Devyn Overcomes the Odds

Sun Safety 101
What You Need to Know

Star Anise Tea
This popular colic cure could actually harm your child—page 8

A Closer Look
MRI has arrived in Broward County
Dear Friends,

If you have considered or have used star anise tea to help treat your child's stomach ailments, you will want to read the article on page 8. Recent research at Miami Children’s Hospital has discovered alarming side effects from the tea, and the Food and Drug Administration is taking notice.

In addition to a dedication to research and clinical trials, Miami Children’s Hospital performs delicate surgeries and provides lifesaving care every day—from newborns in our NICU to teenagers suffering life-threatening injuries. These children display courage and strength that helps them overcome their individual challenges. Nowhere is this more evident than in the inspiring story of Devyn Caven featured in this issue of *Children’s Gazette*. Devyn’s family moved to Miami to receive a breakthrough treatment for her sickle cell disease from the Bone Marrow Team at Miami Children’s Hospital. Although her story begins with Devyn suffering numerous complications of the disease, it ends with happiness. Her younger sister was a perfect match for a bone marrow transplant.

In this issue, you’ll also read about how to shield your children from the harmful rays of the sun—an ever-present problem in South Florida. You’ll learn a four-step plan of protection to keep your children’s skin healthy for life.

From groundbreaking research to lifesaving care, Miami Children’s is committed to caring for children all over South Florida and the world.

Sincerely,

Christian C. Patrick, MD, PhD
CHIEF MEDICAL OFFICER/SENIOR VICE PRESIDENT FOR MEDICAL AFFAIRS
MIAMI CHILDREN’S HOSPITAL
Most families look forward to the holiday season. But for the Caven family of Coral Springs, the fall and winter months have typically been a time of dread. Their 10-year-old daughter Devyn, who was diagnosed with sickle cell anemia as an infant, has spent too many holiday seasons and hundreds of other days throughout the years lying in a hospital bed surrounded by nurses and monitors. But those times are past, thanks to a breakthrough procedure available at Miami Children’s Hospital that offers children with sickle cell anemia a chance for a cure.

**A Difficult Childhood**

Devyn’s genetic blood disorder, which causes red blood cells to change shape, is associated with an array of serious complications, including episodes of chronic pain, increased infections and bone damage. She was particularly vulnerable to complications during the fall and winter flu season. By age 4, Devyn had already battled such life-threatening ailments as pneumonia, respiratory syncytial virus (RSV) and acute chest syndrome (ACS), which often causes death in children with sickle cell disease.

When Devyn started having strokes two years ago, it looked as if her holidays would forever be spent in the company of caregivers—if she even lived to see her teenage years. Only this time her parents were given hope when a neurologist told them that a bone marrow transplant, once reserved exclusively for leukemia patients, could offer a cure for sickle cell anemia.

**A Second Chance**

“We were living in Atlanta at the time, but we wanted the best possible care for Devyn,” says Cecile Caven, Devyn’s mom. “So we moved to Miami in hopes of getting a bone marrow transplant at Miami Children’s Hospital.” The next step was to find someone whose stem cells were compatible with Devyn’s. After each family member was tested, one was determined to be the perfect match—her 7-year-old sister, Danielle.

“We explained to Danielle that she could help Devyn by donating some of her stem cells,” Cecile says. “Danielle was absolutely ecstatic to know she could do something so that her sister wouldn’t have to live with sickle cell anymore.”

John Fort, MD, Director of the Bone Marrow Transplant Program at Miami Children’s—the only freestanding pediatric hospital in Florida accredited by the Foundation for the Accreditation of Cellular Therapy (FACT) to perform this innovative procedure for children—explains that unlike most sickle cell patients, Devyn was fortunate that she had Danielle to donate the lifesaving stem cells.

“We wanted Devyn to have a healthy life,” Dr. Fort says, “and having a family member as the donor significantly increases her chances of being cured.”

Devyn’s procedure was in April 2003, and she has successfully completed her recovery process. Devyn can now play with Danielle and is keeping up with her fourth-grade studies through Broward County’s Hospital Homebound program. To her, the best part about having the transplant is the fact that “I can laugh a lot more now!”

