

If you met Sheila Simpson, (aka Lady-Bug), from Hendersonville, Tennessee, you would never know from her witty personality that she is suffering from the devastating effects of Primary Hyperoxaluria (PH).

To know Sheila, is to know a strong, joyful, positive and enthusiastic woman, whose spirit shines through her every word. Sheila has been given the gift of gab and can instantly put you at ease. When you are done speaking to Sheila, you are confident that no matter what life throws at you, everything will be okay.

Sheila was 4 years old when she had her first kidney stone, 7 when she had her second and then on her 12<sup>th</sup> birthday, while out of town with her family, Sheila experienced the most excruciating, unbearable pain of them all. Sheila said, "I will never forget the frightful, helpless look on my dad's face as he carried me from emergency room to emergency room, begging for someone to help." Eventually her dad found a doctor who dispensed pain medication and flew her home to a local hospital that same day.

Sheila recalls Dr. Furman, the urologist, putting her at ease by drawing a picture of her kidneys and bladder on one of her gift boxes and explaining what was about to happen. Sheila had surgery to remove a large kidney stone, but was left with a scar completely across her stomach. Sheila recovered quickly and was able to get back to all the friends and fun of a 12 year old. Fortunately for Sheila, until she turned 40 she suffered only minor symptoms by maintaining a regimen of drinking large amounts of water daily. Unfortunately, the next three years were filled with severe bladder/kidney infections.

Just two weeks after she was married and three hours after the birth of her first grandson Jaxon, Sheila became very ill. Sheila was actually at a small, rural East Tennessee hospital visiting the new baby when it all hit her. Sheila's blood pressure plummeted, hospital staff rushed to help her. Sheila said to her daughter Emily, "I think God is taking me today to make room for my new grandchild, I am so sick, this can't be happening to me."

The next 6 weeks were spent in the hospital with family by her side. Although terrified, Sheila made the decision that she was not going to give up hope. After exhausting the small hospital's resources, the doctors arranged to transport Sheila by ambulance 200 miles to Centennial Hospital, a much larger facility in Nashville. Luckily for Sheila, a nephrologist there suspected that she was suffering from PH and quickly referred her to the OHF funded, Mayo Clinic Hyperoxaluria Center.

Once she arrived at Mayo, Dr. Monico's team performed a liver biopsy and sent it to a lab in London for review. Sheila said, "My husband was so supportive and never made me feel like a burden, he vowed to get me well no matter what it took." The liver biopsy confirmed what the doctor in Nashville had thought. Sheila was diagnosed with PH Type 1 and was told that she

would eventually need a kidney-liver transplant. Trying to remain positive, Sheila began to appreciate life one day at a time to help get her through the devastating reality that she was eventually going to need a double organ transplant.

Over the next 2 years Sheila spent many days and nights in her local emergency room and hospital. Adding insult to injury, Sheila was also diagnosed with severe fibromyalgia, a neuromuscular condition which leaves her in near-constant pain and takes a big toll on her energy levels. Sheila bounced around from doctor to doctor trying to persuade her local physicians to take her complicated case to no avail. Finally, the physical effects of PH took their toll and Sheila was declared disabled.

In November 2008, Sheila met Dr. Sundar Venkatesh, a physician close to home who agreed to consult with the team at the OHF Funded, Mayo Clinic Hyperoxaluria Center. This was reassuring for Sheila as she required constant monitoring and frequent medical visits.

Unfortunately, Dr. Venkatesh had to deliver the crushing words to Sheila that she needed to start dialysis. Due to Sheila's other medical complications, she has been unable to be listed on a transplant list. However, Sheila remains positive, knowing that without dialysis, she would not be alive today, saying "Finally I have at least found a doctor in my home state who cares about me and who refuses to give up."

Sheila says, "Dialysis takes adjusting, there are ups and downs but I am working to get through it." Being the social butterfly that she is, Sheila has chosen to bring her life to dialysis and not let dialysis isolate her. Through her journey with PH, Sheila has learned to appreciate every moment on earth, every breath she takes, every scent she smells and every embrace of her grandchildren, stating, "PH has made me a better person because everything has more value to me."

What Sheila does enjoy these days are the same things she enjoyed before. She fills her time with a house full of family and home cooking. She is enjoying her two grandchildren who love their Nana dearly, Jaxon - 3, and Natily - 1.

Sheila has many favorites, her favorite book is the Bible, favorite movie, "*It's a Wonderful Life*," and she is a huge Alan Jackson fan. Sheila's favorite holiday is Christmas which begins in her home on the first of November. She even decorated her hospital room last Christmas with a hot pink tree. Sheila hopes to someday be able to return to her work at the famous Dollywood. Her gift of gab came in real handy with all the guests, as she has "never met a stranger. "

What Sheila would like the PH community to know is how thankful she is for Kim Hollander, Executive Director of the OHF and the OHF funded, Mayo Clinic Hyperoxaluria Center. Without the OHF, Dr's Milliner and Monico and their team, Sheila knows that her quality of life would

not be as good as it is. She is grateful that the OHF has put a face to the names of so many patients from around the world.

Sheila would like to remind all patients and families to register on line at [www.ohf.org](http://www.ohf.org) and participate on OHF talk; it will give you hope, support and love when you need it the most. Sheila is a member of the newly developed OHF Patient Advisory Board (PAB); she even volunteered to be the president. The PAB thanks her and feels lucky to have her as a member. Sheila's goal is the same as the PAB; continue to do all she can to make the world aware of PH and to find a cure.

Sheila's husband Don (aka Butter Bean) said, "I am amazed at my wife, she is a tower of strength and encouragement to others, no matter how she feels, she is truly an amazing woman." He is hopeful with all of the medical research being funded by the OHF that the cure is on the horizon. Sheila would like to thank her family for being there for her always, without them she wouldn't have made it this far.

You may reach out to Sheila via OHF talk. Sheila hopes that hearing her journey will inspire all to support the OHF, as it remains the ONLY foundation in the world dedicated to finding a cure for PH.