Dental Medicine Plus: Care for Veterans, Diabetes and Gum Disease A Dr. Seuss Discovery

Unbroken
Determined parents put their trust in a pioneering treatment for cleft palate.

Schedule of Events

- Tufts Dental alumni, faculty, family and friends are invited to participate!
- Golf Tournament: 9:30 a.m. shotgun start, 11 a.m. special tee off for Tufts dental students, 2:30 p.m. awards dinner.
- Tennis Tournament: 10 a.m. start, 2 to 4 p.m.
- Reception: 4 p.m.
- Awards Dinner: 5 p.m.

Registration Fees

- Golf Tournament: $350/player, $1,300/foursome if signed up together.
- Tennis Tournament: $200/player.
- Reception and Dinner Only: $75 for guests and noncompetitors.

Come join the Tufts University Dental Alumni Association for the 30th Annual Wide Open Golf & Tennis Tournament.

Monday, September 24, 2012
Wellesley Country Club
300 Wellesley Ave.
Wellesley, Massachusetts
Tufts Dental alumni, faculty, family and friends are invited to participate!

All proceeds benefit the Dental Alumni Student Loan Fund.
The diagnosis was cleft palate. How one family entrusted their baby to dentists and surgeons to undertake something that had never been done in Massachusetts.

The island of Martha’s Vineyard sits seven miles off Cape Cod, a 45-minute ferry ride to the mainland and then a 65-mile drive to Boston—but it might as well be an ocean away if something is terribly wrong with your child. Carol Vieira was four months pregnant with her third baby when a routine ultrasound revealed something wasn’t quite right. Her doctors at the island hospital suspected cleft palate.

A lifelong islander, Carol, an occupational therapist, and her husband, Garrison, a corporal on the West Tisbury police force, took the news about as well as any expectant parents could. “No one ever wants to hear that their child will have to suffer in any way, and that was very true for us,” says Carol. But cleft palate often means there are other health problems, some of which can’t be ruled out until after a baby is born. “Those question marks caused more stress for us,” she says.

The couple ended up in Boston, at the Cleft Lip and Palate Clinic at the Floating Hospital for Children at Tufts Medical Center, where the diagnosis was confirmed. There, the Vieiras met two Tufts pediatric dentists, who offered a way to ease their anxiety about their unborn baby, a girl. The couple learned about a relatively new orthodontic therapy that would make the eventual surgery to repair their baby’s cleft palate less complicated.

If the Vieiras agreed, their baby, due in February 2011, would be the first to undergo the procedure, called nasal alveolar molding, or NAM, at Tufts Medical Center, the only Massachusetts hospital that offers the treatment. Their daughter’s split palate would be gently moved together, millimeter by millimeter, over the first few months of her life.

BY JACQUELINE MITCHELL
dentists and surgeons to undertake something that had never been done in Massachusetts

PHOTOGRAPHS BY KATHLEEN DOOHER
The dentists, Serena Kassam, A02, D05, and Jessica Chiang, DG09, surely would have understood if the Vieiras decided they didn’t want their baby involved in something so new, never mind the fact that she would be the first. But in Carol and Garrison Vieira, who had taken in a foster infant just seven weeks before their older daughter, Alyssa, now 2, was born, the Tufts dentists found parents who were resolute in confronting the challenge dealt them. They chose to go forward.

“They presented NAM with such clear and confident authority [that] we never questioned that plan of action. We felt like pioneers,” says Carol, whose diminutive features belie a well of inner strength. “Knowing what to expect in terms of her diagnosis, as well as her features are quite pliable and growing rapidly. A few weeks after birth, when the craniofacial malformation such as cleft lip and palate are the most common birth defects in the United States, occurring in one of every 1,000 newborns, according to the National Institutes of Health. Although the cause remains unknown, scientists believe an olio of genetics and environmental factors may be at work. The defect occurs when the nose and upper jaw fail to fuse properly, somewhere between the third and sixth weeks of fetal development. Cleft lip and palate can occur independently or together, and malformations can range from a tiny hole in the roof of the mouth to a more dramatic misalignment of the facial features. A unilateral cleft creates a gaping hole in a baby’s face, and the nose may be pushed off center. In a bilateral cleft, the premaxilla, the bony ridge that contains the tooth buds for the upper front teeth, may overly protrude from the mouth, and the nose appears widened and flattened.

Nasal alveolar molding was developed in the 1990s at New York University’s Langone Medical Center by an orthodontist, and a plastic surgeon. NAM is becoming the preferred initial treatment for cleft lip and palate because it doesn’t require general anesthesia—which should be avoided for babies under 3 months old—and therapy can start a few weeks after birth, when the craniofacial features are quite pliable and growing rapidly.

