

# FACING THE FUTURE

Foundation for  
Faces of Children  
**SCHOLARSHIP  
PROGRAM**

Each spring, we award scholarships to two or three students from New England to pursue post-secondary education at an accredited college, university, vocational or technical school. The application deadline is April 1, 2004. For more information, including award requirements and application forms, visit our website at [www.facesofchildren.org](http://www.facesofchildren.org) or call Mary Lania, Scholarship Committee Chair, at 781-255-8931.

## Seventh Annual FFC Walk-a-Thon: Miles for Smiles



Dr. June Wu, Patrick Hughes of Synthes Corporation, Co-Presidents Joey Smith and Jane McDaid, and Dr. Gary Rogers and his daughter are prepared to walk.

The Foundation for Faces of Children held its Seventh Annual "Miles for Smiles" walk-a-thon on October 19, 2003, at Lake Quannapowitt in Wakefield, Massachusetts. This year, the children were entertained by the Arthur character from the Marc Brown series, courtesy of WGBH, the PBS affiliate in Boston. Arthur was such a big hit that we asked him back for next year's walk-a-thon!

In spite of the chilly weather, walk participants enjoyed delicious barbecue provided by Patrick Hughes of Synthes Corporation (a manufacturer of prosthetics and surgical implants) and prepared by Blue Ribbon Barbecue of Arlington, Massachusetts. We are grateful to Patrick and his company for their liberal support.

Beverages were donated by Redstone Liquors of Woburn, Massachusetts. Joe Carroll of our Advisory Board provided free T-shirts specially made for our event. Tables and chairs were provided without charge by Festive Occasions of Woburn, Massachusetts. Additional financial support was provided for the event by Gregory Campbell of Edy's Ice Cream.

We are grateful to all who helped put together this fun and successful fundraising effort, including Advisory Board member Paula Woodman and our four teenaged volunteers from Belmont High School,

Rae Brownsberger, Michelle Lydenberg, Bethany Post and Christina Varasso. We also thank the First Parish Congregational Church of Wakefield for their invaluable help in so many ways.

Finally, special thanks to all who participated as sponsors and walkers, as over \$5,000 was raised for the Foundation's programs and services. We greatly appreciate your continuing support! 🐾

## Grant Received from New England Hi-Tech Charity Foundation

Representing the FFC at a check presentation ceremony on November 21, 2003, Co-President Jane C. McDaid accepted \$3,000 from the New England Hi-Tech Charity Foundation. The funds will be used for a print piece that explains and introduces the FFC and its services to families and medical professionals.

A multi-year donor to the FFC, the New England Hi-Tech Charity Foundation brings together the region's technology community to raise funds that support social, medical and educational organizations that benefit the children of New England. 🐾

## FFC Website Update

Launched in June, 2003, at [www.facesofchildren.org](http://www.facesofchildren.org), the FFC website has been well-received by interested visitors from all over the world. Monthly "hits," a measure of usage, increased from 9,000 in June to 62,000 hits in November 2003. Frequently-used pages include: the glossary of terms and search functions, Team Care, and Issues for New/Expectant Parents. Many of the "conditions" pages are highly popular as well, including especially Craniosynostosis, Deformational Plagiocephaly and Hemifacial Microsomia.

Messages have been received from many states and countries, including orders for videos from around the US, from Australia, Brazil, Canada, Great Britain, Hong Kong, Saudi Arabia, South Africa and more. We also receive requests for help, information and referrals. A volunteer Spanish translator is assisting us with Spanish language inquiries, primarily from Mexico.

We encourage you to visit the site, tell us what you think, and make some suggestions. We anticipate additional enhancements in 2004. 🐾

Find more photos  
from the Walk-  
a-Thon inside!

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# Attention Young Adults

## We Need Your Feedback!

### **Dilemma:** Some patients choose not to complete the surgical plan for correction of craniofacial conditions.

- ✂ Did you choose to complete the surgical plan for correction of a craniofacial condition?
- ✂ Did you defer the “Final Operation?”
- ✂ Help us gather information so that *we* can help others.

### Finish What You Start

Why do some young adult patients, of high school and college age, decline additional or final operations? Surgical programs often anticipate final procedures when the face and jaw have stopped growing, yet many young people choose not to finish the course. We want to know why.

- Were you aware of the schedule, and clear about the overall plan?
- Is it fear, or concern about pain?
- Are you concerned about recovery time or personal appearance or appliances/braces/splints during recovery?
- Is it about missing school or work, sports, or other activities?
- Does peer pressure become part of the decision?
- Is this operation viewed as optional, or as merely cosmetic, rather than as the necessary finale of a planned program?
- Do you understand the operation?
- What about predictability? Is there really one final operation, or will there be complications or revisions?
- Do you have confidence that you know the truth?

**We'd like to hear from you. Please respond to a few of the questions on this page, or just send your own thoughts:**

### The Clock and the Calendar

WE ALL FEEL THE PRESSURES OF TIME. What is the impact of timing on your decision to schedule an operation? IS SUMMER BETTER? Is it the **ONLY** acceptable time? Can the surgeon make appointments available at the end of the school year so that recovery can be complete when school begins again? **How long does it really take to feel better? To look better?** To resume all activities? **Does one year make a real difference? Two? When is it okay to defer the “final” operation? For how long?**

### The Choice is Yours

Important choices can be difficult decisions to make. **It is your decision.**

Caring parents want the best for you; but **what really is the best?** Are you satisfied with your appearance, but your **PARENTS OR DOCTORS ARE NOT? You** will live with the **results.**

What is **best in the long term?** If you forgo the operation, could there (will there) be **trouble later with breathing or with speech?** What about the impact of one operation over the course of a long and happy life? Will you have adequate health insurance **later** to pay for the procedure? What about other **responsibilities later in life;** will you be able to take the **time for yourself?**

### Tell Us What You Think

Have you deferred the “final” operation? If so, how long do you plan to defer it? Did you complete the course of treatment? What are you planning to do about this?

