



Service to those affected by chronic kidney disease

## Lori Hartwell Biography

### In Brief

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Lori Hartwell's mission is to help people living with chronic kidney disease. Hartwell suffered kidney failure at the age of two, survived 50+ surgeries and 13 years of dialysis, and is now living with her fourth kidney transplant. Hartwell founded Renal Support Network in 1993 to instill "health, happiness, and hope" into the lives of fellow patients; she serves as President to this day and has inspired patients, family members and healthcare professionals. She has built a national network of people who she refers to as her "kidney kin" to help let them know they are not alone in this journey and help them find the tools needed to navigate this illness.

She has led patient support groups since the early nineties, produced educational podcasts, meetings, unique programs, testified on patient issues at the state and federal level, authored peer-reviewed and medical journal articles on care and policy issues, and served on the boards of industry and provider organizations as a trusted patient advocate who knows the issues. Hartwell is the author of *Chronically Happy – Joyful Living in Spite of Chronic Illness*, the first book written by and for a patient with kidney disease to ever reach national distribution. She has hosted the KidneyTalk Podcast since 2006 that shares inspiring and educational perspective, insight and hope to her peers.

People Lori connect with come to see kidney disease in a totally different light – that although it is difficult, it is manageable. She helps them recognize the need to take control of the course and management of their illness through storytelling. Learning from another patient's experience and point of wisdom to live successfully and navigate care is vital for success.

She has always had a knack for thinking outside the box and her past work experience of working in the entertainment field, managing dialysis medical equipment sales, editing medical journals and consulting on patient centered programs allowed her to gain professional perspective that carries through in the life-enriching programs she has created to benefit people who have kidney disease.

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### Lori's Story

Lori Hartwell was put on dialysis at the age of two when her kidneys suddenly stopped working. She was the youngest person ever in California to be placed on dialysis and her doctors didn't expect her to live. But Hartwell survived, experiencing the pioneering stages of renal replacement therapy, and has been beating the odds ever since. She was on dialysis for almost 13 years – both peritoneal dialysis and hemodialysis – and has had four kidney transplants.

Hartwell took a strong interest in her medical care from a young age and absorbed as much information as she could from nurses, nephrologists, technicians, and fellow patients. She began her career working in the entertainment industry. Creating packaging and promotion material for the studios, record companies and new products coming to market. She soon realized her heart was with the kidney community and decided to concentrate her efforts on sharing her unique perspective and ideas on what the kidney care community needed. Hope was a new concept in the early 90s.

An illness is too demanding when you don't have hope!  
– Lori Hartwell, RSN Founder and President

## Renal Support Network

She began her medical working career in dialysis medical technology sales, visiting more than 500 freestanding and hospital-based dialysis units in 30 states. She then transitioned to medical journal publishing and patient education consulting.

Hartwell established Renal Support Network (RSN) in 1993 to instill “health, happiness, and hope” into the lives of those affected by chronic kidney disease. She has developed the organization into a national resource offering a broad array of non-medical information and support. With RSN, Hartwell has established patient-led support groups, produced educational podcasts and programs, issued calls to action and advocacy, and developed a robust platform hosting resources for patients and their families. Hartwell produces RSN’s annual virtual Hope Week, a groundbreaking, five-day conference covering topics vital to the health and well-being of kidney patients featuring medical experts as well as the voices of patients and caregivers. Her signature event is the annual Prom for teens who have kidney disease. She spent all her teenage years on dialysis and had two transplant that didn’t work. She was home schooled due to her many absences. She felt isolated and alone and if it wasn’t for her black poodle Pepi, she would have felt hopeless at times.

***Chronically Happy – Joyful Living in Spite of Chronic Illness***, is Hartwell’s personal story of deciding to take simple, logical steps to live a full life and realize one’s dreams. Published in 2002, it is the first book written by a kidney patient ever to reach national distribution.

Hartwell has drawn on her career experiences in design, media, and marketing to provide creative and enjoyable outlets for the kidney patient community, such as RSN’s Annual Essay Contest and Annual Renal Teen Prom (a tradition spanning over two decades).

Through RSN, Hartwell has produced and disseminated resources via the KidneyTalk® Blog, KidneyTalk® Magazine, KidneyTalk® Podcast, and much more. She has built strong coalitions with kidney care and professional organizations and has become a nationally recognized, trusted voice of the kidney patient community. She continually advocates for patients to legislators, in policy forums, and in professional meetings.