That early start is one reason NAM is catching on, says Andrew Scott, a pediatric facial plastic surgeon and codirector of the Tufts Cleft Lip and Palate Clinic. “There’s a rising community of those who do NAM,” says Scott. “Those of us who have seen it in action are all believers.”

NAM therapy uses a custom-made acrylic orthodontic plate—much like the retainer many of us wore when our braces came off—to move the two sides of the palate closer together. Surgical tape anchored to the mouth plate and secured across the baby’s cheeks exerts enough tension to gradually move the upper jaw and gum ridges into better alignment. Several weeks into the therapy, when the baby’s face is a bit more symmetrical, the dentists begin using nasal stents—acrylic balls attached to wires embedded in the mouth plate—to give more shape and structure to the baby’s nose. The stents nudge the nasal cartilage forward to create a more natural profile. In traditional cleft palate therapy, the nose remains untouched until the first surgery.

Dentists and plastic surgeons work as a team, adjusting the mouth plate weekly to take advantage of a newborn’s rapid growth spurts. The goal is to move the gum ridges, upper jaws and nose, not to their final destination, but into the best possible position for a plastic surgeon to close the cleft lip when the baby is 3 to 5 months old. A second surgery to repair the palate generally happens around the child’s first birthday.

Kassam, an assistant clinical professor, and Chiang, an assistant professor, both in the pediatric dentistry department at Tufts School of Dental Medicine, are something of pioneers themselves. With Mohammad Mansoor Ahmed, DG09, the trio helped establish the only two NAM clinics in New England, one at Tufts and one in Rhode Island.

While teaching part-time at Tufts Dental School, Ahmed completed a fellowship in craniofacial pediatric dentistry at Langone Medical Center, where he learned to do nasal alveolar molding from Barry Grayson, one of the coinventors. Kassam and Chiang also learned the technique there.

Ahmed and Kassam established a NAM program at St. Joseph Hospital in Providence, R.I., where Kassam did her residency in pediatric dentistry. When she returned to Tufts, Kassam recruited Chiang to help establish the first NAM clinic in Massachusetts. “These young faculty really provided the impetus and drive to bring NAM to Tufts,” says Stanley Alexander, D75A, professor and chair of pediatric dentistry.

The demand for nasal alveolar molding continues to grow, Kassam says, but there are not enough dentists and surgeons trained in the technique to meet the need. While the NAM itself is not difficult to learn—it’s similar to making dentures, Chiang says—it is time-intensive, for the families and for the many specialists who care for the infant during the first year. The Tufts team was trying to identify the ideal first patient in Massachusetts when they met the Vieiras.

FEELING IN CONTROL
NAM combines the best of traditional cleft-repair therapies and eliminates some of their greatest drawbacks. The most common is a mechanical appliance called the Latham device, which is surgically implanted in a baby’s palate three months after birth. Once the baby heals, doctors reposition the gum ridges and jaws by turning a screw in the implanted metal device. The technique is often effective, but causes some babies significant discomfort, and some have trouble feeding.

An older treatment, still used for less-severe cases, is lip adhesion, in which a surgeon stitches the edges of the cleft lip together. While this creates enough tension to move the jaw and gum ridges into better alignment before the baby undergoes another surgery to correct the cleft palate, it is still surgery requiring anesthesia, and creates scarring before the final lip repair.

While the larger aim of NAM is to close the cleft as much as possible before palate-repair surgery, there are several short-term gains. The orthodontic mouth plate plugs the hole in the cleft, keeping milk or formula out of the baby’s nose and allowing the infant to create enough suction to drink, gain weight and thrive. Scott, the pediatric surgeon, recalls one case in which a baby’s bony gum ridges were rotated up into his nasal cavity, blocking his airway on one side. The pediatric dentists used the NAM mouth plate to push the bony ridge out of the way. “That’s incredibly important because children must breathe through their nose or they can’t eat or drink. So it had immediate functional implications,”
says Scott, an assistant professor of head and neck surgery at Tufts School of Medicine.

Perhaps just as important as the therapy is the emotional benefit to parents of not having to wait to start treatment until their baby is old enough for surgery. Parents of these infants sometimes feel helpless or even guilty, Scott says, unable to do anything to help their fragile newborn. The three-to-five-month wait before their baby can undergo corrective surgery can be unbearably painful. “NAM offers them something to do that feels proactive,” he says. “That can be very helpful for these parents psychologically.”

That was certainly true for Carol and Garrison Vieira. “NAM gave us the opportunity to feel like we had a little control in a situation where you really don’t feel like you have any control at all,” says Carol. When their daughter was born on February 3, 2011, the couple named her Nayelli, a Native-American word that means I love you. “We knew she would need a little extra love,” Carol says.

