



## Lori Hartwell Biography

(October 2009)

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### 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. A kidney patient since age two and now living with her third 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 educating and inspiring patients 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 other non-medical issues that come up in the course of chronic disease. Lori has been a guest on radio talk shows nationwide, and her annual Renal Teen Prom has enjoyed local broadcast and nationwide television coverage. She has received numerous awards in recognition of her leadership and is a sought-after inspirational and motivational speaker. In 2009 she produced a play called *Who Lives?* by Christopher Meeks- a moving drama about hope, despair, life, death and choice; based on the early history of kidney dialysis- which opened in Los Angeles and sold out the last weeks of production. Lori created and co-hosts *KidneyTalk!*, a web-streaming interview program podcast. She continually encourages kidney patients to tell their stories, and her contributions toward improving the well-being of people with chronic illness are widely recognized.

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### 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 --but not the last-- time she beat seemingly insurmountable odds to survive, and she continues to improve 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 peritoneal dialysis (a cleansing of the peritoneum in the abdominal cavity). Following 12 years on dialysis (including

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

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hemodialysis, which cleans the blood) and three kidney transplants—the last of which took place in 1990 and continues to serve her well— she 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 describes her approach to fulfillment by taking simple, logical steps in order to realize one's dreams. *Chronically Happy*, published in 2002 and distributed by the Renal Support Network, is the first book written by a person with kidney disease about the illness ever to reach national distribution.

### Career

Ms. Hartwell began her career in the renal field as a technical sales specialist for HemaMetrics, 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 enabled 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 consulted on and created 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 country giving motivational and educational presentations to renal healthcare professionals and patients, both at national nephrology conferences and at the regional/local level.

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

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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 provides service, support, and advocacy to patients and their families and builds coalitions within the renal community.

One of the most adventuresome programs of RSN is "KidneyTalk," a podcast uploading new interview shows every other week, which Ms. Hartwell created in order to present information to the kidney community more palatably in a light, bright and breezy format. To help her realize this goal, she enlisted actor/director/producer Stephen Furst, a kidney transplant recipient well-known for comic roles such as Flounder in "Animal House," and, in a more serious vein, Dr. Axelrod in the Emmy-award winning television show, "St. Elsewhere."

### **Patient Advocacy**

As 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 the many programs within the Renal Support Network. She has advocated on the 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 Food and Drug Administration. 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 the impact of current and potential policies on people with chronic illnesses. She has served as chair of the Patient Advisory Committee for the Southern California Renal Disease Council and is a board member of the California Dialysis Council and Kidney Care Partners. She has been a consultant for the Centers for Medicare & Medicaid Services' Clinical Performance Measures Project on Vascular Access. Ms. Hartwell was appointed to serve on former California state Governor Gray Davis' State Rehabilitation Council.

### **Recent Television Appearances**

- September 2009: CNN Local Edition, two interview segments with Brad Pomerance
- March 2009: ABC, interviewed by George Pawacki about the production of *Who Lives?*
- May 2008: Fox News, interviewed for the First RSN Renal Teen Prom in Washington DC.
- February 2008: NBC *Nascar Angels* Television Show

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- January 20, 2008: Fox News, coverage and interview for the 9<sup>th</sup> annual Renal Teen Prom in Los Angeles
- October 2005: NBC TV, nationwide broadcast, *Starting Over* program (appearance as patient advocate specialist and author of *Chronically Happy - Joyful Living in Spite of Chronic Illness*)
- May 2004: Lifetime Network, *LifeMoments* special on annual Renal Teen Prom in Los Angeles.

### Recent Awards & Recognitions

- Recipient of the American Business Women's Association Verdugo Glen Chapter award
- Received the Certificate of Special Congressional Recognition for outstanding and invaluable service to the community from Congressman Adam Schiff.
- Testified before the Food and Drug Administration Joint Advisory Committee on how Medicare drug guidelines on ESAs and anemia affect quality of life for kidney patients.
- Awarded the National Renal Administrators Association "Mark Zawinski Memorial Award for Outstanding Leadership and Service to the Renal Community".
- Recipient of the "Women in Business Award," presented by the California State Legislature
- Named "Citizen of the Week" by KNX Radio, Los Angeles, CA
- Named "Woman of the Year" (2005) in the 21st Senate District by California State Sen. Jack Scott (D-Pasadena)
- Recipient of the "2003 Quality of Life Award," presented by *Nephrology News & Issues*
- Received the National Kidney Foundation's "Southern California Community Service Award"

### Recent & Upcoming Speaking Engagements

- American Nephrology Nurses' Association conference
- California Dialysis Council
- Canadian Association of Nephrology Nurses and Technologists in Toronto, Canada
- Great Lakes Renal Network (two presentations)
- Kaiser Permanente of Southern California Annual Dialysis Conference
- Kidney Urology Foundation
- Montana State Renal Meeting
- National Kidney Foundation of South Carolina
- National Renal Care, South Africa
- Northwest Kidney Expo in Seattle, Washington
- Polycystic Kidney Disease Foundation National Meeting

