

For the love of butterflies

An interview with Luz Manso, the 2004 iKidney.com essay winner

LORI HARTWELL

Ms. Hartwell is president of Hartwell Communications and the Renal Support Network. She is also author of the book Chronically Happy—Joyful Living in Spite of Chronic Illness.

Every year, I get the distinct pleasure of spending time with iKidney.com's first place essay winner. Luz Manso, from New Haven, Conn., joins a group of talented essay winners. The theme this year was "Tough times—A memory or dream that gets me through." Her winning essay, entitled "A Memory of Butterfly Wings," will inspire you to cherish the simple things in life and reflect on the everyday beauty around us. You can read her essay at www.ikidney.com/iKidney/Community/JustForFun/Boutique/LuzManso.htm

As the winner of the 3rd annual essay contest sponsored by iKidney.com and Watson Pharma, Luz won an all-expense-paid trip for two to the Renal Support Network's inaugural national patient meeting held in Denver, Colo. last September.

Luz has an incredible capacity to light up a room when she enters. Her spunky spirit coupled with her love of telling stories made her an absolute delight to be with. Her love of butterflies is obvious; you will find them displayed in her hair clips and necklaces, and I learned she has an extensive collection at home. With a video camera in tow, Luz and her fiancée Carlos documented every moment of the trip to the conference. From the airport limousine ride to the decorative meals served at dinner, it was apparent they did not want to forget one moment of this memorable trip.

Luz is a veteran when it comes to dealing with adversity. At age 15, she was diagnosed with glomerulonephritis, and at the age of 21 she started hemodialysis. Shortly after that, she received a kidney transplant that lasted for three and a half years. After another year of dialysis, she received a second kidney transplant that lasted for 12 years.

During this time she adopted a two-week-old baby, Robert Lewis, who is now a rambunctious eight-year-old. Her second transplant failed in 2001, and she remains on hemodialysis today waiting for a third kidney transplant. She considers herself very lucky to have Carlos and her son to help weather the rocky storms when she has health challenges. In addition to her butterflies, they also serve as her inspiration.

iKidney.com: What emotions did you feel when you learned you had won the essay contest?

Luz Manso: I was sitting at a Chinese restaurant with my son and Carlos, and my cell phone rang. Once I learned I had

won the contest, I screamed. I dropped the phone and got disconnected. Everyone in the restaurant looked at me.

iKidney.com: Is this the first time you have been recognized for your writing?

Manso: Yes, I couldn't believe it because after I entered the contest, I forgot about it. I was amazed that something I wrote could actually touch someone, not to mention win a contest!

iKidney.com: When did you start writing and why?

Manso: I started writing at the age of 14. I was shy and often kept to myself. Writing allowed me to release my feelings. Sometimes I write poetry, other times I write about the thoughts of the day.

iKidney.com: Was the dialysis staff at your facility excited to learn you won the essay contest?

Manso: The dialysis staff was surprised and excited to learn the news. Some told me they didn't realize I wrote. My doctors and fellow patients told me they were very proud of me. They teased me about being a celebrity after the local news station did a segment about how I won the contest.

iKidney.com: What were some of your most memorable moments at the Renal Support Network conference?

Manso: The most memorable moments were meeting so many renal patients who were a big source of inspiration for me. One in particular was John Newmann. He taught me that I can live a long time on dialysis without a third transplant and his perseverance and his attitude towards life gave me faith and hope.

iKidney.com: What were some of the most useful things you learned at the conference?

Manso: There were so many things I learned, and all were very useful. I particularly loved the patient panel. They told their stories and answered questions from the audience. It was interesting to see how people with the same situation managed and dealt with their illness. I also learned a lot from Dr. Geoffrey Block, who spoke about phosphorus control. He helped me understand why it's so important to control my phosphorus and the new medications available to help me reach that goal.

The "Be Your Own Expert" roundtable luncheon with Dr. Paul Sakiewicz proved to be life saving. I had the opportunity to ask all the questions I needed answered by a nephrologist.



One of the questions was concerning my fistula. He told me I needed to see a vascular surgeon right away and to be careful. I took his advice. Upon my return to my clinic, my nephrologist made an appointment for the following week. The day before the appointment, I had a burst in my access and had to call the paramedics. Since attending this educational conference I have been more watchful of my access and now know what to do in case of an emergency.

iKidney.com: Do you plan on writing more short stories?

Manso: Writing has always been a part of me. I don't think I would have been able to go through so much without it. There have been times when the pain inside me was so great, I couldn't share it with anyone. Paper holds so much pain. I have filled many notebooks with tears and joy. Through writing I have found a release for my spirit. I will continue writing about the good and the not-so-happy moments in my life.



Luz Manso (l) with fiancée Carlos.

iKidney.com: What are your plans for the future?

Manso: I am planning to go back to college to finish my Bachelor's degree in Library Science. I will have a small wedding and marry the man of my dreams, and continue to be the best mom I can be.

iKidney.com: What is your dream for the future?

Manso: My dream is to see my writings published and hope that they can touch and inspire many people.

iKidney.com: In addition to your

winning essay, what else would you like to tell fellow patients who are reading this interview?

Manso: That life for renal patients can be very difficult, nonetheless it is a life. Life is a gift given to us to enjoy

and live to the fullest. On days when it seems too hard to bear, know that the pain won't last. If you hold on for just a little bit, the sun will shine. Seek your dreams, fulfill your fantasies, have *faith*, have *hope*, but most of all be *happy*.

Get Your Pens Ready!

Next essay contest begins April 1

iKidney.com and Watson Pharma's 4th annual essay contest for patients begins April 1 and is accepting entries through July 1. "That Special Someone" is the theme, and the essay should focus on how a loved one, fellow patient, beloved pet, or health care professional inspired you as a patient to better yourself, pursue a dream, or overcome adversity. Essays should be no longer than 750 typed words, with the author's complete name, address, phone number, and e-mail address (if available). The only requirement to participate is that the author be diagnosed with chronic kidney disease. All essays will be judged based on their appropriateness to contest theme, originality and creativity, and technical expertise. Entries may be mailed to iKidney.com, c/o Hartwell

Communications, 1311 N. Maryland Avenue, Glendale, Calif. 91207. They may also be faxed to: 818.244.9540 or emailed to hartwellcom@aol.com. The Grand Prize winner will receive a four-day, three-night, all expenses paid trip for two, to his/her choice of one of these national patient education meetings:

- Renal Support Network Annual Patient Convention, Chicago, Ill., Sept. 30–Oct. 1, 2005. (www.renalnetwork.org).

- American Association of Kidney Patients Annual Convention, Las Vegas, Nev., Sept. 1–4, 2005 (www.aakp.org).

Second and third place winners will receive \$250 and \$50 gift checks, respectively. Winners will be announced on www.iKidney.com in mid July.

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better understand their perspectives of the problems. Involving Mexican physicians in a study would also yield information on access issues in that country, and more clearly discern the relationships of the two adjacent health care systems. A nationwide survey of all personnel involved in the care of patients (emergency physicians, social workers, dialysis staff) would provide us with better insight into the day-to-day challenges of providing care for this unfortunate population.

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