

FACING THE FUTURE

Attention: Scholars

If you're a high school senior or graduate living in New England, you may be eligible to win a \$1,000 scholarship to a college or vocational/technical school. Apply now for the 2006 Foundation for Faces of Children (FFC) scholarship.

Begun in 1999, the scholarship program benefits young adults with craniofacial conditions. Each spring, FFC awards two or three scholarships to deserving students from New England (Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, and Vermont). Since the program's inception, 18 scholarships have been awarded.

The application deadline is April 1. For details, visit our website at www.facesofchildren.org or call Mary Lania, Scholarship Committee Chair, at 781-255-8931 (evenings or weekends).

A Well-Rounded Child

At birth, Rebecca Carley's first-born son, James (pictured below at nine months), was a healthy baby with a round head covered with light brown hair. As time went by, she noticed that he always slept with his head to the left side and when awake, often tracked objects with his eyes rather than turning to look at them. After a couple of months, she was startled to see that he had developed a flat spot on his head. Although James's pediatrician recommended physical therapy for his neck muscles, she expressed little concern about the flattening of his head. But she suggested a possible evaluation at Children's Hospital Boston.

Flattening of the head can be asymmetric (plagiocephaly, derived from Greek for "oblique-shaped head") or symmetric (brachycephaly or "short head"). Either type can be caused by positional forces (deformational) or fusion of a cranial suture (synostosis). Deformational plagiocephaly and brachycephaly stem from positioning in the uterus. Restricted head mobility *in utero* leads to neck tightness, which limits head rotation during the first few months of life. The rapidly growing infant head meets resistance from the flat resting surface (e.g., bed or car seat), and growth is re-directed.

The result is progressive cranial flattening. In plagiocephaly, this leads to asymmetric growth of the forehead, cheek, and ear on the same side as the flattening. In brachycephaly, the width of the head increases, making the head look "bigger." Synostotic forms of plagiocephaly and brachycephaly are much less common and require surgery.

A Side Effect of "Back to Sleep"

The incidence of deformational plagiocephaly has increased dramatically since 1992 when the American Academy of Pediatrics recommended that infants be

placed on their backs during sleep to reduce the risk of sudden infant death syndrome (SIDS). The "Back to Sleep" campaign has successfully prevented deaths but has led to many misshapen heads.

In the US, an estimated 15 percent of children, or approximately 1 in 7, now have deformational plagiocephaly. Babies who routinely sleep on their backs apply pressure to the rapidly growing cranium, which encloses the brain. (Although this affects the shape of the head, no reliable evidence suggests that brain development is affected.) Yet back-sleeping is only one contributing factor. "Position in the uterus plays a big part in the development of plagiocephaly," says Gary Rogers, MD, the plastic surgeon at Children's Hospital whom Rebecca Carley consulted. "Two-thirds of kids have flattening on the right side, because of the way they were positioned *in utero*.

"During the last trimester, space in the uterus is often limited, and the baby's head may be lodged in a way that leads to neck muscle stiffness and contracture."

Tightening of one side of the neck, known as torticollis, occurs most commonly in babies who are: twins (or other multiple births), large in size

continued on page 2



News from Arizona

"I am enjoying college life at the University of Arizona Tucson," reports **Rachael Leigh Ronald**, one of last year's scholarship winners, in a recent letter to FFC. "I have decided to double major in political science and Latin American studies, and double minor in pre-law and Spanish."

Her first semester was successful. She made the dean's

list and became active in a number of campus organizations.

Rachael thanked FFC for the scholarship saying, "Make no mistake about it; the Foundation for Faces of Children has done much more than award a scholarship to me. This invaluable resource has made it possible for me and my family to see well beyond a craniofacial condition."



Doing Their Part... and More

High school senior **Jennie Keniston** of Plainville, Massachusetts, chose to raise awareness and funds for cleft lip/palate as her project for DECA, the association of marketing students to which she belongs. Born with a cleft lip, which was surgically corrected when she was six weeks old, this was a cause she could relate to.

Jennie and her DECA partner, **Alicia Pacheco**, also of Plainville, began their efforts by rounding up a dozen walkers to join them in participating in Foundation for Faces of Children's fall walkathon in Wakefield.

