

# Lori Hartwell Biography

#### In Brief

Lori Hartwell has made a difference in the lives of people with chronic kidney disease. She is the model of living a fulfilling life despite chronic illness. Living with kidney disease since age two, having survived 40 plus surgeries, 13 years of dialysis and now living with her fourth kidney transplant, Lori founded the patient-led Renal Support Network in 1993 to instill "health, happiness, and hope" into the lives of fellow patients. As RSN President, Lori travels throughout the country and to places as far as Canada and South Africa educating and inspiring people with kidney disease and healthcare professionals with her stories, insight, and humor. She is the author of *Chronically Happy - Joyful Living in Spite of Chronic Illness*, an inspirational guidebook for handling lifestyle and numerous other non-medical issues that come up in the course of chronic disease.

### Lori's Story

When doctors put two-year-old Lori Hartwell on dialysis after her kidneys mysteriously stopped working, they didn't expect her to live. That was the first time she beat seemingly insurmountable odds to survive, and she continues to "one-up" the statistics today.

As a young patient, Ms. Hartwell encountered the pioneering stages of renal replacement therapy. She was the youngest person in the state of California ever to be placed on dialysis (a washing machine-like mechanism that helps clean the blood). She was on dialysis for almost 13 years (both peritoneal dialysis and hemodialysis) and has had four kidney transplants—the last of which took place on February 4, 2011. Ms. Hartwell has emerged as a powerful example of how people with chronic illness can lead complete and productive lives.

The insightful, often humorous, and touching story of how Ms. Hartwell chose to live life rather than succumb to its obstacles is laid out in her book, *Chronically Happy - Joyful Living in Spite of Chronic Illness*, which chronicles her approach of taking simple, logical steps in order to realize one's dreams. *Chronically Happy*, published in 2002, is the first book written by a kidney patient ever to reach national distribution.

Ms. Hartwell realized one of her most ambitious dreams to date when, in 1993, she founded the Renal Support Network (RSN) to instill "health, happiness, and hope" into the lives of those affected by chronic kidney disease (CKD). The influence of this patient-led organization—which started out as a Southern California grassroots effort—now extends across America. RSN's mission is to identify and meet the non-medical needs of people affected by CKD, whether they are in the early stages of the disease, on dialysis, or with a kidney transplant. RSN accomplishes this by providing service, support, and advocacy to patients and their families, and by building coalitions within the renal community.

An illness is too demanding when you don't have hope!

#### Career

Ms. Hartwell began her career in the renal field as a technical sales specialist for HemaMetrics (formerly In-Line Diagnostics), developers of a hematocrit-controlled hemodialysis technology. She then accepted the position of Western Regional Sales Manager for Medcomp, distributors of vascular access catheters, where she oversaw company activities in seven states. These positions allowed her to visit more than 500 freestanding and hospital-based dialysis units in 30 states. As such, she was able to develop a broad-based, multi-faceted view of the U.S. renal patient population, and to witness the importance of a mutual understanding between patients and healthcare providers in the quest for quality care.

This broad-based first-hand knowledge of patients and kidney disease led naturally to publishing where Ms. Hartwell became editor of the medical journal *Contemporary Dialysis & Nephrology* and of the lay journal *For Patients Only*. She was the content publisher of the popular Web site iKidney.com, which served the entire renal community. Combining this experience with her knowledge of renal disease from both the patient and industry perspectives, Ms. Hartwell established Hartwell Communications in 2000, for which she consults on and creates patient-related educational materials.

She wrote and produced "Communication Prescription for the Renal Care Professional," a 60-minute video that shares practical advice, creative communication concepts, and stories of hope from people who live with kidney disease as well as from veteran renal care professionals. This video, which won a 2001 Aegis Award for its production quality, illustrates the positive impact that renal care professionals can have on people's lives.

Ms. Hartwell continues to travel the world giving motivational and educational presentations to renal healthcare professionals, patients, and industry representatives, both at national nephrology conferences and at the regional/local level.

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## **Patient Advocacy**

As a person who has lived successfully with Chronic Kidney Disease, Ms. Hartwell has a passion to give patients with chronic illness a reason to live and hope for the future. Her motto, "An illness is too demanding when you don't have hope," is heard throughout the U.S. nephrology community and has informed the development of many programs within the Renal Support Network. She has advocated on a national level, speaking with congressional and state leaders about legislative issues affecting the kidney community and giving testimony before the Joint Advisory Committee of the FDA. By example, she encourages other patients to take a positive step by taking active roles in the many patient-directed programs of RSN.

#### **Public Service**

Ms. Hartwell works with elected officials to advise on how policies impact people with chronic illnesses. In 2000, she was asked to serve on the Governors Rehabilitation Council for the state of California. She is former Chair of the Patient Advisory Committee for the Southern California Renal Disease Council and is an active patient member on the Board of Directors of the California Dialysis Council and Kidney Care Partners (KCP).