Please e-mail us at [info@facesofchildren.org](mailto:info@facesofchildren.org) with your thoughts and considerations, ideas and questions.

**THANK YOU.**

# Distraction Osteogenesis in Craniofacial Surgery

by Bonnie L. Padwa, DMD, MD, Children's Hospital, Boston, Massachusetts

Distraction osteogenesis (DO) was first used in the early 20th century to lengthen bones in the leg, but it was not until 1990 that the technique was applied to the facial bones. Rather than transplanting bone from one part of the body, DO involves stretching bone, using the body's natural healing mechanisms to create new bone. A cut is made in the bone and a distraction device is fixed to the two ends of the bone and gradually activated, separating the edges. Consequently, a bony gap is created, the soft tissue is also stretched, and new bone forms within the gap in response to tension created across the gap.

First, an incision is made to expose

the facial or jaw bone. The planned bone cut is made, the distraction device is positioned and fixed to the bone, and the incisions are closed. After waiting 2-4 days (latency period), the distraction device is activated (turned) two times a day. Each turn of the device is 0.5 mm, so that the rate of lengthening is 1.0 mm per day. Premature healing occurs if distraction proceeds too slowly. If the rate is too fast, bone will not form in the distraction gap. Distraction continues daily until the amount of desired bony length is achieved. Once active distraction is stopped, the device stays in place for twice the number of days of active device turning. This is called the consolidation phase, when bony healing occurs.

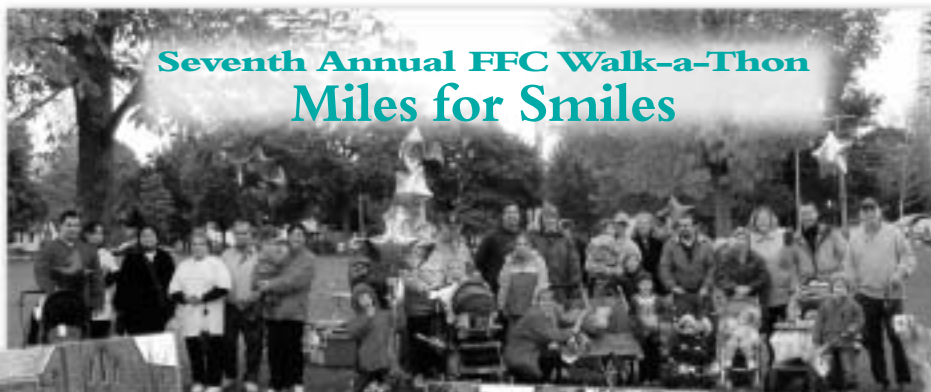
There are a variety of distraction devices that have been designed for craniofacial repair. Some devices are placed on the bone and under the skin, and others have external pins that exit the skin and are attached to an external

device. The type of device used depends on the bone being distracted and the amount and direction of movement.

Distraction osteogenesis has been applied to lengthen and move the upper and lower jaw and midface (and less commonly, the forehead). This technique has the benefit of being a smaller procedure than standard operations, with less complications and blood loss, as well as shorter ICU and hospital stays. Bone forms naturally in the distraction gap so bone grafts are not needed, eliminating the discomfort at the graft donor site. An equally important benefit of DO is stretching the soft tissues around the bone over days to weeks. This permits greater bony movement than was possible by traditional one-stage procedures, in which the bony segments are moved in the operating room and fixed in position with plates and screws using bone grafts to stabilize the repositioned bony segments. The use of DO to move the bones of the facial skeleton also gives a more

*continued on back*

**"...correction of many craniofacial anomalies will become possible through this minimally invasive technique."**



## Seventh Annual FFC Walk-a-Thon Miles for Smiles

Paula Woodman, Patrick Hughes, Dr. John Mulliken and Cathy Noonan check out the post-walk BBQ.



Lisa Carroll and her children gather some balloons at the start of the walk.




Board member Anne-Marie Gagnon and her son Charlie work the registration table.




Stan Parks and his son Ryan prepare to start the walk!

## Apert Syndrome Workshop Scheduled

The Craniofacial Program at Children's Hospital, Boston is planning a workshop about Apert Syndrome on Saturday, May 8, 2004. The workshop is aimed at supporting and informing families who have children with Apert Syndrome. Established families will have an opportunity to share experiences and meet new families. Registration begins at 9:30 am and the workshop will run until 3:00 pm. Anyone who is interested is welcome and encouraged to attend. Childcare will be provided. To RSVP or for more information, please contact Elizabeth Leonard via email at [elizabeth.leonard@childrens.harvard.edu](mailto:elizabeth.leonard@childrens.harvard.edu) or by phone at 617-355-3417. 

### Distraction Osteogenesis — continued from inside

stable result with less chance for relapse. Investigators are studying how the new bone forms in the distraction gap in attempt to find ways to shorten the treatment period. Distraction devices are continually being designed and miniaturized. Computer software treatment planning systems for precise and accurate movement of the bone are being developed. As distraction osteogenesis continues to improve, the correction of many craniofacial anomalies will become possible through this minimally invasive technique. 



**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.

(617) 355-8299 | [www.facesofchildren.org](http://www.facesofchildren.org)

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