

Five Questions With: Laura Adams

[By Richard Asinof](#)

For Laura Adams, president and CEO of the Rhode Island Quality Institute, her personal life suddenly and unexpectedly converged with her professional life when she received a diagnosis of breast cancer. She found herself carrying her own medical records around with her as she went from appointment to appointment, while, at the same time, in her professional life, she was championing the creation of a seamless electronic health information exchange in Rhode Island.

Adams made the personal decision to share her diagnosis; she said it was not only a way to raise the visibility of her work. Her life, she realized, literally depends on the performance of the health care system.

Providence Business News asked Adams to share the reasons behind her decision to be very public about her diagnosis and treatment

PBN: Why did you make the decision to be very public about your diagnosis of breast cancer, sharing it as part of your interview with E. Robert Wasserman, the chief medical officer of Generations Health, at the Life Sciences Technology Showcase?

ADAMS: Sharing my diagnosis not only feels empowering to me personally as I try to keep my chances for survival high, it's an opportunity to raise the visibility of everything we're working for at RIQI. I believed in our work before, but I really believe in it now that my life literally depends upon the performance of the health care system.

PBN: The convergence of your personal life with your professional work – having to carry around the medical records from appointment to appointment, while at the same time, creating a health information exchange in Rhode Island that will make that information available through a secure network – really seemed to resonate with you. How does your own experience change the way you see your own professional efforts?

ADAMS: Although I feel confident that I will live to see my son grow up, I'm now acutely aware that I have "limited life moments" even if I beat this cancer. This awareness has infused my work with more urgency than ever – I hear a clock ticking loudly for patients who need the benefit of RIQI's work. For example, my diagnosis permits me to talk about the urgency of a health information exchange with a new level of credibility. I wouldn't have believed it was possible, but I have even more passion and energy to advance our initiatives.



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PBN: One of the points stressed in your discussion, “Pathways to Individualized Health Care,” was the importance of patients to educate themselves when talking to physicians and options for care. How important has it been for you?

ADAMS: It’s been critical. My care team armed me with information to research my options and ignore irrelevant and sometimes terrifying information not germane to my circumstance. But as a “health care insider,” I’m equipped to use this information to locate appropriate and trustworthy information.

I’d like to see “information prescriptions” for patients. The average patient could really benefit from help with getting straight to sources of credible information that apply to them.

PBN: The Rhode Island Quality Institute has positioned Rhode Island to be in the vanguard in the adoption of electronic health records and the health information exchange. What are remaining challenges to creating the exchange?

ADAMS: Data is now flowing in from such organizations as Lifespan, Care New England, South County Hospital, East Side Labs, Cumberland Primary Care. Our challenge now is to continue adding “data sharing partners” until we’re all connected. These include the rest of the hospitals, primary care and specialists, behavioral health, long-term care, visiting nurses, home and hospice care, and all the way to patient-reported data. They’re definitely on the care team, after all.

However, our biggest challenge is to establish our long-term funding to support the operations of current care, the health information exchange.

PBN: What kind of support have you found in the workplace and the community in response to publicly sharing your diagnosis?

ADAMS: My 12-year old son and I started a “Silver Linings List” to document all of the positives that have come from this diagnosis. The pages-long list includes learning to permit myself to be openly vulnerable and receive all of the love, good wishes, prayers and expressions of caring that have poured in. This diagnosis is bigger than me. The inspiration and strength I’ve drawn from my Rhode Island colleagues and community is as critical to my survival as the surgery and treatment I’m about to have. This I know for sure.

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