### Career

Before entering the renal field, Lori worked at Four Corners and Disney and learned first-hand how to create and produce point of purchasing displays and packaging for the Entertainment industry. She had a boss tell her that your work defines you and she made the decision to change careers.

Ms. Hartwell began her career in the renal field as a technical sales specialist for a developer of a hematocrit-controlled hemodialysis technology. She then accepted the position of Western Regional Sales Manager, 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.

She took these experiences to the world of publishing, becoming editor of the medical journal ***Contemporary Dialysis & Nephrology*** and of the lay journal ***For Patients Only***, and content publisher of the popular website iKidney.com. She established Hartwell Communications in 2000 to help create patient education materials.

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Hartwell won a 2001 Aegis Award for “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 and from renal care professionals. In 2002, she published her personal story in ***Chronically Happy – Joyful Living in Spite of Chronic Illness***, the first book written by a kidney patient ever to reach national distribution.

## Renal Support Network

She is known for her creativity and “thinking outside the box.” She had the idea to produce a play called “Who Lives” and cast professional patient actors who had kidney disease. The synopsis is in the early 1960s, an anonymous committee of ordinary citizens in Seattle selected kidney disease victims from a pool for an experiment with something new: a kidney dialysis machine. If the experiment worked, a small number of people would live instead of surely die from kidney failure. But who among the pool lives? How will the committee choose? Playwright Christopher Meeks centers the action on one person, attorney Gabriel Hornstein, who desperately needs what the committee offers.

Who Lives was nominated for five Los Angeles Ovation Awards. “Director Joe Ochman and executive producer Lori Hartwell have come up with an absolutely riveting and heart-pounding telling that succeeds on many levels.” –Jose Ruiz, ReviewPlays.com

This is just one example of the many creative ideas that Hartwell developed and implemented.

Through RSN, Hartwell has built strong coalitions with kidney care and professional organizations, has served on several industry and patient care boards, and has become a trusted voice of the kidney patient community. Her list of published articles, recognitions and awards is extensive, and she continues to speak for patients in policy forums and professional meetings in the U.S.

She is a founding member of Kidney Care Partners, Sevres on the National Quality Forum and a Patient Voice Editor for CJASN. She participates on various committees and workgroups, but her heart is with her peers and is constantly figuring out ways to engage them. It’s not uncommon for her to be chatting or typing with a one of her peers giving them suggestions on how to navigate care or a dose of hope.

### **Patient Advocacy**

Lori Hartwell’s motto is “An illness is too demanding when you don’t have hope.” She’s made it her mission to share kidney patients’ perspectives with healthcare providers, medical technology companies, and policymakers. Hartwell advocates at the state and national level, including testifying before the Joint Advisory Committee of the FDA. She has served on multiple industry and kidney care boards and is regularly invited by medical journals to contribute articles on the patient’s perspective. She has served on several Technical Expert Panels for Center for Medicare and Medicaid Services to provide the patient’s perspective. She also produces calls to action for the RSN community, encouraging patients to take an active role in advocating for policies that promote quality care and quality of life. Among the many successful programs, she’s started at Renal Support Network is Hope Week, a virtual conference that educates and empowers patients, their families, and the kidney care community on a broad range of topics. In 2018, she was named 28th Congressional District Woman of the Year by Congressman Adam Schiff. Schiff stated for the Congressional Record, “A resilient survivor of chronic kidney disease (CKD), Lori has dedicated her life to the renal field and patients with chronic illness.”

### **Public Service**

Lori Hartwell works with elected officials and government agencies to help them improve quality of care and quality of life for people with chronic kidney disease. She has served on multiple councils and boards in the renal field: past Chair of the Patient Advisory Committee for the Southern California Renal Disease Council, past Chair of the Patient Council for Kidney Research Institute ASCEND Trial focusing on helping kidney disease patients with depression; on the Board of Directors for Kidney Care Partners; on the Governor’s Rehabilitation Council for the State of California; and on the California Dialysis Council Board. Hartwell publicly advocated for the federal policy put in place in 2021 to provide COVID-19 vaccine booster shots for kidney/organ transplant recipients and kidney patients that are immunocompromised. She reviews and comments upon on the periodically released Center for Medicare Services (CMS) proposed rules for managing and paying for kidney patients’ care, with a consistent focus on patient needs.