“She has more energy than she ever has,” Cecile says. “For the first time, my child actually has a chance to live a normal life. There aren’t words to express our gratitude for Dr. Fort and all of the doctors, nurses and social workers at Miami Children’s Hospital.”
What Every Parent Needs to Know about the Sun

You might remember the commercial of the little girl running around with that wonderful, golden tan and gleaming white bottom. But before you let your child become the next beach baby, take a look at this vital information about the sun, your skin and why you need to protect your wee ones.

The sun’s warm rays can be enticing even to those most savvy about protecting their skin. While it’s wonderful to send your children outdoors to bask in its warmth and soak up some needed vitamin D for strong bones, the sun has a down side—harmful, invisible ultraviolet (UV) rays that damage the skin’s cells and potentially cause skin cancer.

Shining Facts

“Nearly 80 percent of the sun exposure you get in your lifetime occurs in childhood,” says Ana Duarte, MD, pediatric dermatologist on staff at Miami Children’s Hospital.

- “The effects of this exposure are irreversible. It’s this childhood exposure that counts against you in terms of developing skin cancer and aging when you’re an adult.”
- In fact, one blistering sunburn during childhood or adolescence can double your risk for skin cancer, notes Dr. Duarte. Furthermore, even if you don’t get burned, a suntan itself and most freckles are signs that the skin has been damaged by the sun.
- Before you begin to protect your children as well as yourself from the sun, you need to know what you’re up against. The sun produces two types of invisible rays, ultraviolet-A (UVA) and ultraviolet-B (UVB). UVA rays penetrate the skin at a deeper level than UVB rays and can damage more of the skin’s connective tissue. Sunburns are typically associated with UVB.

Did You Know...

- Window glass blocks the sun’s UVB rays (which primarily cause burns) but not UVA rays that damage the cells, causing wrinkles, age spots and skin cancer.
- You can accumulate skin damage from the sun even if you never get burned.
Devise a Protection Plan

To protect your tots from the discomfort of sunburns and potential accumulative damage in adulthood, follow this four-step plan.

**Step 1:** Wear sunscreen daily.

**Step 2:** Stay inside or at least in well-shaded areas during peak hours (10 a.m.–4 p.m. or 9 a.m.–3 p.m. during daylight savings time).

**Step 3:** Wear protective clothing (hats, tightly woven fabrics and sunglasses with UV protection).

**Step 4:** Get an annual skin exam by a dermatologist. Dr. Duarte recommends an examination even for children who are 1 year old if they have moles.

“Seeing a dermatologist on an annual basis will offer the family time to gain new knowledge about sun safety,” says Dr. Duarte, “and the physician can examine the child’s skin, taking note of any suspicious moles for future monitoring.”

**All about Sunscreen**

When you’re shopping for a sunscreen to keep in your sun-protection arsenal, look for one that offers both UVB and UVA protection (often called a broad-spectrum sunblock). Broad-spectrum sunscreens have either avobenzone or oxybenzone listed as an ingredient.

**A Burning Question**

Q: What level of sun protection does your child’s white tee shirt afford?

A: If you think your child’s plain white tee will protect him or her from the sun, surprise! According to the American Academy of Dermatology, the standard white shirt has only an SPF of 3.

Another element to consider is the sun protection factor (SPF). The greater a product’s SPF, the greater the protection you get. According to the American Academy of Dermatology, a person with fair skin typically burns within 20 minutes of afternoon sun exposure without a sunscreen. By applying an SPF 15, he or she can then be outside potentially 15 times (300 minutes) longer without burning.

“Get a sunblock that offers an SPF of 30 or greater,” says Dr. Duarte. “Apply it 30 minutes before going outdoors and reapply at least every two hours even if it’s a waterproof or sweatproof formula.”

You can find these sunscreens in several forms including creams, sticks, gels, sprays and lotions. “Gel-based formulas are nice because they dry quickly,” notes Dr. Duarte, “but they can be irritating especially to a child with sensitive skin because they’re based in alcohol. Lean toward using products that are labeled for babies or sensitive skin.”

