

Uncertainty

by Lori Hartwell, weKAN President



The last couple of months have brought so much uncertainty, pain, and grief to people across the world.

Hurricanes, floods, and earthquakes have caused many to reconsider whether they can truly believe that things will ever get better.

Last December, I had to undergo double knee-replacement surgery. I really didn't have a choice, since it was becoming too difficult for me to walk without severe pain. Thirty-seven years as a kidney patient had taken its toll, along with years of ice-skating.

When I awoke from surgery, I was overcome with uncertainty, pain, and the profound question, "What in the world just happened to me!?" I could not do anything without help. I had no control.

The day after surgery, the hospital workers got me up to walk, but the

pain was unbearable. I felt like I would never be the same again. But if nothing else, my years of experience in dealing with one health crisis after another have taught me that "This too shall pass" and to take "One day at a time."

With the love and support of my family and friends and the skilled abilities of many healthcare professionals, I slowly improved. Walking around dependent upon a walker for six weeks gave me a deeper understanding of patience, for I often get impatient with myself when I think that life is moving faster than me.

Every other day for two months I had to go to physical therapy and undergo painful massages in order to remove or break up the scar tissue left over from the surgery. The hardest thing was making my legs stand straight (hyper-lock) so that I could stand for more than a minute at a time. I had the opportunity to talk with others who had gone through the same type of knee surgery. Hearing their words of encouragement, stories of hope, and ways to speed along my recovery helped me immensely.

The downtime surrounding my recovery gave me an opportunity to reflect on what I really want out of life. I spent time reading, making arts and crafts, and listening to music. Tapping into my creativity, which requires downtime to stir up, made my recovery smoother and faster.

My goal has always been to help provide patients with a platform from which they could help fellow patients by sharing with one another their experiences, strengths, and hope. This has been accomplished through RSN's Renal Teen Prom, the *RSN Directory*, the weKAN newsletter *Live & Give*, and the RSN National Patient Meeting "Health, Happiness & Hope." It's nice to see dreams come to fruition in the form of new programs designed to help fellow patients.

RSN's newest program is called PEPP (Patients Educating Patients & Professionals). PEPP comprises a series of educational programs to be led by patient-speakers. Its goal is to improve the outcomes of people with chronic kidney disease by increasing their knowledge of the disease, thereby encouraging involvement and self-management in their own care.

I am happy to report that when I reached three months post-double knee-replacement surgery, I was able to deliver a 45-minute presentation 3,000 miles from home. At six months post-surgery, my husband and I walked all over Boston on a personal guided tour led by former governor Michael Dukakis. At nine months post-surgery, I personally made 27 visits to congressional offices on Capitol Hill over the course of only three days.

My new knees (I feel like the Bionic Woman!) are allowing me new freedom to walk without pain. I don't take this feeling for granted. Is this the silver lining of adversity, that we don't know what we have until we lose it?

It's sometimes hard to make sense of pain and suffering. But we need to continue to show up and participate to the best of our ability and take charge of our most powerful ally, our mind.

Look at what you can do instead of what you cannot do. One of my favorite sayings is, "When one door closes, another opens, but it is hell in the hallway!" I have to thank my friends and family for pushing me through that hall.

This holiday season, please be sure to give thanks to all the people who have helped you. Reach out to a fellow patient and share your story... and listen to his or her story. And most importantly, make a list of what you are grateful for, and remember to hang onto hope!

Chronically Yours,

Lori Hartwell

President & Founder of Renal Support Network

weKAN Live & Give is a publication of the Renal Support Network, a patient-run non-profit organization whose mission is to identify and meet the non-medical needs of those affected by chronic kidney disease.

weKAN Patient Activists serve to mobilize, educate, motivate, and empower fellow chronic kidney disease survivors to advocate for themselves and for one another. Together we can make a difference.

Editor-in-Chief

Lori Hartwell

Managing Editor; Production & Design

Shari Gifford

Director of Communications

Joseph Herman

Distribution

Renal Support Network

Printing

Vindan Print Brokers, Inc., Denver, CO
George Bravdica, owner

Contact Information

Renal Support Network

(818) 543-0896 (9 AM-5 PM PST)

Submissions and Newsletter Business

shari@renalnetwork.org, or mail to RSN

Address Changes & Distribution

ATTN: weKAN Live & Give

Renal Support Network

1311 N. Maryland Ave.

Glendale, CA 91207

info@renalnetwork.org

EIN#95-4672679

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