



All Children's Hospital Foundation

# Dream Builders

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## Near Tragedy Brought the Walkers to Johns Hopkins All Children's Hospital; Healthy Children and a Love for the Hospital Made them Dream Builders

Betsy Walker and her husband, David, welcome any opportunity to meet up with their three children and their spouses, and especially their three granddaughters. Whether it's for a holiday dinner or a University of Florida football game, the Walker family gatherings can be large and lively events. However, Betsy and David don't mind. They know how lucky they are to have such a happy, healthy family.

Thirty-three years ago, after experiencing a very early miscarriage, Betsy discovered she was still carrying two other babies. Her doctor mandated bed rest for the remainder of her high-risk pregnancy. At 28 weeks, Betsy, David and their then 2-year-old daughter, Kyle, went to her weekly appointment eager to learn how the twins, Brett and Kyndall, were growing. Excitement quickly turned to fear when Brett's amniotic sac ruptured during the exam. Betsy's doctor, knowing how critical the situation was, quickly arranged for her transfer to St. Petersburg, where Johns Hopkins All Children's specialists and Neonatal Intensive Care Unit (NICU), a regional referral center for the most critically ill newborns, would be within minutes of her delivery room.

"My doctor said that for my babies to have any kind of a chance for survival, they had to go to Johns Hopkins All Children's Hospital," explains Betsy. "I had never heard of the hospital before, but we were incredibly grateful to learn that such a place existed so close. It was in that moment that I felt like we were giving Brett and Kyndall a real fighting chance."

Within three hours, Betsy went into hard labor. Doctors performed a C-section to avoid any head trauma for these incredibly fragile babies. Brett was the first to arrive. Betsy recalls, "Though I didn't see him, I did hear him cry. He sounded like a kitten." She was elated to hear his soft whimpers and expected to hear the same from Kyndall upon her arrival. When she only heard silence, Betsy frantically asked "What's wrong with my baby?" Minutes, seeming more like hours, passed before she heard Kyndall's cry for the first time.



The Walker family (L-R: Kyndall, Kyle, Brett, Betsy and David)

The Johns Hopkins All Children's team had successfully resuscitated Kyndall. Betsy was able to see her shortly thereafter. "She was bundled in a blanket, and all I could see was her tiny face and big, beautiful eyes."

Although Betsy could not accompany the twins, David was able to join the Johns Hopkins All Children's specialists as they transferred the babies to the NICU. Betsy required further surgery and ultimately was advised that she should not have any more children. Such news made her even more grateful that her babies survived birth, but at the same time very anxious to visit them in the NICU.

"I was able to see them the day after my surgery," said Betsy. Brett weighed only one pound, thirteen ounces and was 13 ¼ inches long at birth, just slightly larger than a Barbie doll. Kyndall was a tad bigger at two pounds, two ounces and 13 ½ inches long. "They were lying on their tummies and hooked up to so many wires." Brett and Kyndall, despite their size, were strong. Both were already off oxygen, which came as a surprise to both the family and caregivers given their prematurity. The good news continued until about a month later, when Brett had a medical emergency.

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Anthony Micelli visits his doctors at the Johns Hopkins All Children's Cancer & Blood Disorders Institute.

## Targeting a Tough Cancer Using Precision Medicine

Wobbling around the house or squealing with glee over his favorite cartoon, 2-year-old Anthony had plenty of toddler energy—but suddenly it disappeared. At first his doctor was not concerned. Then one day Anthony woke up gasping for air.

Nikki, Anthony's mom, rushed her son to the emergency room at Johns Hopkins All Children's Hospital, where tests revealed a mass in the chest that was blocking Anthony's airway. The tumor was surgically removed and diagnosed as stage-4, high-risk neuroblastoma, a childhood cancer that begins in early nerve cells and is often found in the chest or abdomen.

Anthony was treated with chemotherapy, but a year later he relapsed. This time, the cancer was in his lungs. Even more devastating, a search for potential new drug targets revealed that Anthony's tumor cells had a rare mutation called anaplastic lymphoma kinase (ALK) that results in uncontrolled cell growth. It is often chemotherapy-resistant.

There was also reason for hope. The ALK mutation can be targeted with a relatively new medication, part of a new approach called precision medicine that can match the treatment more closely to the genes being expressed by a patient's tumor. The opportunity for Anthony to join a drug trial to optimize his treatment is one of the benefits of being a patient at the Johns Hopkins All Children's Cancer & Blood Disorders Institute.

"Anthony is an energetic youngster who has been thriving in the face of adversity," explains Gregory Hale, M.D., a pediatric oncologist at Johns Hopkins All Children's Hospital

and professor of oncology with the Johns Hopkins University School of Medicine. "His disease did not respond well to relapse therapy and he was then treated with crizotinib—a targeted therapy that inhibits ALK—along with cyclophosphamide and topotecan, two chemotherapy drugs that are frequently used to treat cancer." Anthony responded well.

"Anthony's treatment is an example of precision medicine where crizotinib was added solely because his tumor included this ALK mutation," says Hale. "He continues to have a very low level of measurable disease. Hopefully we can omit or reduce chemotherapy to patients like Anthony in the future once we better define the cellular abnormalities in cancer cells."