By following this four-step plan, you’ll be helping your children have fun in the sun and healthy skin for all their years to come.

To learn more about sun protection for your child, call Miami Children’s Hospital’s Physician Referral Service at (888) MCH-DOCS or (305) 624-4543 for a referral to a pediatric dermatologist.

Apply sunscreen to your children once they are 6 months old. Prior to that age, keep them out of direct sunlight and dress them in protective clothing made of tightly woven fabrics.

Examine a Sunless Alternative

Does your teen want a deep, golden tan, but you want to protect her from sun damage? Try one of the sunless tan products available at practically any supermarket, drug store and salon.

“A lot of progress has been made in artificial tanners,” says Ana Duarte, MD, pediatric dermatologist on staff at Miami Children’s Hospital. “Sunless tan creams and lotions are completely safe for adolescents who want a suntanned look without any of the harmful effects of the sun.”

Your teen may be tempted to try one of the new spray tans, but proceed with caution. The tanning solution many of these systems use contains dihydroxyacetone (DHA), a color additive used in most sunless tan products. DHA is approved by the FDA for external use only. When applied in a spray booth, DHA reaches the eye and mouth areas, which are regarded as internal body parts. For safety’s sake, your child will need protection for the eyes, lips and other mucous membranes and a means to prevent inhalation.
Miami Children’s Hospital’s dedication to caring for your child and family has again won it recognition as a top South Florida hospital.

In a feat never before achieved by an area hospital, Miami Children’s Hospital has won the region’s Consumer Opinion Award for two consecutive years.

The award, announced earlier this year, is bestowed based on survey results from consumers who have received care at area hospitals. Of the 15 South Florida hospitals included in the 2003 survey, Miami Children’s patients and families reported the highest levels of patient satisfaction. The same was true in 2002.

“Customer service will be a major force in business in the 21st century,” says Raul O. Chao, Senior Vice President of The Systema Group, the Coral Gables-based research group who gave the award. “The Consumer Opinion Award is an outward sign of Miami Children’s commitment to patients and their families.”

The Consumer Opinion Award is not the only distinction the hospital received in 2003. In July, Miami Children’s was recognized as one of the nation’s 25 top pediatric hospitals in U.S. News and World Report’s 14th annual report on America’s Best Hospitals. Miami Children’s was the only pediatric hospital in the state of Florida included in the list.

South Florida Parenting also named Miami Children’s the “Best Hospital for Pediatrics” and “Best Hospital for Emergency Care” in its 2003 Kids Crown Awards.

Miami Children’s now offers online preregistration for many diagnostic and treatment services—at your convenience, in the comfort of your home. Any individual or physician’s office can now access the hospital’s web site at www.mch.com and complete the preregistration process.

“Time is precious for everyone,” says Barbara Day, Director of Patient Access at Miami Children’s Hospital, “and online preregistration saves our patients time by enabling them to complete the registration process early, at a time that’s best for them.”

You can now preregister for the following services:

- inpatient admission
- ambulatory surgery
- laboratory
- radiology
- ultrasound
- CAT scan
- nuclear medicine
- MRI scan
- cardiology
- pulmonary care
- neuro-diagnostic services
- EEG (electroencephalogram)
- polysomnogram
- biofeedback

Please note that these services are available to you through Miami Children’s Hospital; you may not preregister online for a doctor’s office visit or any other physician service.

Also, you must be preregistered at least three full days before your scheduled check-in or appointment date. You can still preregister by telephone for a hospital service taking place in less than three days. Please call (305) 663-8413 for outpatient diagnostic services or procedures or (305) 740-5038 for ambulatory surgery or inpatient services.

At Miami Children’s Hospital, we want to bring you the best in health care and make it as convenient as possible.
When people think of company gifts, they may imagine baskets of fruit or chocolate, specialty coffees or gift certificates to popular stores. But for the past 20 years, U.S. Foundry has chosen another option for spreading cheer that is making a huge impact on the lives of children in the community. It makes a charitable donation to Miami Children’s Hospital Foundation and sends a card to its customers announcing that a gift was made in their honor.

