

FACING THE FUTURE



Victoria Seager



Lindsey Spoor



Noah Sleeper

2010 FFC Scholarship Awards

The Foundation for Faces of Children awarded scholarships to three outstanding college-bound students at a reception held at Children's Hospital Boston on June 8. Scholarship committee chair Mary Lania announced the following winners of the \$1,000 awards:

Victoria Seager graduated from Gilford High School in Gilford, N.H., where she participated in both field hockey and lacrosse and was the team manager for the varsity football team. Victoria also was active in the Interact Club (a Rotary-sponsored service organization), youth government, Amnesty International, and the Spanish club. A member of National Honor Society, she was nominated for the Congressional Student Leadership Conference in Washington, D.C., as well as summer programs at both St. Paul's College and Johns Hopkins University. She also enrolled in a summer sports media program at Ithaca College.

Victoria, who was born with craniosynostosis, will attend Syracuse University this fall. She wants to pursue a degree in sports journalism and sports management, and in 10 years, she hopes to be a reporter for ESPN.

Lindsey Spoor graduated from Dartmouth High School in Dartmouth, Mass., where she performed in many plays and musicals, often in starring roles. Lindsey is an accomplished dancer in multiple genres and a member of a World Champion Indoor Percussion Dance Team. She also plays the piano and is proficient in Portuguese. A member of the Key Club, TCAN (Think Community, Act Now) Club, and drama club,

Lindsey served as a mentor to incoming freshmen. In addition, she has worked as a volunteer for Habitat for Humanity, building houses for Hurricane Katrina victims; soup kitchens; animal shelters; and children's groups during the holiday season. Last summer, she completed a college-level sociology course at UMASS-Dartmouth.

She will be attending Mass College of Pharmacy and Health Sciences, where she was accepted into the honors nursing program. Lindsey, who was born with bilateral cleft lip, hopes to become a nurse practitioner and, in 10 years, work in pediatrics with children born with facial anomalies.

Noah Sleeper graduated from Deering High School in Portland, Maine, where he participated in the Academic Decathlon, Mock Trial, Model United Nations, and Student Senate. He also was a member and vice president of the National Honor Society. In the summer of 2008, he enrolled in an American History program at William and Mary College in Virginia, and last summer, he spent three weeks in Switzerland learning French. This past semester, he took a Western Civilization course at University of Southern Maine. In his spare time, he enjoys reading science fiction novels and watching movies with his friends. Noah will attend Bates College in the fall and has not decided on a major yet, but in 10 years, he sees himself completing graduate school.

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Maximizing Your Health Insurance Benefits

In April, FFC presented talks on "Overcoming Insurance Obstacles" at Children's Hospital Boston. Information from this event will be posted on the FFC website as well as details on an upcoming fall session.

Among the guest speakers at the event was Beth Dworetzky, project director of the Massachusetts Family-to-Family Health Information Center, which provides assistance to families raising children and youth with special health needs.

The Center operates a toll-free number for families to call for information. Here are answers to some commonly asked questions:

Q What services does the Massachusetts Family-to-Family (F2F) Health Information Center offer?

A The Center, staffed by parents of children with special health care needs, helps families navigate the health care financing maze, access resources and services, and work in partnership with their health care providers and others. Anyone can call 1-800-331-0688, extension 210, for free, confidential assistance.

Q I live outside of Massachusetts, where can I go for help and information?

A To find the F2F Health Information Center in your state, go to www.FamilyVoices.org and click on "FamilyVoices in Your State."

Q Who is eligible for Medicaid?

The Massachusetts Medicaid system, known as MassHealth, offers a variety of health insurance programs. Among them are: MassHealth Standard, which is based on financial need, and MassHealth CommonHealth, which is based on medical need and has no income or asset limits. If your family income is too high for MassHealth Standard, your child may be eligible to enroll in CommonHealth. Premiums for CommonHealth coverage are determined by total household income and set on a sliding scale.

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Maximizing Your Health Insurance Benefits *continued from page 1*

If you have a high deductible and co-pay for your employer-sponsored plan, buying coverage for your child through MassHealth CommonHealth may make good financial sense. Check to see if the premiums are less than your current out-of-pocket expenses. For example, if you have a \$5,000 deductible, but your CommonHealth premium is \$100 a month, paying \$1,200 in premiums is more cost-effective than laying out a \$5,000 deductible. Note: CommonHealth only pays for services for a family member with a disability, so costs incurred for other family members do not count. (If you live outside Massachusetts, contact your F2F Health Information Center to find out about your state's Medicaid programs and eligibility.)