### **Awards & Recognitions**

- 2013 American Society of Nephrology President's Medal
- 2013 ABWA Top Ten Candidate for Woman of the Year
- November 2013, "President's Medal", American Society of Nephrology (ASN)
- June 2013, American Business Women of America (ABWA) Verdugo Glen-Chapter Woman of the Year
- September 2012, Business Life Magazine Women Achievers honoree
- March 2012 City of Glendale Commission on the Status of Women, Jewel of Glendale 2012
- March 2012, ABWA Verdugo-Glen Chapter Woman of the Year
- March 31, 2011, recipient of "Heart & Excellence Award", presented by YWCA of Glendale
- 2009-2010 "Associate of the Year", by American Business Women's Association
- May 3, 2010, recipient of National Kidney Registry "Patient Advocacy Award"
- September 2007, received prestigious NRAA "Mark Zawinsky" award for Outstanding Leadership
- October 2005, recipient of the "Women in Business Award," from the California State Legislature
- May 2005, named "Citizen of the Week" by KNX Radio, Los Angeles, CA
- March 2005, named "Woman of the Year" in the 21st Senate District by California State Sen. Jack Scott (D-Pasadena)
- January 2004, recipient of the "2003 Quality of Life Award," presented by Nephrology News & Issues

#### **Publications**

- December 2013 NN&I The Renal Support Network, 20 Years Later
- November 2013 Renal Business Today Rehabilitation Options for Kidney-Disease Patients
- August 2013 NN&I Transplantation: What every patient and health care professional should know
- August 2012 NN&I Why Support Groups Provide Hope and Help
- June 2012 NN&I I want to be at least a 10: The impact of changes in metrics and labeling of ESAs.
- October 2011 Dialysis & Transplantation A Product of Medical Advancements

## Renal Support Network

- August 2010 NN&I Patient Engagement: Reality or Annoyance?
- August 2009 NN&I "Who Lives?"
- August 2008 Dialysis & Transplantation One Friend Can Make a Difference
- 2008 Sponsored Educational Supplement Management of Mineral and Bone Disorders In Patients on Dialysis: A Team Approach To Improving Outcomes
- November 2007 Dialysis & Transplantation Top 10 Concerns Patients Have for Bundling Dialysis Services
- July 2006 NN&I Two trees in the forest, A patient's perception of quality of life
- January 2006 NN&I Adding a little more 'PEPP' to the renal community
- March 2005 NN&I "For the Love of Butterflies"
- January 2004 NN&I Chronically Motivated
- September 2003 NN&I Patients Educating Patients

## Hartwell Mentions and Articles by other Authors (Partial List)

- December 20, 2012, Four kidney transplants later, Glendale woman gets retail with fundraising, Glendale News Press
  http://www.glendalenewspress.com/community/tn-gnp-1220-four-kidney-transplants-later-glendale-woman-gets-retail-with-fundraising,0,3914774.story
- December 12, 2012, The Fiscal Cliff, the Patient, the Clinic and the Wallet, Renal Business Today <a href="http://www.renalbusiness.com/blogs/kasia-michalik/2012/12/the-fiscal-cliff-the-patient-the-clinic-and-the-wallet.aspx">http://www.renalbusiness.com/blogs/kasia-michalik/2012/12/the-fiscal-cliff-the-patient-the-clinic-and-the-wallet.aspx</a>
- December 6, 2012, Kidney dialysis center in Town and Country under investigation for injecting patients with cleanser
  http://www.stltoday.com/lifestyles/health-med-fit/health/kidney-dialysis-center-under-investigation-for-injecting-patients-with-cleanser/article\_ac20b204-0fc8-5ad5-987b-48a3a26d5d5c.html
- April 10, 2011, Women honored for heart, excellence, News-Press & Leader, serving Glendale and Burbank
- August 7, 2012, Chronically Happy Book Review, <a href="http://sunroomdesk.com/2012/08/07/chronically-happy-lori-hartwell/">http://sunroomdesk.com/2012/08/07/chronically-happy-lori-hartwell/</a>
- April 2011, Patient advocate Lori Hartwell has fourth kidney transplant, NN&I
- November 24, 2010, Dialysis Industry May Expand as Study Sways Medicare, Bloomberg
- February 2010, Lori Hartwell: Living with Purpose with Chronic Kidney Disease, livenow <a href="http://livenow.info/GetLiving/Lifestyle/LivingwithPurposewithChronicKidneyDisease.aspx">http://livenow.info/GetLiving/Lifestyle/LivingwithPurposewithChronicKidneyDisease.aspx</a>

### Radio Interviews (Partial List)

- September 23, 2012, KROQ 106.7 FM "Openline", hosted by Scott Mason
- March 18, 2010, KNX 1070 NEWSRADIO