Then, on their own, the teens organized a benefit show featuring four bands. Held at a local church hall, the event raised \$800. Thinking that wasn't enough, Jennie and Alicia also conducted a raffle to win the right to "pie" the assistant principal of her school, King Philip Regional High School in Wrentham. This pie-in-the-face event, which Jennie describes as "wicked funny," raised an additional \$200.

The twosome then wrote a 30-page business manual describing their entire project. This manual recently won the district DECA competition and will now compete at a state level in Boston and, perhaps, nationally in Dallas.

In addition, the energetic duo has created a brochure about cleft lip/palate, which they brought to the Massachusetts State House to raise awareness among lawmakers. With assistance from their local state senator, Scott Brown, they

held a question-and-answer session about cleft lip/palate at the State House. ■

Well-Rounded, *continued from page 1*

(typically male), or firstborn (since the head may engage early in the pelvis). It's also associated with oligohydramnios (too little amniotic fluid during pregnancy) and breech presentation. In addition, torticollis is particularly prevalent in premature babies.

Newborns with torticollis on one side usually lie with their head tilted to the tight side with the face rotated in the other direction. Until they develop head control (usually by three months of age), the infant is unable to shift head position and stretch the neck muscles to overcome the imbalance. Unfortunately, during these critical three months, the cranium is rapidly growing against a flat surface and the flattening worsens.

An Ounce of Prevention...

Does your newborn tend to look one way more than the other? The answer to this question can lead to early detection and prevention of deformational plagiocephaly.

"For babies up to three months of age with a tendency to put their heads to one side, I advise treating them with a molding cup," says Dr. Rogers, who designed the device, made exclusively at the NOPCO Brace Shop located at Children's Hospital in Boston. The foam molding cup, which Dr. Rogers hopes to make available commercially, cradles and gently reshapes the head while the baby is lying down. More than 200 babies have already benefited

from the use of the molding cup.

Based on his research, which will soon be published, Dr. Rogers rejects the notion that positioning can solve the problem. "Positioning is very ineffective," he says. "The neck tightness strongly resists parental efforts to reposition the child's head."

The Flat Pumpkin

Without developmental delays, babies can turn their necks and roll over at three or four months. Movement stops further flattening, but a misshapen back of the head cannot be outgrown.

"The flat spot won't pop back out," says Dr. Rogers. "It's analogous to a pumpkin that starts out nice and round, but from growing against the ground, it becomes flat after several months. You can turn it on its end and let it grow for another few months, but you'll still see the flat spot."

James was nine months old when he first visited Dr. Rogers. He had grown big and

healthy, but his flat spot persisted. Dr. Rogers diagnosed plagiocephaly by measuring his head diagonally in two directions (right rear to left front, and left rear to right front). These measurements, which should have been equal, had a striking difference of 18 millimeters. Dr. Rogers recommended that James wear a helmet to help redirect his head growth.

"We didn't realize how significant the problem was," says his mother,



Taking the Pressure Off

To help prevent flat spots from developing on your baby's head, the American Academy of Pediatrics and the National Institute of Child Health and Human Development recommend these guidelines:

- Provide "tummy time" when your baby is awake and being watched. (Placing babies on their stomachs also helps strengthen head and neck muscles.)
- Change the direction your baby lies in the crib from one week to the next. (A baby has a natural tendency to face toward the entrance to the room. A weekly change of orientation may cause the baby to sleep with the head turned to one side, then the other.)
- Avoid too much time in car seats, carriers, and bouncers, which put pressure on the back of the head.
- Have upright "cuddle time."





In Their Own Words

By Kerri Ramos

My daughter, Ella, is almost six months old. She was born with a complete unilateral cleft lip and palate, undetected in two ultrasounds.

I was in labor a long time. Before she was delivered, my doctor said, “She will look a little different. She has a cleft lip and palate.” I cried and apologized to my husband. I wanted to know what I did wrong.

The staff was very supportive, but I don’t think there are a lot of children here with clefts. We were told she would need to have plates in her jaw to close her cleft and bring her cheekbones in.

Only one nurse was comfortable with the feeding. She came in with a flashlight in the middle of the night and asked, “Did they show you her cleft palate?” She opened the baby’s little mouth and shined the light in. What a big help with feeding that was! But an ounce of formula still felt like forever.

I called and told my mother who lived an hour and a half away. When she got to the hospital, I remember handing her my baby girl with the cleft covered in a blanket. I was scared to death to take her home.