Because cleft lip and palate can interfere with such basic things as eating and learning how to talk, from day one, Nayelli had a team of specialists devoted to her well-being: otolaryngologists, geneticists, audiologists, speech and occupational therapists, psychologists, plastic surgeons, pediatric dentists and prosthodontists. “There are so many different aspects of care for these children. There’s just no way to do this without having a team,” says Arnold Lee, an assistant professor of head and neck surgery at Tufts Medical School and the other codirector of the Cleft Lip and Palate Clinic.

The most crucial members of the team, though, are not dentists or surgeons. Unlike other treatments for cleft palate, NAM depends heavily on the parents’ involvement—and that’s on top of the weekly clinic visits. The Vieiras had to remove Nayelli’s mouth plate once a day to clean it and the inside of her mouth. They had to reattach the surgical tapes properly, making sure there was enough tension to move her features without pulling too hard on the skin. “The good part of NAM, as well as the bad part, is that it requires so much family participation,” says Scott.

“The worst part of it was that she hated it,” Carol Vieira says of the daily ritual. “But it’s

“NAM [therapy] gave us the opportunity to feel like we had a little control in a situation where you really don’t feel like you have any control at all.”

—Nayelli’s Mom, Carol Vieira
not a big thing at all. It really isn’t. You bathe them once a day, you wash their face, you just add this to the routine.”

Not everyone is as determined as Nayelli’s mom. “We do have parents who will give up if we don’t prepare them well enough,” says Chiang, the pediatric dentist.

Since Nayelli inaugurated the Tufts program, four more babies are receiving NAM therapy. A sixth family, overwhelmed by the daily care required for a successful outcome, gave up. That’s why the cleft team begins preparing parents early, ideally during prenatal visits, as they did with the Vieiras. Chiang uses a baby doll with a realistic-looking cleft lip and palate and its own NAM mouth plate to teach parents how to care for their baby. That put Carol and Garrison at ease. “We knew what we were coming home with,” says Carol.

“Once a family determines they want to work with you, we have to become like a member of their family,” says Chiang.

“It’s not a staff, it is a family. That sounds cliché, but it’s true,” says Garrison, recalling the times the surgeons rearranged their schedules to see Nayelli when the Vieiras happened to be on the mainland. The dentists frequently adjusted the course of treatment in response to Carol and Garrison’s observations or concerns. When Nayelli’s cheeks got too irritated from the pressure of the surgical tape, the dentists adjusted the angle so the tape tugged less. That slowed down progress a bit, but Nayelli felt better. “They really did listen to us and respond,” says Carol.

**A GOOD WEEK**

When Francis Pereyra and Perla Zapata arrive at the Tufts clinic with 6-week-old Jayden, it does feel a bit like a family reunion. Jayden’s parents are all smiles. After just one week wearing the NAM device, their son’s cleft is dramatically smaller.

“Mommy’s happy because she can see the results,” Chiang says as she eases Jayden onto a child-sized dental chair in the center of the tiny exam room. The boy fusses half-heartedly as Chiang peels the tape off his face and removes the mouth plate. His mother, seated in the corner, clucks at him softly, and the tiny patient drifts off to sleep, even as Chiang and two students who have come to observe, Eunice Lee, D12, and Elizabeth Ackerman, a postgrad in pediatric dentistry, buzz about the baby. When Chiang measures the gap, it has closed by nearly an eighth of an inch. “You are doing a really good job,” she tells the parents more than once.

Chiang exudes confidence and optimism. As she works, she maintains a constant upbeat banter with Jayden’s parents, describing what she’s doing and cluing them in on what to expect as the therapy progresses. She reaches into her toolkit, brimming with dental impressions, wires, surgical tape and sundry instruments, for a flashlight. As she peers into the baby’s mouth, checking for any irritation the mouth plate might be causing, Chiang peppers Jayden’s parents with questions about their week. How did the baby eat? Sleep? Tolerate the mouth plate? The boy ate well, his delighted parents report, and that helped him sleep better. Chiang picks Jayden up. “He got a lot heavier,” she says with a wide grin as she slides the baby back into his mother’s arms.

Cradling the boy’s plastic mouthpiece in her left hand, Chiang uses a dental drill to sculpt it so it will close Jayden’s cleft palate more in the week ahead. She deepens the troughs where his gum ridges sit to nudge those tissues to grow in that direction. She adds putty where she wants to create pressure to push bony tissue into the trough. To the casual observer, the work seems more art than science. “It can appear to be very mysterious to those of us who don’t know what we’re doing,” says Scott, the surgeon. “Jessica [Chiang] is very adept at it.”

Chiang and Scott confer, their heads bowed over the tiny mouthpiece, as they pool their expertise to assure the best possible positioning of Jayden’s gum ridges and upper jaw before he undergoes corrective surgery in a few more months. “Being able to do that together every week is an added bonus that’s unique to our program,” says Scott.

