

Press Kit

"If you want to be inspired, simply turn the page."

SANJAY GUPTA MD
CNN MEDICAL CORRESPONDENT



The Reluctant Donor

BY SUZANNE F. RUFF

Press Release

FOR IMMEDIATE RELEASE

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Eden Prairie Woman on a Mission to Spread the Word About the Importance of Organ Donation

(Eden Prairie, Minn.) – The last time you renewed your driver’s license, did you check the box that says “Organ Donor?” Suzanne Ruff of Eden Prairie, Minn., hopes the answer is yes.



“My family would have pretty much been wiped off the face of the Earth if it weren’t for the generosity of organ donors,” she said. Her mother and two sisters, as well as several aunts and uncles and cousins have all needed kidney transplants to save their lives. Her family carries the gene for Polycystic Kidney Disease (PKD), a hereditary disease for which there is no cure.

Those who inherit PKD develop fluid-filled cysts on both kidneys. Over time, these cysts grow and multiply, causing the kidneys to increase sometimes dramatically in size. More than 60 percent of people with PKD will develop kidney failure and be forced to depend on dialysis or a transplant to live.

Ruff’s mother and sister, Janice, received their transplants from strangers. When her other sister collapsed in renal failure, something she cannot explain stirred deep within her. Ruff was the only one of the sisters who was not sick. “Right after learning that JoAnn had collapsed and was in the hospital, I called her up and offered to donate one of my kidneys,” said Ruff.

During the 10 months that lapsed between the day she made the offer and the day of the surgery, Ruff considered backing out several times. She kept her emotions in check through prayer and by journaling, eventually going through with the surgery on Oct. 19, 2004.

More than five years later, both women are doing great, and celebrating the publication of Suzanne’s book about their journey. A portion of the proceeds from *The Reluctant Donor* (Beaver’s Pond Press, April 2010, \$14.95) will go towards kidney disease research.

“This story is not so much about me as it is about my mother and her siblings, who taught my sisters and me how to handle this disease. I want anyone who is diagnosed with PKD now to know what it was like, to see how much progress has been made and to have hope,” said Ruff.

Dave Kappas, central regional chapter manager for the PKD Foundation, an organization that promotes programs of research, advocacy, education, support and awareness about PKD, says

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Ruff's book is a wonderful resource for everyone affected by PKD. "I think one of the things that has helped Suzanne's entire family is that they have been proactive, doing advocacy, research, participating in the Transplant Games and volunteering. Even though right now there is not a treatment or cure, it's important for people affected by PKD to follow their example. They should get involved and do what they can to promote research."

Ruff's sister, JoAnn, wants people to know how deeply touched she has been by the selfless act that saved her life. "In the morning as I take my pills I drink my water and say, 'This one is for Suzi,' the name of my kidney, then I say 'This one is for me. Now go do your work because I promised Suzanne I would take good, good, good care of you because you're taking good care of me.'"

The Reluctant Donor (Beaver's Pond Press, April 2010, \$14.95) is available for purchase at Barnes and Noble, Borders, Amazon.com and at select independent bookstores. The book can also be purchased through the publisher's website: www.beaverspondbooks.com and at www.TheReluctantDonor.com

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About the Author

SUZANNE RUFF

On the day she found out her younger sister had been stricken by the same disease that had taken the life of their mother, Suzanne Ruff of Eden Prairie, Minn., offered to donate one of her kidneys to save her sister's life.

During the 10 months that passed between the day that offer was made and the actual surgery, she considered backing out several times, but eventually went through with the surgery. More than five years later, both she and her sister, JoAnn, are doing great.



Suzanne Ruff and her husband, Bill, live in Eden Prairie, Minn. They have two daughters, Rachel and Colette.

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For more information or to purchase copies, visit www.TheReluctantDonor.com

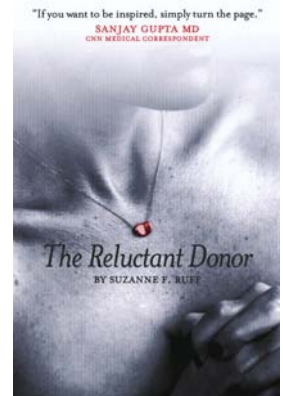
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Praise for the Book

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Praise for...
The Reluctant Donor
By Suzanne Ruff



“As soon as I started reading *The Reluctant Donor* I knew I had found a special book that would restore my faith in my belief about the goodness of everyday people. This book is a 60-year long epic journey of triumphs and tragedies of a beautiful and inspiring family. Even more than that, though, it is a story of unbridled love one sister had for another, and how that love was tested. If you want to be inspired, simply turn the page.”