I feel uncomfortable appealing insurance denials. Is it worth the effort?

Yes, even though the insurance appeals process is difficult. By advocating for a service to be covered, you will be modeling the skills that your child will need to talk to a teacher, coach, boss, or medical professional. This is an important way to show your child how to build personal relationships and partner in their care.

What is the difference between self-insured and fully insured employer-sponsored health insurance plans? Does it matter which you have?

These terms describe different financial relationships between the employer and the health insurer. If an employer-sponsored plan is fully insured, the insurer is responsible for health care costs and pays providers for services. If the plan is self-insured, the employer is responsible for health care costs and reimburses the insurer for each health service that the employees and covered family members use.

When a plan is fully insured, the insurance company is required to meet the state's 52 health service mandates, such as newborn hearing screening. (Note: Massachusetts is not currently one of the 14 states that requires coverage of cleft palate services. See "Pushing for Passage" on page 4.) Self-insured plans, while they may choose to provide mandated health services, are exempt from state laws and mandates.

How can you prove medical necessity?

Focus on how the surgery, therapy, or other service will improve a bodily function, such as breathing, eating, or speaking. If possible, talk about the standard of care (for example, the importance of a team approach) and any recent research that relates to your child's condition.

What advice do you have for successfully dealing with insurance issues?

Here are a number of tips:

- Read the service benefit plan, the directory of approved providers, and any other information from your health insurer.
- Know what services are covered and what are not.
- Read the mission or values statement from your health insurer.
- Know your plan's definition for medical necessity.
- Request a case manager to ensure your child's health care needs are met.
- Review every explanation of benefits.
- If you call your insurer with a question or concern, write down the name of everyone you speak to, the date, and a summary of the call. Be polite!
- Make your case with dollars and 'sense.' ■

The Gift of a Smile



The Solomon Schechter Day School community in Newton wanted to bring smiles to the faces of children and their parents in the waiting room of the Craniofacial Clinic at Children's Hospital Boston. So on March 7, as part of the school's annual "Mitzvah Day," a group of 20 volunteers, including children ages 5 and up, painted 50 tiles with a "Smile" theme.



These colorful ceramic tiles were then fired in a kiln and applied to a large table, built by Jim O'Sullivan of FFC's Board of Directors with assistance from fellow carpenter John Nicholson. Bari Popkin, a Schechter parent and FFC supporter, presented the table on behalf of the school at the recent scholarship awards event.



Thanks to all the students, parents, and teachers, who contributed their artistic talents; Bari Popkin, who planned and coordinated the project; and Jim O'Sullivan and John Nicholson, who donated their fine woodworking skills. ■



Jared and Hallie Popkin proudly display the Solomon Schechter Day School's gift of a handmade table.



Paces for Faces Walk Family Picnic

Lace up your sneakers and join us on Sunday, September 26, for "Paces for Faces," the 14th Annual FFC Walk and Picnic. Enjoy fun and food with other families, while you support a good cause.

WHERE? Lake Quannapowitt, Wakefield, Mass.

Meet on the common by the First Parish Congregational Church. Parking is available on the street.

WHEN? Sunday, September 26

Registration starts at 11:30 am with donuts and coffee. The walk kicks off at noon, followed by lunch and special activities for the kids at 1 pm, downstairs in the church. The event will be held rain or shine.

WHY? This fundraising event helps make available FFC's free publications, videos, and fact-filled website about facial differences. Donations also support informational meetings for individuals and families as well as annual student scholarships.



5 STEPS TO SUCCESS

Step 1: Form a team. Invite family, friends, co-workers, and neighbors to join in the fun and walk with you. If they aren't able to, ask them to sponsor you.

Step 2: Set a goal. FFC encourages participants to set personal fundraising goals of \$100 or more. But anyone can participate, and donations of any size are welcome. All donations are tax deductible.

Step 3: Sign up. Contact FFC Director Mairi Bleakie at **781-875-1914** or mbleakie@facesofchildren.org, and let her know in advance how many will be in your group and their T-shirt sizes. Or, sign up online and create a personal fundraising page through First Giving, www.firstgiving.com/16357.

Step 4: Collect your pledges. Please bring your sponsor sheets (available through www.facesofchildren.org) and collected pledges to the walk. Make checks payable to Foundation for Faces of Children. Mail any remaining pledges by October 26, 2010 to FFC at: 258 Harvard St., #367, Brookline, MA 02446.

Step 5: Pick up your free T-shirt and walk! Check in at the registration table the day of the walk and receive your official walk T-shirt. Then enjoy your walk around the lake. (The loop around the lake is about three miles, but families are welcome to walk any portion of that distance.)

