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Regina Holliday and the Walking Gallery



[Regina Holliday](#)

*****@***yahoo.com

Patient Activist and Speaker -
The Walking Gallery

[LinkedIn](#) [Twitter](#)

Patient Activism, Patient Advocacy or Patient Engagement. Whatever label you give it, one thing is for certain: the movement towards Patient Power is central to the future of healthcare. While patient activism pre-dates the explosion of the web, the trend towards patients participating in their own healthcare goes hand-in-hand with the development of eHealth and mHealth as patient advocates use cyber space to inform, support, empower and inspire on the subjects of everything from cancer care for young people to multi-disciplinary care, organ donation to lupus, medical technology innovation to the effects of chemotherapy. Patient Activism is not solely focused on patient care; it is also impacting on policy and, when working hand-in-hand with a scientific perspective and input, has the power to open new vistas in healthcare.

Many patient activists are or were patients themselves or are close to patients. This experience has fuelled their initiatives. Artist Regina Holliday is one such activist and speaker. During her husband's illness with metastatic kidney cancer, she encountered brick walls trying to get hold of his medical records. After her husband passed away from the disease, she made it her mission to advocate for patient rights – largely through The Walking Gallery of Healthcare. *HealthManagement.org* had the pleasure of catching up with her.

If you had to describe what you do with The Walking Gallery to someone new, how would you explain it?

An artist or artists interview medical professionals and lay individuals to form a patient-centric narrative. The artist then creates representational imagery and paints that picture story upon the business jacket of the provider of the narrative account. The provider of the patient story, aka "Walker", will wear the jacket to medical conferences and events in order to disseminate the patient story to a large group of policy-minded attendees and to represent

the individual patient voice in venues where they are underrepresented. Further, both artist and Walker will support the spread of the story and image via social media. This is the fourth year of the Walking Gallery of Healthcare. We now number 357 members walking around the world with patient story paintings on our backs. There are now 43 artists in the Gallery.

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This Walking Gallery is changing minds and opening hearts. Walkers are attending medical conferences where often there isn't a patient speaker on the dais or in the audience. They are providing a patient voice and by doing so, are changing the conversation.

What was your first happening?

Our first gathering was June 7, 2011. We had 56 walkers and 5 artists.

What inspired you to start The Walking Gallery?

The Walking Gallery exists because of three moments of inspiration: Firstly, on June 29, 2009 I attended my first medical conference entitled Connect 2009. I noticed the people with the power wore business suits. Secondly, after a social media exchange with Tech investment developer Jen McCabe, she asked me if I would paint a series of paintings on the back of her blazers to wear to upcoming health meetings. I told her I would be honoured to paint jackets for her. Lastly, in April 2011, I attended the opening of the Kaiser Permanente Centre for Total Health in DC, I asked them to host an art show there, but not on the walls. On that night, a space that is a shrine to technology and the power of electronic communication became a Gallery and the ,mart walked. Over 50 people walked around

that space wearing patient stories on their backs. I saw something amazing happen; they became their story. I saw doctors throw aside being defined by their profession. I saw administrators and government employees drop their distancing titles and simply be the patient that they were. I saw teachers talk with CEOs and artists meet programmers and all were connected through their stories. In every blog post and tweet I have read about the impressions of the Walking Gallery, I hear the same things again and again. It is electric, passionate, fiery and so very filled with positive energy and we are filled with the spirit of change. That day we became a movement. We now walk and spread the message.

What are your proudest moments in terms of the impact you have had on patients and healthcare?

I was honoured to testify for Meaningful Use (in the U.S. the use of the certified electronic health record technology to improve care quality and safety and engage patients). I was also honoured to take part in the healthcare reform debates in the U.S.

What, in your view, is the most critical issue facing patients today and do you intend to highlight it with The

Walking Gallery?

Including the patient voice in the wider discussion of medicine and health policy is the most important thing that The Walking Gallery can highlight. We do not represent one concern or disease; we represent them all.

What keeps you going with The Walking Gallery?

I love being completely inclusive in my activism and The Walking Gallery is a wonderful vehicle for that.

Find out more about Regina Holliday's work at: www.reginaholliday.blogspot.com

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