



What do the Kentucky Derby, Lilly Pulitzer® and MitoAction all have in common?

The answer is Sandra K Russell.

Sandra Keery was 5 when, in 1961, Jacqueline Kennedy appeared in Life Magazine wearing a Lilly Pulitzer® shift. Jackie summered on the Cape. Sandra summered on the Cape. It was all the connection a little girl needed to inform her fashion sense. For young Sandra, a clothing devotee in general, an affinity for the fun, carefree, preppy look of Lilly Pulitzer® was born. Fast-forward to 1997, when, with her husband, businessman Gordon Russell, the grown-up Sandra Russell opened the first in the nation Lilly Pulitzer® Signature Store. The shop, fittingly enough, is located on Nantucket, where the Russells had a second home. The Russells chose the name *In the Pink* for their store and then set out to expand to nine seaside locations from Cape Cod to the coast of Maine.

In the Pink was squarely in the black, and life was going swimmingly for the Russells, who were raising their two sons, Buck and Jonathan, and tending to their growing business. Then, in 2003, Sandra started complaining that she couldn't hear her customers well enough during busy moments in the store. Her husband was also noting that "she wasn't keeping up as well, lacking energy and also focus." Some years before, doctors uncovered in Sandra what Russell called a "leaky kidney -- protein in her urine," which was kept under control with medication. No connection to mitochondrial disease was yet made.

All still seemed normal enough when, in October 2004, Sandra suffered her first seizure and stroke, a full-blown affair during which she lost consciousness and that left her having a bit of trouble communicating. Her sons at the time were both freshmen -- one in college, one in high school. Sandra spent 17 days in Brigham and Women's Hospital but no apparent cause was found. Several months later she was diagnosed with mitochondrial encephalopathy with lactic acidosis and stroke-like symptoms, or MELAS. It's one of 43 types of mitochondrial disease that have so far been classified, all falling under the umbrella of muscular dystrophy and together striking more commonly than cystic fibrosis. The mitochondria are the energy powerhouses of all the body's cells, and when they malfunction, the body doesn't work properly. In Sandra's case, her brain wasn't getting the energy it needed to thrive and, as Russell put it, "It was short-circuiting." In hindsight, he had seen signs. "A hallmark of mitochondrial disorder is exercise intolerance and temperature intolerance," he explained. "When we were dating, she had to quit after a couple of games of tennis -- even when she was beating me. I remember looking at her face -- it was all flushed and red. This was back in 1983. In 1987, I remember her pushing Buck in a baby carriage through some sand on a hot day. She stopped and said, 'I think I'm having a heart attack.' Again her face was flushed. It was transitory but those were symptoms. On some level, she was fighting this for her entire life.

"As far as the diagnosis, we were fortunate to get it as soon as we did," Russell said. "Some people go years. It may sound odd, but even a horrible, life-ending diagnosis is better than not knowing." At first, Russell said, "I was wildly searching for a cure. That's what you do when faced with something like this. I was up all night surfing the Internet. Then it dawned on me that I was wasting my time because there wasn't going to be anything I could do to save Sandra. So I focused on managing her quality of life to the best degree possible," which included shuttering the doors on a couple of *In the Pink* shops to

spend more time with his wife. Their locations shrunk from nine to six. “Other people have their golden years,” Russell said. “I refer to that period as Sandra's *golden months*.”

Much of the help came from **MitoAction**, a Boston-based organization whose mission is to improve the quality of life for people with mitochondrial disease through support, education, advocacy, and outreach initiatives. “The impetus behind starting MitoAction,” says Executive Director Cristy Balcells, herself the mother of a 7-year-old daughter with mitochondrial disease, “was that there was no resource, no organization providing the day-to-day support patients and their families need.” MitoAction's network of patients and their loved ones currently spans the United States, Australia, the United Kingdom, and Canada.

Support couldn't halt the course of the disease, however, and with each seizure, which would come after a quiet plateau period, Sandra's brain function deteriorated a bit more, from an estimated 97 percent after the first episode to 84 percent after the second, 73 percent after the third, and so on. Sandra succumbed to the disease on August 6, 2008, at age 52, a few months after Buck graduated from college and Jonathan from high school. She was able to attend both her boys' graduation ceremonies. In both her business and personal life Sandra was supremely driven and goal-oriented. Not only did she travel to North Carolina to take part in all the festivities surrounding Buck's graduation, she planned, prepared, and hosted a graduation dinner for her “baby.”

Jonathan, at their home in Wellesley. Weeks later she entered the hospital for the last time. As Russell says, “Sandra's boys were her life; she put her heart and soul into raising them to be great young men. She knew she had accomplished her most important goal.”

It wasn't long after that Balcells asked Russell to be on MitoAction's board of directors. She had gotten to know him and his wife well, often visiting when Sandra was in the hospital.

After hearing stories about how Sandra loved to celebrate the arrival of spring by hosting annual parties at their home on Kentucky Derby Day, MitoAction decided to use this as inspiration to create an annual fundraising event. And so the Sandra K Russell Derby Day Benefit for Mito was launched in 2010 in honor of Sandra. Simultaneously, Gordon mentioned to Janie Schoenborn, whom he calls “the big mucky-muck for design” at Lilly Pulitzer®, that “any time I see images depicting a mitochondrion or the human genome, I'm struck by the color and shape of these things that I'm looking at. They remind me of Lilly prints.” Schoenborn asked him to show her what he meant, so he sent her about a dozen images of mitochondrial cells and human genome components. Schoenborn and her design team got to work and a beautiful Lilly Pulitzer® silk blend “Mito Murfee” scarf of hot reds, deep blue, tropical greens, and pale pink was born. A depiction of mitochondria appears in the red flowers (and, true to Lilly, you have to be “in the know” to recognize it), while the green ribbons of color represent the awareness icon for mitochondrial disease. The human genome is in there, too.

The limited-edition scarf was launched at the 2010 SKR Derby Day Benefit and became available at all *In the Pink* locations and on inthepinkonline.com. All net profits of each \$118 scarf support MitoAction.

At the 2011 SKR Derby Day Benefit for Mito at Mandarin Oriental, Boston, Lilly Pulitzer® will debut its new Mito Tote. Once again all net proceeds will benefit MitoAction and the tote will be available at all *In the Pink* locations and inthepinkonline.com.

Talk about fashion forward. Sandra would have liked that.



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