in style  
As we admire displays  
In designer shop windows

My parents treat me  
To dinner  
At an expensive steakhouse  
Where all the upscale  
Businessmen have  
Business dinners  
With their  
Most important clients  
It's my last  
Solid meal  
For two weeks  
I'll ice my swollen mouth  
With popsicles

The glamour life is over  
We go to  
Children's Hospital,  
The real reason we're here  
But surgery is just as fun  
And as high-class  
After all,  
Models pay millions for this  
  
After a short stay  
Within rainbow-splashed walls  
I'll go home  
with a beachball  
for a face.

**I am a junior at Hampden Academy, my local public high school, in my hometown of Hampden, Maine. At school, I am a member of National Honor Society and am on the math team at my school. I also am the president of my local chapter of the Junior Classical League, which is a national organization dedicated to the study of the Latin and Greek. I play three varsity sports: cross-country, indoor track, and tennis. Because I love to be outdoors, I do many activities throughout the year including skiing, biking, kayaking, water-skiing, and snowshoeing. For the past three summers, I have volunteered at a local hospital.**

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

Visit our new site  
on the web!

**A Few Minutes with Elizabeth Leonard, Craniofacial/Cleft Lip and Cleft Palate Coordinator at Children's Hospital, Boston.**

**FFC:** "Elizabeth, please tell us about your position with the craniofacial clinic. What is your role within the team? How do you help patients and families?"



As the coordinator for the cleft lip and palate and craniofacial programs at Children's Hospital, Boston, my main role is to organize the Friday clinics. The patients' charts/medical information must be up-to-date (which includes needed

tests, studies, and reviews) so that the doctors can make appropriate treatment plans for the patients. Many children who come through the clinics have severe medical conditions, which require numerous studies and tests in order for the doctors to recommend successful treatment plans. In organizing for the clinic each week, I set up appointments, order tests and studies and collect results, advocate on behalf of patients for insurance coverage, send out blood to be genetically tested, and set up reviews with

the doctors so that patients from out of state or outside the country can get their medical questions answered. I also help to schedule procedures for patients.

I like to think I also help the families feel more comfortable about coming to the clinic by answering their questions and when I can't answer them, finding out the answers and getting back to them. I try to give the families a good idea of what to expect when they come in for their visits. I also assist families in obtaining services like early intervention by writing letters of support and sending out up-to-date medical information.

On clinic days my role is to make sure (or try to make sure) that the clinic runs smoothly and that each patient sees all the appropriate doctors. I follow up on Monday by ordering tests, setting up appointments, and organizing medical record reviews.

This job can be very interesting. I meet patients and families from all over the world and I am never bored. I am always learning new things and my days are never the same.

**FFC:** Do you have any tips for patients and families during clinic visits?

The main tip I have for those attending the clinic is to try to remain patient. Since many of these visits require that the

patient see a number of doctors, the appointment can end up being pretty long. I suggest bringing snacks and one or two small toys that the child can play with as he or she waits. I also suggest that the parents bring a book to read.

Keep in mind that even though the visit can take up to half the day or more, most of the time, a clinic visit is only once a year.

**FFC:** "Please tell us about yourself, where you are from and any interests you have outside of the hospital."

I grew up in Lancaster, PA. I went to college in Virginia, then moved out to Seattle to join the AmeriCorps program. As an AmeriCorps member, I worked in an elementary school as a teacher's

assistant and also as an after school program coordinator. I then made a move to Denver,

Colorado where I went back to school to get my master's degree in social work. I moved to Boston in October of 2002.

Outside of the hospital, I like to be outdoors. Although I like to ski and snowshoe, I look forward to warmer weather so that I can camp and hike, go to the beach, and enjoy the water. I also like to travel, especially when it is to visit my family and friends. 🍷

**Tips for visiting your care team:**

[www.facesofchildren.org/teamcare/tips.html](http://www.facesofchildren.org/teamcare/tips.html)

**The Benefit Recital**



Jerome F. Murphy welcomes Dr. Stephanie Kwei to M. Steinert & Sons.



Jane C. McDaid, FFC co-president, and webmaster John Crowley of Concinnitas, a web architecture and strategy firm, enjoy the reception.



Scholarship recipients Jesse Kristin and Chantal Dewey are congratulated by Dr. John Mulliken.



Elizabeth Leonard, Cathy Noonan and Dr. Bonnie Padwa smile for the camera.

Dr. Stephanie Kwei (far right), celebrates a great performance with her parents and husband.

## We Can't Do It Without You!

If you would like to tell us your story, or would like to submit an essay or other information for our newsletter, please let us know. We regularly run a column entitled "In Their Own Words" to publish entries from friends, patients, and families. Readers like to learn about the experiences of others. So, please, get in touch with us!

### Foundation for Faces of Children

258 Harvard Street, #367  
Brookline, MA 02446  
(617) 355-8299  
[www.facesofchildren.org](http://www.facesofchildren.org)  
[editor@facesofchildren.org](mailto:editor@facesofchildren.org)

### Board of Directors

Jane C. McDaid,  
*Co-President*  
Attorney Johanna (Joey)  
Smith, *Co-President*  
William L. Pratt, CPA,  
*Treasurer*  
Attorney Alfred C. Frawley,  
*Clerk*  
Anne-Marie Gagnon, MSW  
Mary Lania, RN  
John B. Mulliken, MD

### Advisory Board

Joe Carroll  
Patricia Connery  
Attorney Kristin DeKuiper  
Ellen Kelly  
Dorothy M. MacDonald,  
RN, BSN  
Attorney Sheryl Rosner  
Attorney Beth Tomasello  
Paula Woodman



**The Foundation for Faces of Children** is dedicated to improving the lives of children with craniofacial conditions, including cleft lip, cleft palate, and other head and facial differences. We concentrate our efforts on education, training, family support systems, and the dissemination of accurate and timely information. We also fund targeted research about the causes, treatments, and outcomes of these congenital conditions. The goals and strategies of the Foundation for Faces of Children are to...

- Provide leadership and advocacy through research and education.
- Distribute accurate and timely information as quickly and widely as possible to children, families, medical professionals, and the community at large.
- Endorse the team approach to treatment of craniofacial conditions; we believe that the best outcomes result from collaborative treatment by an experienced group of specialists.
- Partner with organizations that have similar goals and values.

We are a 501(c)3 not-for-profit organization supported entirely by private donations, grants, and fund-raising initiatives. We receive no government funding. If you are interested in having a board member speak to your group about our organization, or if you wish to participate in or sponsor a fundraising event, please write or call us — Foundation for Faces of Children, 258 Harvard Street, #367, Brookline, MA 02446 or call us at 617-355-8299

Non-Profit  
Organization  
U.S. Postage  
**PAID**  
Boston, MA  
Permit No. 54528



Foundation for Faces of Children  
258 Harvard Street, #367  
Brookline, MA 02446