“The annual donations have always been made in the names of our customers as a way to say thank you for their business,” says Alex L. DeBogory, Executive Vice President and Chief Operating Officer of U.S. Foundry, one of the nation’s leading producers of utility castings, including manhole covers and iron and steel grates. “We feel this is a great way to honor them and do something good for the community at the same time.”

Meeting Needs Both Big and Small
One of the interesting things about U.S. Foundry’s annual gifts is the way the money is donated. Many times, companies will make a contribution but will allocate the money for one specific purpose such as for cancer care or cardiology treatment. While every gift is greatly appreciated, unrestricted monies are the most difficult to raise, according to Ivette Diaz, Director of Marketing and Community Relations for Miami Children’s Hospital Foundation.

“The funds given by U.S. Foundry have not been earmarked for a specific area and can therefore be used in many different ways throughout the hospital,” explains Diaz. “Monies are used throughout the year to meet the individual needs as they arise. This is vital to the success of our organization.”

Dedication to the Cause
U.S. Foundry’s dedication to children is evident in the diligence of their contributions. They understand the significant impact of their gifts on the lives of children and their families and the community as a whole.

“Those of us who have our health are fortunate, and we know that not everyone has such good fortune,” says DeBogory. “We benefit from donating to Miami Children’s Hospital Foundation in several ways. We enjoy knowing that our contributions are going to such a worthy cause, our customers really appreciate the idea that we donate in their name, and it has become a worthwhile tradition in our companies that we plan to continue.”

Consistent Giving
“U.S. Foundry demonstrates company philanthropy by supporting a facility that cares about the health and well-being of children,” says Diaz. “We hope other companies in this area will follow U.S. Foundry’s lead and support Miami Children’s Hospital Foundation with the same generosity and consistency.”

Miami Children’s Hospital Foundation is extremely grateful for the dedication to giving shown by U.S. Foundry. Their contributions are improving children’s health and helping find new treatment options for children across the state and around the world.

For more information on how you or your company can contribute to the Miami Children’s Hospital Foundation, please contact Ivette Diaz at (305) 666-2889.
Research at Miami Children’s Hospital reveals hidden hazards in what has been a common household remedy for centuries.

The Food and Drug Administration has issued a warning against the use of tea made from star anise, thanks to research conducted at Miami Children’s Hospital that has brought to light complications associated with children consuming the popular brew.

“For hundreds of years, star anise has been the standby for mothers trying to calm their infants,” says Barbara M. Peña, MD, MPH, a board-certified emergency medicine physician on staff at Miami Children’s Hospital who served as principal investigator in the study. “Unfortunately, that’s no longer a safe option.”

The Cause: Contamination

There are two types of star anise—Chinese and Japanese. Whereas Chinese star anise may be useful to calm a troubled stomach, the Japanese strand is intended for decoration and incense. In recent years, the two types of star anise (which are virtually indistinguishable) have been mixed together before being shipped to America. When this contaminated star anise is used for “tea,” vomiting, fidgeting, rapid eye movement and seizure have been reported in infants, children and adults who have consumed the brew as well as in breastfeeding babies whose mothers have imbibed the tea.

This same phenomenon has been noted in a number of countries, and star anise has been banned from some of them. The first recognized case in the United States was seen in 2003 at Miami Children’s, where Dr. Peña associated a child’s seizures to ingestion of star anise. Since then, seven of the documented 40 cases of neurologic deficit due to star anise in America have been patients at Miami Children’s.

The Solution: Avoidance

As a result of Dr. Peña’s groundbreaking research, the Food and Drug Administration issued a warning that no one should ingest even the smallest amount of star anise for any reason.

“Many people think negative reactions to star anise occur due to using too much of it,” Dr. Peña explains. “However, the quantity of star anise doesn’t matter—the quality does. And though Chinese star anise was used safely in the past, it’s now tainted with the Japanese version, and all forms of star anise should therefore be avoided.”