### A New Frontier

"Neuroblastoma is one of the greatest challenges we see as pediatric oncologists and so the next frontier where we can make advances is targeted therapy," says Peter Shaw, M.D., deputy director of the Johns Hopkins All Children's Cancer & Blood Disorders Institute. "The ideal cancer treatment would be a targeted drug that just goes after the unique mutation in—or a protein marker on—an individual person's cancer cells while having minimal if any effects on healthy cells. This approach is the ultimate in precision medicine as even tumors that look identical under the microscope rarely respond the same to standard chemotherapy."

Precision medicine is an important component of pediatric cancer care now and in the future, and the institute is establishing a phase I experimental therapeutics program so that more cutting-edge treatments like ALK-mutation targeting are available to patients right here in the Tampa Bay area.

Personalized treatments like this are at the forefront of care for kids like Anthony, whose gleeful laughter is reason for hope.



# Ending the Year Well

The end of the year is fast approaching and with it so is your opportunity to reduce your taxes



## Six Tax-Saving Solutions for the Year End

With planning, you can trim your tax bill and avoid paying too much. Here are six things you can do to make your money work harder for you.

1. **Pay your Mortgage Early** – Make your January mortgage payment in December.
2. **Defer Income** – Defer income or a year-end bonus until next year.
3. **Give to Charity** – Give to your favorite qualified charity, like Johns Hopkins All Children's Hospital.
4. **Manage Your IRA** – If you are required to take a distribution from your IRA, take only the required amount to reduce taxable income.
5. **Balance Stocks** – To offset any capital gains, sell some stock for a loss and rebalance your portfolio.
6. **Gather Deductions** – Make early payments for any deductible expenses.

## Tax-Wise Charitable Planning Strategies

There are a number of charitable planning strategies that can help you lower your income and taxes this year. Here are some ways you can shift tax dollars to charitable dollars and support our cause.

- **IRA Charitable Rollover** – Persons age 70 ½ or older can rollover up to \$100,000 from their IRA to a qualified charity like Johns Hopkins All Children's. This can lower your income and taxes.
- **Outright Gift of an Asset** – Make a gift of stock, real estate or another asset, avoid paying capital gains tax on the transfer and receive a tax-saving charitable deduction
- **Donor Advised Fund (DAF)** – Make a tax deductible gift to a DAF, which gives you the ability to make grants to your favorite charities this year and in future years,
- **Zero-Tax Gift and Sale** – Make a gift of an investment or property you intend to sell, avoid paying capital gains tax on the sale, and receive cash back.

## May We Help?

If you would like further information on any of these end-of-year planning strategies, please contact us. We can help you create a plan that meets your needs and goals. Contact All Children's Hospital Foundation at 727-767-8914 to get started.

## Here are some of the requirements for making an IRA rollover gift this year:

You must transfer money directly from your IRA to a qualified charity.

You must be 70 ½ or older.

You can give annually up to \$100,000 from your IRA.

Tune in and tell your friends about the 9th Annual US 103.5 Cares for Kids Radiothon on Thursday, December 1 and Friday, December 2 from 6 a.m. to 7 p.m. All proceeds benefit Johns Hopkins All Children's Hospital through Children's Miracle Network Hospitals.

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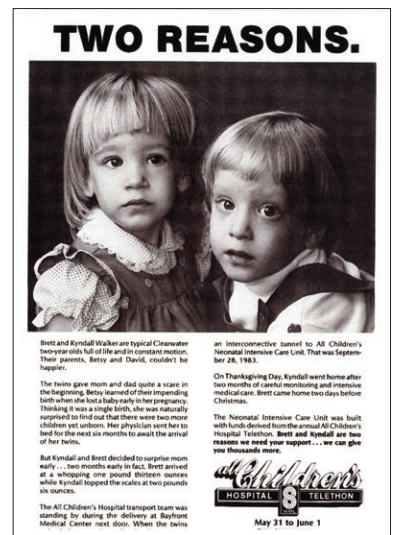
He was diagnosed with necrotizing enterocolitis (NEC), a serious disease where bacteria invades the wall of the intestine and causes local infection and inflammation that can ultimately destroy the wall of the bowel. Brett's care team took immediate action and replaced his feeding tubes with an IV containing an antibiotic and another IV with a new type of nutritional solution. Betsy later learned that the solution was developed through pediatric research specifically to treat NEC. He recovered 100 percent.

Betsy and David feel passionate about the role Johns Hopkins All Children's clinical and research expertise played in helping their children. "Research and medical advancements saved my babies' lives. That's what this is all about. Research takes money. Our family believes that if we can spare just one other family from experiencing the loss of a baby, we'll do what's needed."

Since this experience, the Walkers have been devoted advocates and supporters of Johns Hopkins All Children's Hospital. Brett and Kyndall participated in and were the poster-children for the hospital's annual telethon broadcast through Children's Miracle Network Hospitals. Betsy, David and the whole family also hosted an annual fundraising auction in their home for 16 years, with all proceeds benefiting the hospital. Today, they continue to give back as Dream Builders by including Johns Hopkins All Children's in their will.

Betsy reflects with sincerest gratitude, "I woke up that morning 33 years ago not knowing what adventure that day had in store for us. I didn't know that we would need a place like Johns Hopkins All Children's, but thank goodness it was there. Johns Hopkins All Children's didn't just give our kids a chance to live, they gave us a chance to be the family we are today."

There are many ways for you to become Dream Builders like Betsy and David Walker. Contact All Children's Hospital Foundation to get started.



Kyndall and Brett at age two on the All Children's Hospital Telethon poster.

*If we can help you find ways to lower your taxes and leave a gift in your will, please give me a call today.*



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