# Renal Support Network

## Awards & Recognitions

- August 23, 2021, [IDEAS Patient Engagement Award Spotighting Excellence in Patient Engagement](#)
- October 17, 2020, [NASW-CA Public Citizen of the Year](#)
- April 2018, Congressman Adam Schiff's [28th Congressional District Woman of the Year](#)
- May 2014, Recipient of the Clyde Shields Distinguished Service Award by Northwest Kidney Center
- 2013 American Society of Nephrology President's Medal
- 2013 ABWA Top Ten Candidate for 2014 Woman of the Year
- June 2013, American Business Women of America (ABWA) Verdugo Glen-Chapter Woman of the Year
- September 2012, "Business Life Magazine Women Achievers" honoree
- April 2012, City of Glendale, CA, Jewel of Glendale Women of Courage honoree
- 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*
- Executive Producer, *Who Lives?* A Play. Nominated for 5 L.A. Ovation Awards.  
"Director Joe Ochman and executive producer Lori Hartwell have come up with an absolutely riveting and heart-pounding telling that succeeds on many levels." –[Jose Ruiz, ReviewPlays.com As Seen in @This Stage Magazine](#)

## Publications (partial list)

- September 2021 – *CJASN Clinical Journal of the American Society of Nephrology* – [Developing Patient-Reported Outcome Measures that Can Improve Kidney Care](#)
- June 2021 – *American Journal of Managed Care* – [Contributor: It's Time for Medicare to Cover Oral Alternative Therapies for Iron Deficiency Anemia](#)
- December 2020 – *Medpage Today* – [Op-Ed: We Must Prioritize Vaccinations for CKD Patients — Their elevated risk makes it life or death](#)
- August 2020 – *American Journal of Managed Care* – [Under New Rule, MA Plans Can Keep a Blindfold on Dialysis Facility Choice for Individuals With Kidney Failure](#)
- December 2019 – *CJASN Clinical Journal of the American Society of Nephrology* – [Public Policy and Patient Choice of Dialysis Modality](#)
- October 2018 – *Oxford Academic: Nephrology, Dialysis, Transplantation* – [Perspectives on symptom experiences and symptom reporting among individuals on hemodialysis](#)
- March 2018 – *CJASN Clinical Journal of the American Society of Nephrology* – [Responsive Designed Interventions Are Needed to Support Positive Outcomes of Children and Adolescents with CKD](#)

## Renal Support Network

- March 2018 – *Toastmasters Magazine* – [Navigating the Two Sides of Healthcare](#)
- June 2017 – *American Journal of Kidney Diseases* – [Understanding Dialysis Patient Perspectives on Advocacy](#)
- May 2015 – *Nephrology News* – [Be proactive about monitoring your potassium](#)
- December 2013 – *Nephrology News* – [The Renal Support Network, 20 years later](#)
- November 2013 – *Renal Business Today* – [Rehabilitation Options for Kidney Disease Patients](#)
- August 2013 – *Nephrology News* – [Transplantation: What every patient and healthcare professional should know](#)
- August 2012 – *Nephrology News* – [Why support groups provide help and hope](#)
- June 2012 – *Nephrology News* – [I want to be at least a 10: the impact of changes in metrics and labeling for ESAs](#)
- October 2011 – *Dialysis & Transplantation* – [A product of medical advancements](#)
- August 2010 – *Nephrology News* – [Patient Engagement: Reality or Annoyance](#)
- August 2008 [Nephrology News – Who Lives? \(We all do now—but it wasn't always that way\)](#)
- August 2008 – *Dialysis and Transplantation Magazine* – [One Friend Can Make a Difference](#)
- November 2007 – *Dialysis and Transplantation Magazine* – [Top 10 Concerns Patients Have for Bundling Dialysis Services](#)
- July 2006 – *Nephrology News* – [Two trees in the forest A patient's perception of quality of life](#)
- January 2006 – *Nephrology News* – [Adding a little more 'PEPP' to the renal community](#)
- March 2005 – *Nephrology News* – [For the love of butterflies](#)
- January 2004 – *Nephrology News* – [Chronically Motivated](#)
- September 2002 – *Nephrology News* – [Patients Educating Patients](#)

### External Media (recent, partial list)

- January 2021, ABC7 Los Angeles – [Scientists on brink of breakthrough to help thousands in need of kidney transplant: growing artificial kidney](#)
- November 2020, Medscape Medical News – ['Kidney' vs 'renal': experts say words matter](#)
- November 2020, Center for Dialysis Innovation Symposium invited keynote speaker for [Bill Peckham Lecture](#)
- January 2018, Los Angeles Times – [Youths get to enjoy an evening of dancing, fun at Renal Teen Prom](#)
- January 2016, Regulatory Affairs Professionals Society – [Convergence Keynote Speaker Lori Hartwell Passionate About Patients](#)