For more information on star anise, log on to www.fda.gov.

So Now What?

If the recently discovered dangers of star anise have you scrambling for a new way to calm colic, take heart. Here are a few ways to help your baby fight back the tears without star anise.

• Take him or her for a drive in the car or for a walk.
• Turn the radio or television to a station with poor reception to create white noise.
• Try over-the-counter medication such as Mylicon®.
• Wait it out and remember that the crying won’t last forever.

When all else fails and you can’t handle the crying any longer or you’re afraid your child’s fussiness isn’t due to colic, contact your physician or call Miami Children’s Hospital at (305) 666-6511.
As part of its commitment to bringing high-quality pediatric care to the children of South Florida, Miami Children’s is introducing state-of-the-art pediatric MRI services at its Dan Marino Center.

Before April 7, pediatricians and pediatric subspecialists in Broward County had to send their patients to adult facilities for MRI imaging. Because these institutions aren’t equipped for the special needs of children, the initial procedure often had to be repeated. Families often had to travel for additional imaging. But those days are in the past.

“We’re excited to bring MRI to children in Broward County,” says Albert Rego, Administrative Director at the Dan Marino Center. “There are no other pediatric MRI services in the area, and these duplicate the same quality of care available at Miami Children’s. In fact, the radiologist at Miami Children’s monitors each MRI as it’s performed via a high-speed data connection.”

The state-of-the-art scanner can image a child’s small body structure with excellent resolution and detail. In addition, a variety of special coils and antennas assist the technologist in generating the best images.

The entire staff, from radiologists to technologists, has been specially trained and is highly experienced in imaging pediatric patients.

“Children are not just small adults—their disease processes are different and they’re best evaluated by specially trained pediatric radiologists,” notes Nolan R. Altman, MD, Chief of Radiology on staff at Miami Children’s Hospital. “Broward County children will greatly benefit from the experience of the pediatric radiologists providing and evaluating the MRI exams.”

To learn more about pediatric MRI services available at the Dan Marino Center or to schedule an appointment, call (954) 385-6234.

The Physician Referral Service receives more than 700 calls and electronic requests per month. Callers are provided with names and phone numbers of physicians to match their criteria and can also learn about prospective physicians’ educational backgrounds and credentials, as well as Miami Children’s Hospital services. Physician referral information is also available through the hospital’s website at www.mch.com. Just click on the “Find a Doctor” prompt.

“Finding the right physician to meet your child’s needs can be a time-consuming process,” says Saran Zamora, Physician Services Program Coordinator at Miami Children’s Hospital. “We are pleased to be able to provide this convenience to busy parents.”

Here are some Physician Referral Service facts and figures:

- **Calls exceed 700 per month.**
- 83 percent of callers are women.
- 22.5 percent are from outside of Miami-Dade County.
- 3 percent of callers are from out of state.

The next time you need help finding a physician, call the Miami Children’s Physician Referral Service at (888) MCH-DOCS or (305) 624-4543 or visit www.mch.com.
Get On Your Feet
Participants at the Seventh Annual FIU Dance Marathon stayed on their feet for 25 hours. The annual CMN event had over 150 dancers and raised $64,055 (includes gift in kind donations) for CMN. Thank you to Papa John’s Pizza and Crystal Springs Water for once again donating all the pizzas and water for the event. Congratulations to the Dance Marathon committee who worked non-stop during the past year to make this year’s event a huge success!

Corporate Golf Invitational
Once again, the Biltmore was the venue for the Miami Children’s Corporate Golf Invitational. This year’s golfers enjoyed a beautiful day of golfing while helping to raise funds to benefit Miami Children’s. Thank you to the corporate sponsors and to all the teams that participated.

Miami’s Most Photogenic Baby Contest
The 2004 Miami’s Most Photogenic Baby Contest was held at Aventura Mall. There were over 200 participants and this year’s event raised more than $5,400 for CMN.