— Sanjay Gupta, MD, CNN Medical Correspondent

“Suzanne Ruff may have given one of her kidneys to her sister, but she’s poured her heart and soul into this book. It’s a compelling story of the struggle between fear and faith, with love casting the deciding vote.”

— John DeDakis, Author, *Fast Track*

“*The Reluctant Donor* is the story of a ticking time bomb in one family’s DNA, a generations-long battle with kidney disease. With heart and humor, Suzanne shares her family’s trials and triumphs, and challenges us all to think deeply about what is most important in our lives. This wonderful book is a testament to the gift of organ donation and its power to transform the donor as well as the recipient.”

— Jeff Richert, Volunteer Coordinator, LifeSource

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About the Author

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About Suzanne Ruff

Suzanne Ruff of Eden Prairie, Minn., comes from a family that has been plagued by kidney disease for generations. In her lifetime, she has lost her mother, several aunts and uncles and cousins to Polycystic Kidney Disease (PKD), the most common of all life-threatening genetic diseases. Both of her sisters inherited the disease. She did not.



When her younger sister fell ill shortly after their mother's death in 2003, Ruff decided to do something about it. She had always been afraid of doctors and needles, but says with God's help she found the courage to save JoAnn's life by donating a kidney.

In the months leading up to the surgery, which took place on Oct. 19, 2004, Ruff spent a lot of time journaling, and just recently published a book based on her notes and memories. Her hope is that *The Reluctant Donor* (Beaver's Pond Press, April 2010, \$14.95) will find its way into the hands of others who are facing a difficult life-and-death decision, and help them find the courage they need to get through it.

Her family has been active with the Polycystic Kidney Disease Foundation since its founding days in 1982. The PKD Foundation is a source of information for newly diagnosed patients with PKD and helps fund research to find a cure.

Suzanne is also a volunteer and speaker for LifeSource, the non-profit organization dedicated to saving lives through organ and tissue donation in the Upper Midwest, and a volunteer for the National Kidney Association (NKF). She was just appointed to the Living Donor Council Executive Committee. Suzanne will be a living donor athlete at the National Kidney Foundation Transplant Games to be held July 30 – Aug. 4, 2010, in Madison, Wisc.

Suzanne Ruff and her husband, Bill, live in Eden Prairie, Minn. They have two daughters, Rachel and Colette.

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Suggested Questions

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Ask Suzanne Ruff Author, *The Reluctant Donor*



1. What is PKD and how prevalent is it?
2. The title is “The Reluctant Donor.” Why were you reluctant?
3. I understand you’re the only one in your immediate family who didn’t inherit the disease. How does that make you feel?
4. How is your sister doing now?
5. Now that the book is out, what are you hoping it will accomplish?

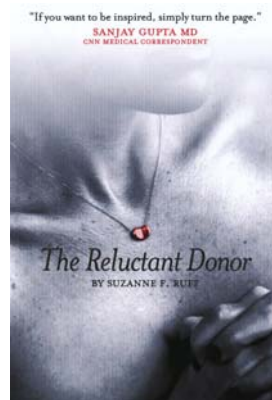
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Eden Prairie Woman on a Mission to Find a Cure for the Disease that Has Devastated Her Family

EDITOR'S NOTE: This article and the accompanying photographs are being offered to you copyright free and cost free. High resolution versions of the images are available upon request. – Rachel M. Anderson



CAPTION #1: *The Reluctant Donor*, written by Life Source volunteer Suzanne Ruff, is the story of her family's journey to find a cure for PKD, a devastating genetic disease.
CAPTION #2 Suzanne Ruff is a living donor who saved her sister's life with the gift of a kidney.

(Eden Prairie) - There are a lot of causes worth fighting for, but none as important to Suzanne Ruff of Eden Prairie, Minn., than finding a cure for PKD. "I have lost eight close family members, including my mother, to Polycystic Kidney Disease," she says.

(MORE)

PKD, the most common of all life-threatening genetic diseases, is a condition in which fluid-filled cysts develop on both kidneys. Over time, the cysts grow and multiply, causing the kidneys to increase dramatically in size.