Chiang gently slips the device back into Jayden’s mouth and replaces the surgical tape. The boy’s cheeks, slightly red from the tape, are full and round, and his chubby feet and hands peek out from his tiny corduroys and button-down shirt. Though he’s clearly a good eater, Scott asks his mother to give her son a bottle to make sure the newly adjusted mouth plate won’t interfere with his eating in the week ahead. When Jayden begins to drain his bottle, the family is ready to make the hour-long drive back home to Lawrence, Mass. They’ll be back next week for another adjustment and progress check. Not every week is so easy, Chiang reminds the couple.
“When I see a really big change like this, that’s how I keep going.”

—Pediatric Dentist Jessica Chiang

“It can be discouraging at times,” she adds. Sometimes the gap doesn’t close much. Other weeks a baby won’t or can’t tolerate the device very well. But visits like the one today with Jayden negate any setbacks. “When I see a really big change like this, that’s how I keep going,” Chiang says.

Right now, Chiang is something of a one-woman dental team at the Tufts Cleft Lip and Palate Clinic. Kassam has been on a fellowship in Guayaquil, Ecuador, training a prosthodontist and an orthodontist to do NAM therapy. In Ecuador, cleft palate is more prevalent, about one in every 350 births. This spring, Kassam and her trainees are using NAM to treat 20 babies. Ahmed, who grew up in Dubai, is setting up a NAM clinic at Dubai Health Authority Hospital, where he is a senior specialist in the pediatric dentistry department.

CELEBRATIONS ALL AROUND
At birth, the cleft in Nayelli Vieira’s palate measured 16 millimeters wide, more than half an inch across. “She could fit her whole tongue in there,” says Scott, the pediatric surgeon. After she wore the NAM appliance for five months, Nayelli’s cleft was just four millimeters wide, less than the diameter of a pencil-top eraser. Narrowing the divide that much “makes a huge difference in reconstruction down the road,” says Scott, who repaired Nayelli’s lip when she was 5 months old. “[Drs. Kassam and Chiang] were able to stretch her lip a little bit and mold her nose so that the surgery that I did was technically easier and had, I think, a better outcome than it would have without the NAM,” he adds.

Nayelli had her palate repair surgery on January 31, and celebrated her first birthday in the hospital four days later. A tiny rock star, she had well-wishers from her cleft team visiting all day. Hospital staff decorated her room and brought presents, balloons and cake.

A month later, the little girl with big blue eyes like her mom’s is as beguiling and flirtatious as any 1-year-old. On this bright Sunday in March, the Vieira family—Carol, Garrison and Nayelli, plus big brother Micah, 9, and sister Alyssa, 2, and the family dog, Tao—walk the beach near their island home. The wind is nippy, but the warmth of the sun hints at the season to come. Clad in fleece, Nayelli takes a bottle from her mom as the two perch atop an overturned rowboat. The sisters take turns riding on their parents’ shoulders, while Micah, dreaming of his upcoming baseball season, snaps a ball into his glove. “We have a really happy family,” he says, mostly to himself.

Side-by-side in a double stroller, the Vieira sisters look, well, like sisters. Only the faint scars on Nayelli’s upper lip indicate what she has been through to get to this glorious spring day. Her nose is not quite symmetrical and will require more surgery once she finishes growing, likely well into her teens. “These kids typically require procedures even when they are not kids anymore,” says Arnold Lee, the surgeon. “It’s a lifelong process, really. We do expect to be working with patients and their families for a long time.”

In many of these kids, the growth of the upper jaw lags behind that of the rest of the face, resulting in a pronounced underbite that the surgeons will have to correct. Most children born with cleft palate eventually need braces. No one can predict what Nayelli may need down the road. “It’s a moving target,” says Scott, the other surgeon. “We care very much about how these children look, but in the end, we care most about how they function.”

Nayelli’s baby teeth are just beginning to come in, and the Tufts dentists are monitoring that milestone closely. In children with cleft palate, the teeth can be too small, or conical, or just the wrong shape. That doesn’t matter so much with baby teeth, though, so for now, the goal is to prevent decay. “She’s already had a lot of surgery,” says Chiang. “We want to take care of those teeth so she doesn’t get cavities and wind up in the operatory.”

It’s been more than six months since Nayelli completed her NAM treatment, and the little girl no longer recognizes Chiang. It is bittersweet for the pediatric dentist, who admits she has grown attached to her first NAM patient. After Nayelli’s palate repair surgery, Chiang was among the birthday visitors in her hospital room. She cried when she saw how much Nayelli had grown, how different she looked after her operation. Though they don’t see each other regularly anymore, Chiang says she can’t forget the little girl and her own role “in the early stages of her lifetime.”

Adam Bottrill, a pediatric dentist from Portsmouth, N.H., who is learning the NAM technique, watches Jessica Chiang as she examines Jayden Pereyra.