Receive Rewards: We want to thank you for your fundraising efforts.

- If you raise \$100, you will receive an FFC baseball cap.
- If you raise \$250, you will receive an FFC long-sleeve T-shirt.

Note: FFC merchandise will also be available for sale (payable by cash or check) on the day of the walk.

Win Raffle Prizes: The day of the walk, you'll also have an opportunity to participate in a raffle. Buy tickets for \$1 for a chance to win the basket of your choice.

Be an Angel Walker: If you can't join the walk on the 26th, you can still collect donations and be eligible to receive thank-you gifts. Angel walkers can send donations to FFC at 258 Harvard Street, #367, Brookline, MA 02446.

For directions, sponsor sheets, and more information, visit our website at www.facesofchildren.org.

Hope to see you there!



Making Connections

FFC is now partnering with Prescription Parents, a Boston-based support group, which has helped parents of children born with cleft lip and palate for more than 30 years. By working in cooperation, the two organizations hope to provide parents with the best possible information and team experience for their children.

"We know that people can find support in other ways today, such as online chat groups, but we still believe face-to-face support is important," says Anne-Marie Gagnon, MSW, a Prescription Parents volunteer, whose 10-year-old son Charlie was born with cleft lip and palate. "We are looking to help parents in their medical and emotional journey."

Starting this summer, the FFC website will feature information about Prescription Parents and news of their upcoming parent meetings and family social events. On the FFC homepage, www.facesofchildren.org, simply click on "Connecting with Others" and then Prescription Parents.

"We are open and free to any and all," Anne-Marie says. "We have no affiliation with any particular medical team."

Support group meetings are generally held in a home in Newton, but volunteers are also willing to meet one-on-one with parents in a coffee shop or other informal setting. To contact a parent volunteer, e-mail prescriptionparents@facesofchildren.org or call 617-499-1936.

Teens and young adults can also go to the "Connect with Others" button for support and information on social events.

If you know of a support group that could be helpful to FFC families, please contact FFC Director Mairi Bleakie at 781-875-1914 or mbleakie@facesofchildren.org. ■

Scholarship recipients *continued from page 1*

Born 15 weeks premature with craniosynostosis, Noah spent the first 100 days of his life in neonatal intensive care and has since overcome huge obstacles. His own experience led him to become a dedicated March of Dimes volunteer. He has helped package prenatal vitamins and prepare information packets about premature birth as well as lobby classmates to sign a petition for more oversight of C-sections and induced labors. Each year since eighth grade, he has participated in the March of Dimes “Walk for Babies” fundraiser.



Noah as an infant, prior to his first craniofacial operation.

First Recipient of Jane McDaid Scholarship

For his outstanding accomplishments and volunteerism, Noah was specially recognized with FFC’s First Annual Jane McDaid Scholarship. Jane McDaid, a past president of FFC who passed away last year, worked tirelessly to make the Foundation a better organization. So her husband asked that the recipient of the honorary scholarship also be someone who had a real cause.

“Working with the March of Dimes to improve the health of babies is truly Noah’s cause,” said Mary Lania at the scholarship awards event, “and with that in mind, we would like to bestow upon Noah Sleeper our first honorary FFC scholarship, the Jane McDaid Scholarship.”

Pushing for Passage



Once again parent advocate Adrienne Musto is spearheading an effort to pass House Bill 932, which would provide insurance coverage for medically necessary treatment—including dental care—for cleft lip and cleft palate. In April, Bill 932 was merged with House Bill 1034, which would guarantee insurance coverage for treatment of all craniofacial disorders.

Bill 932 received a favorable report from the House Committee on Financial Services on April 7, 2010; however, to become law, both bills must first be passed by the House, then taken up by the Senate, and finally signed by the Governor.

Adrienne initiated a successful letter-writing campaign to targeted house representatives in May, which resulted in a July 7 Legislative Day on Beacon Hill to discuss H932 with key committee heads.

“This session of the House breaks at the end of July,” Adrienne says. “We need to get this Bill through the House and Senate by that time, and ultimately on to the Governor to make it law. This is our sprint to the finish. If it does not pass through, we will resume efforts after it is refiled in January of 2011. But we want it passed in 2010. Our collective effort has been amazing.”

For more information, contact Adrienne via e-mail at adriannemusto@hotmail.com.



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:

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

Telephone: **617-355-8299**

E-mail: **info@facesofchildren.org**

Website: **www.facesofchildren.org**

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