Vogue/Vittadini Fashion Day
The ladies of the Community Council joined hosts Constance Fernandez and Mercy Garcia for a special spring fashion day, which started with a delectable lunch held at Pescado and then a dessert and champagne reception with informal modeling at the Adrienne Vittadini Boutique at the Village of Merrick Park. The ladies enjoyed a day of shopping fun and 10 percent of the proceeds benefited Miami Children’s Hospital Foundation.

Ben & Jerry’s Free Cone Day to Benefit CMN
Annie Fernandez and Marisel Hawayek, proprietors of Ben & Jerry’s South Beach, teamed up with Robin Reiter-Faragalli, President of Miami Children’s Hospital Foundation, and Miami Beach City Manager Jorge Gonzalez to scoop for tips, which benefited the Children’s Miracle Network. The yearly “Free Cone Day” celebration was a huge success and a lot of fun for both Robin and Jorge. Annie and Marisel plan to open their second store in September of 2004 in downtown Coral Gables. We’ll see you there!!

Children’s Gazette SUMMER 2004
Upcoming Events

July 17 & 24
One-hour CMN specials will be broadcast on WPLG Local 10, from 1 to 2 a.m. For more information, please call Maria Moldes at (786) 268-1832 or mmoldes@mchf.org.

September 11, 12 & 13
The Sixteenth Annual Hardware Conference will be held at the Marco Island Marriott. For more information, please call Maria Moldes at (786) 268-1832 or mmoldes@mchf.org.

September 19
Second Annual Citgo/Sunshine Gasoline Distributors Family Picnic and Domino Tournament will be held at A.D. Barnes Park. For more information, please call Maria Moldes at (786) 268-1832 or mmoldes@mchf.org.

October 2
The Third Annual Credit Unions of South Florida Golf Tournament benefiting CMN will take place at Jacaranda Golf Club in Plantation at 8 a.m. For more information, please contact George Ferretti at gferret@tfcu-fl.org.

October 30
2004 International Pediatric Hall of Fame Gala at the J.W. Marriott—Brickell Avenue. For ticket information and underwriting opportunities, please contact Ann Lyons at (786) 268-1830 or alyons@mchf.org.

November 6
Marriott’s annual Torch Relay will once again begin its 1,200-mile journey in Miami at Marriott’s Villas at Doral. For more information, please call Maria Moldes at (786) 268-1832 or mmoldes@mchf.org.

November 10
Nordstrom’s—Dadeland Grand Opening Gala benefiting Miami Children’s Hospital Foundation and the Junior League 7–11 p.m., Tickets $150 per person. For more information please contact Ivette Diaz at (786) 268-1822 or idiaz@mchf.org.

November 20–21
Fourth Annual Hasbro Warehouse Toy Sale at 2750 NW 84 Avenue. For more information, please contact Maria Moldes at (786) 268-1832 or mmoldes@mchf.org.

November 29
Swing for Smiles golf tournament presented by Atlantic Dental, Inc. Hosted by MCHF and Hyatt Hotels & Resorts. For more information, please contact Ivette Diaz at (786) 268-1822 or idiaz@mchf.org.

December
Biltmore’s Run for Smiles. Date to be determined. For more information please contact Ivette Diaz at (786) 268-1822 or idiaz@mchf.org.
Tooth Care Is Choote Art!

What is “choote art?” It’s what you get when you scramble up the words “tooth care!” Learn more about how you can best care for your smile by unscrambling the mixed up words in the sentences below.

1. Taking care of your teeth helps prevent UPQALE, a clear, sticky film that attracts RATBECIA.
2. Plaque can cause IVIECAST and STINGGIVII.
3. The UFEDLOI in toothpaste makes your teeth strong and protects them from cavities.
4. The amount of toothpaste you need each time you brush your teeth is about the size of a(n) APE.
5. You should spend about ROFU minutes brushing your teeth after each meal and before going to bed.
6. Strong, healthy teeth help you WECH RUFO FODO, PAKSE LARYELC and KOLO YURO TEBS.

Fun Facts

Answers

1. plaque, bacteria
2. cavities, gingivitis
3. fluoride
4. pea
5. four
6. chew your food, speak clearly, look your best