### Radio Appearances

- *The 2 O'Clock Show*, KPO, Washington
- Interview with Jack Roberts: Cable Radio Network
- *Breakfast with Roger and Royce*

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- March is National Kidney Month, KNX
- British Broadcasting Corporation (BBC) Radio, taped for worldwide broadcast (BBC World Service's Health Matters program, interviewed on organ donation)

### Published Writing (selections)

- *Chronically Happy: Joyful Living in Spite of Chronic Illness* – the novel
- “Who Lives?” in *Nephrology News & Issues: Viewpoint*
- “A Second Chance” in *Live & Give*
- “One Friend Can Make a Difference” in *Dialysis & Transplantation*
- “Telling Your Story- One Person at a Time” in *Live & Give*
- “Top 10 Concerns Patients Have for Bundling Dialysis Services” in *Dialysis & Transplantation*
- “Adding a Little More PEPP to the Renal Community” in *Nephrology News & Issues*
- “For the Love of Butterflies” in *Nephrology News & Issues*
- “The Resilience of the Human Spirit” in *Live & Give*
- “Two Trees in the Forest” in *Nephrology News & Issues*
- “Patients Educating Patients” in *Nephrology News & Issues*
- “Persistence and Hope, a Winning Combination” in *Live & Give*

### Current RSN Programs

- **KidneyTalk** – is a unique online radio talk show for those affected by CKD emphasizing the hopeful side of living a full and active life despite kidney disease. Each half-hour weekly show blends humor and guest interviews with motivation and education, resulting in a half hour of inspiration! KidneyTalk is co-hosted by Lori Hartwell and the actor Stephen Furst, who made his debut in the movie *Animal House* (playing Flounder).
- The **PEPP** program – Patients Educating Patients & Professionals – trains patient speakers to give educational presentations about kidney-related issues to patients and professionals. PEPP speakers are models of hope to those they encounter. Their aim is to motivate patients with kidney disease to become more adherent and more self-sufficient once they see other patients achieving their goals despite kidney disease. PEPP also provides tips to healthcare professionals so they can effectively encourage patients to adhere to their care plan and to become their own advocate.
- The **Wellness and Education Kidney Advocacy Network (weKAN)**, established in 2004, consists of patient activists bonded together with the goal of ensuring that CKD patients receive quality care. WeKAN promotes self-advocacy and self-determination by showing patients how to become actively involved in decisions—medical and legislative—affecting their lives.
- **weKAN Live & Give**—the bi-annual newsletter for patients, their families, and healthcare professionals—provides information about weKAN's ongoing activities, stories of hope, ways

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for patients to better their lives, and ideas on how to assist fellow patients. This newsletter exemplifies RSN's focus on "patients helping patients," as it is written, designed, and printed by kidney patients and/or patient-owned companies.

- The **Annual RSN Renal Teen Prom** is one of the most visible and rewarding efforts of RSN. For the past ten years, a free, senior prom-type gala has been held for "kidney teens" throughout Southern California, with teens now attending from other states. This one special night helps convince kidney teens to not give up hope and to continue their journey in maintaining healthful and meaningful lives as they delight – most for the first time – in a real prom night with all the trimmings.
- Each year, RSN offers a series of **Patient Lifestyle Meetings** throughout the United States, organized by a peer-patient, where kidney patients and their families can learn about life-enhancement and illness-related issues. There is no charge to attend the meetings.
- The **HOPEline (Helping Others Pursue Empowerment)** is a centralized, toll-free phone line that allows people affected by Chronic Kidney Disease (CKD) to call a fellow patient for peer support from someone who's been there. Callers connect with another person who has lived successfully with CKD and can share their experience, strength and hope.
- **KidneySpace** is an exciting online dialogue and message board with opportunities for sharing health and lifestyle information, fostering personal and social connections, and learning about what's new and different in all of the RSN programs. It has recently expanded to include a well-attended chat room online support group.
- RSN's **renALERT!** is an electronic newsletter which periodically transmits updates to RSN members and its partners on pivotal issues, events, and activities that arise at RSN or in the renal community.
- The RSN website, **www.RSNhope.org**, allows patients and family members to connect with others or learn more about RSN, weKAN, and available resources.
- **KidneyTimes.com** is an online health library with articles written by kidney patients and professionals on medical, social, nutritional, and lifestyle issues. Also the home of the annual KidneyTimes Essay Contest.
- **Chronically Happy: Joyful Living in Spite of Chronic Illness**, a book filled with stories and words of wisdom that inspire readers to embrace a joyful life regardless of their physical limitations.