

Angels at Bethesda

Angel Flight.

CHARITABLE MEDICAL AIR TRANSPORTATION SERVING
PATIENTS OF THE NATIONAL INSTITUTES OF HEALTH

Angel Flight 'A Godsend' for Lupus Patient



Larry has come far since his first, nearly fatal attack of lupus. The picture was taken in August 2007 in Washington, D.C. at Larry's brother's wedding. He poses here with Cindy and Ryland.

No one knows how the word "lupus," meaning "wolf," came to be associated with the disease, but there is no doubt as to its ravaging effects on the body.

Larry N. knows that only too well.

He and his wife Cindy ran a thriving plumbing business from

their home in La Plata, Maryland. They were also new parents. Ryland, their son, was two months old. This was in 1999.

Not Flu but Lupus

When Larry, who ordinarily enjoyed perfect health, developed flu-like symptoms at age 32, doctors treated him with antibiotics. But his 104 degree fever continued.

Finally, his doctor diagnosed systemic lupus. With lupus, the immune system mistakenly attacks healthy cells and tissues.

Unfortunately, the doctor prescribed the wrong medicine and Larry's condition worsened.

"I had to carry him to the bathroom," Cindy said. "Lupus affects you head to toe. His joints ached terribly. We didn't realize the severity of his illness."

Doctors Recommend NIH

With his fever still raging three weeks later, Larry was admitted to Civista Hospital. Doctors there said his blood pressure was so high they feared he'd have a stroke and recommended he go to NIH.

Cindy went home and looked up the number, then had the good fortune of speaking with one of the world's leading nephrologists, Dr. James E. Balow, who told her it was "a miracle that I even answered the phone."

Wrong Medications

After receiving a faxed report of Larry's blood work, Dr. Balow said to bring him immediately to NIH and to refuse all medications since he was getting the wrong ones. He told her Larry was dying.

Returning to Civista, Cindy signed papers for her husband's release and insisted on driving him to Bethesda, nearly two hours away, despite a nurse's prediction that he wouldn't survive the trip.

'Raw Hamburger'

On arrival, Larry was stabilized, then admitted to intensive care. Diagnostic tests revealed extensive damage to his left lung which "looked like raw hamburger," Cindy said. Surgery was scheduled, but doctors said they doubted Larry would survive even two more days. (See 'Angel Flight' on page 2)



Spring Evokes Thoughts of Caring, Sharing



Ed Boyer

The beauty of spring comes in many forms. It comes from God's creation, it comes from the hearts of caring people, and it comes with every sincere "thank you" or "bless you" comment.

2008 is a milestone year, for it marks the 25th anniversary of an important piece of legislation, the Orphan Drug Act, signed into law by President Reagan in 1983. That same year the National Organization for Rare Disorders (NORD) was founded by patients and families who had worked together to pass the Orphan Drug Act.

NORD reports that since its founding, over 1,100 treatments for rare diseases have been placed on track for research, with 300 more approved by the U.S. Food and Drug Administration for marketing.

That's significant progress, but there is still a long way to go in finding cures for over 6,000 rare diseases that affect patients like Larry described in the cover story—real people with great courage in the face of horrendous struggles.

You can read some of their stories in a new book, *Angel Flight Mid-Atlantic*, by Suzanne Rhodes (Arcadia Publishing). Suzanne is Angel Flight's director of public affairs. Her book gives the air charity's history, beginning in the early 1970s and continuing today with a volunteer force of over 1,500 private pilots and a record of serving thousands of patients with medical and financial needs.

Angel Flight wishes all a beautiful time of rejoicing and sharing love with others. This is what life should be about—whether in the clinic or flying at 10,000 feet.

Ed Boyer serves on the NORD board of directors and is the CEO and President of Angel Flight/Mercy Medical Airlift.

Angel Flight (Cont. from page 1)

'We've Done All We Can'

He made it through the 12-hour surgery to remove the lung, but had to be placed on life support. In the days following, Larry spiked fevers and underwent transfusions. When his right lung started to collapse, doctors told Cindy, "We've done all we can do."

Cindy headed to the chapel and prayed fervently for her husband. Forty-five minutes later, doctors said, "There is one thing we can try, though he could die."

The procedure is plasmapheresis. It involves exchanging a patient's blood plasma with a replacement solution. After four days of this blood cleansing, Larry began to improve and finally woke up from a coma. He went into rehab "and had to learn to walk and eat all over again," Cindy said.

On April 5, 2000, after spending nearly four months at NIH, he was well enough to go home, where he continued to improve.

Secret of Strength

The family moved to Hendersonville, North Carolina, in 2006. Larry takes Angel Flights to NIH for regular check-ups. Currently, he is traveling there every three months to be treated by Dr. Gabor Illei, head of the Sjogren's Clinic of NIDCR. Dr. Illei's research includes clinical studies in systemic autoimmune diseases such as lupus.

"Angel Flight has been a godsend. Every pilot has been phenomenal," Cindy said.

When asked, "What is the secret of your strength that enables you to keep fighting?" Larry replied, "Cindy and Ryland. I want to see our son grow up."

Angels at Bethesda is published tri-annually by Mercy Medical Airlift. Editor is Suzanne Rhodes. Contact Marita Eddy at the NIH Office of Rare Diseases, 6100 Executive Blvd., Suite 3B01, MSC 7518, Bethesda, MD 20892. Ph.: 301-451-9646 Fax: 301-480-0269

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