Our first visit to Dr. Canady in Iowa City was overwhelming. A mother with a teenager stopped me and said, “It will be okay, Mom.” Seeing her daughter sitting there—typical teenager in jeans, flip flops, and braces—

was amazing! The visit with the team...wow! Thank God my husband and my father were there! I was like a zombie. It was so much information to take in.

At one point, I broke down crying and left, so no one would see me. How could they be saying all of this? When I was at home with her, it was like the cleft wasn’t there. She was too perfect. I wasn’t in denial. I knew she had a cleft, but it wasn’t until then that the reality of it all set in. One of the doctors met me outside and asked if I was okay, and I told her how I felt. She let me know what I was feeling was normal.



[continued on back page](#)

Rebecca. “Since he had a full head of hair from birth, it wasn’t easy to see.”

Helmets are nothing new, having been designed to treat this condition for 30 years. Yet in the past, plagiocephaly deformities usually affected the front of the head, because most babies were put to sleep on their stomachs. And unlike the cranium, the face, which grows very slowly until age 15 or 16, can self-correct over time.

Helmets, which are open on top for ventilation, redirect head growth using contact pressure (no pushing or squishing). Success depends on the age of the child (the younger, the better), severity of the problem, and compliance or willingness to wear the helmet.

“If a helmet is worn for 24 hours a day, the parent will see some correction in four to six weeks,” says Dr. Rogers. “But if the child wears it 12 hours a day instead, it can take three times as long, since head growth slows with time.”

Most health insurance, with the notable exception of Massachusetts state insurance, covers the cost of a helmet and growth-related adjustments.

Heading in the Right Direction

Based on a computerized head scan, Rusty Miller of NOPCO custom-made a helmet for James, which provides space for his head to grow in the desired

direction. James wears the helmet, which is covered with pictures of cars, planes, and trucks (one of many patterns available), almost continuously with occasional breaks for feeding, bathing, and tummy time.

Once his mother realized how beneficial the helmet was, she got over her initial embarrassment. A fringe benefit of helmet wear, she notes, is worrying less about James hitting his head as he learns to stand and walk.

With the helmet, as well as an hour a week in physical and occupational therapy, James has made great progress. In less than a month, his asymmetry has been reduced from 18 to 8 millimeters.

“The helmet has made a huge difference,” says Rebecca. “The first week, he had a tough time [adjusting to it]. But not after that... Now it doesn’t faze him.”



Dr. Gary Rogers with a helmet (left) and the foam molding cup he designed (right).

In Their Own Words, *continued from page 1*

My second visit I looked forward to seeing the little cleft kids! A mother with a gorgeous blonde little girl was in front of us at the registration desk. She asked me how old my daughter was and other questions about her. I thought it was so wonderful that someone else knew what I was going through. Then she asked me her name. When I said “Ella,” her face lit up.

“My daughter’s name is Ella, too! Did you find out [about the cleft] through ultrasound?”

“No,” I told her, “she was my little surprise.”

She asked if I knew what the name Ella meant. I had no clue — I just liked the name. She told me Ella means “whole and complete,” and I got goose bumps. They had picked out the name Ella for that specific reason.

My daughter’s first surgery is February 7, and my emotions are everywhere. I cry every day. When she was born, I cried because I had this little girl who I didn’t even know if I could feed. Now I cry because I’m going to miss that gummy smile, the spit bubbles coming out of her nose, babbling through her little notch, and the “two for one” slobbery kisses she loves to give.

Thank you so much for the video! I wish I had the opportunity to watch it when I gave birth. It was so nice to hear other parents felt the same way and the information on the tape was so helpful! Again, thank you!

UPDATE: Ella’s procedure was a success. Says her mom, “We’re so happy with the results and how well she came through it all!” ■



Foundation for Faces of Children

258 Harvard Street, #367
Brookline, MA 02446



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 to **Foundation for Faces of Children, 258 Harvard Street, #367, Brookline, MA 02446** or call us at **617-355-8299**.

Board of Directors

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

Advisory Board

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

Facing the Future Editorial Staff

Anne-Marie Gagnon, *Editor* Cindy Shields, *Designer*
Nancy Knoblock Hunton, *Writer*

617-355-8299 | www.facesofchildren.org

E-mail: info@facesofchildren.org