According to statistics posted on the PKD Foundation's website (www.pkdcure.org), more than 60 percent of people with PKD will develop kidney failure and be forced to depend on dialysis or a transplant to survive. An estimated 600,000 Americans and 12.5 million newborns, children and adults worldwide are currently battling the disease. PKD affects more people than Down syndrome, cystic fibrosis, muscular dystrophy, sickle cell anemia and Huntington's disease combined. There is no treatment. There is no cure.

Ruff says her earliest memory of PKD is from when she was about 5-years-old. "I remember my mother being sad when she told me that my grandmother had died of kidney disease and I was named after her," she says.

There wasn't much talk about the disease again until she was about 12 and her mother's beloved sister, the nun Sister Mike, was diagnosed. Then when she was 19, her mother's brother, Jack, fell ill. "It was at that point that we learned the disease was hereditary, and I remember being terrified," she says. "I was engaged and didn't know if my husband would marry me, didn't know if I should have children, didn't know if I was going to have a short life."

Shortly after learning the disease was hereditary, Ruff, her mother and two sisters were all tested. She says her parents lied when they got the test results back and told their daughters no one in their immediate family had the disease, when in fact, their mother and her two sisters did.

"The lie," as Ruff refers to it became apparent a few years later when her mother collapsed and entered the hospital. She spent the next 10-years on dialysis before getting a kidney transplant. The same fate awaited her two sisters – first Janice and then JoAnn.

Ruff's mother and sister, Janice, had received their kidney transplants from strangers who had died, but by the time Jo Ann got sick, living donation had become more prevalent. "After JoAnn collapsed with PKD my daughter, Colette, who was 25-years-old at the time, quietly said to me that maybe she could give JoAnn a kidney. I thought, no! I should be the one to step up before my daughter. She has her whole life ahead of her."

Also weighing heavily on her decision, the knowledge that in 2003 there was a five to six year wait for JoAnn if she put her name on the waiting list. "Our mother was on dialysis for ten years and I couldn't bear JoAnn going through that if I was a match, despite my fears," says Ruff. But shortly after making the offer, she started having reservations. "I was scared to death of being operated on," she remembers.

Journaling was one of the key ways Ruff was able to work through the terror she felt about being a living donor. Soon, page after page of thoughts and memories filled her notebook. Ruff originally thought her journal would be something she'd only share with her immediate family. However, after showing it to her daughter, Rachel, who was working as a producer for CNN's Dr.

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Sanjay Gupta, at the time, that changed.

“She told me the story was really good and I should publish it. My husband told me the same thing and around that same time, my father came across a collection of letters I had written to my mom when she was alive,” says Ruff. In one of the letters, she had said to her mom, “I wish I had the courage you do.”

“It had been 20 years almost to the day of our scheduled transplant that I wrote ‘I wish I had the courage you do.’ I considered it a God Wink,” says Ruff, who explains a God Wink as a wonder, a coincidence, a miracle.

“I felt like I was being called to give the kidney,” she says. “But when I got that sign from above from my mother, it was like, Wow! This is really going to be an amazing legacy of my mother and her amazing siblings. I have to get this book published.”

The Reluctant Donor, (Beaver’s Pond Press, April 2010, \$14.95) was published just in time for Donate Life Month. Established in 2003, it’s a celebration of the tremendous generosity of those who have saved lives by becoming organ, tissue, marrow and blood donors. It’s also a time to encourage more Americans to follow their fine example.

“One of the best things about Suzanne’s book is it lets people suffering from PKD know they are not alone. There are options for dealing with it. They can be proactive researching and looking into what’s out there.

“I think *The Reluctant Donor* will do wonders for people just diagnosed, letting them know there is an entire community dealing with it and they are not alone,” says Dave Kappas, central regional chapter manager for the PKD Foundation. His organization’s mission is to promote programs of research, advocacy, education, support and awareness in order to discover treatments and a hopefully a cure for Polycystic Kidney Disease.

“I hope Suzanne’s book will help people think about becoming a living donor by showing them that their lives will be the same as they were before, only enriched by the experience. I also hope it will bring awareness to this disease that my family has lived with for so long,” says Ruff’s sister, JoAnn Villanueva, who now lives in Charlotte, N.C.

Copies of *The Reluctant Donor* are available for purchase at Barnes and Noble Bookstores, Amazon.com, the publisher’s website: www.beaverspondbooks.com and via the author’s website: www.TheReluctantDonor.com. A portion of the proceeds will fund kidney disease research.

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About Rachel M. Anderson

Rachel is a freelance writer who lives in Minnetonka, Minn. She has written professionally for the Minneapolis Star Tribune, Minnesota Christian Journal and Tampa Tribune newspapers.