



Reflecting on 2017, Anticipating 2018

2017

I ended 2016 with

My Note to Myself: Continue to do what I'm doing. Appreciate the small stuff (fresh running water, regular garbage pickup). Appreciate living within our means. Appreciate the warm rocks of my honey and my family. Appreciate my empathetic and skilled health team. Stick to my health and safety routine every day. Mentor bright young minds. Have fun when collaborating to do good work.

Three words: Balance. Caregivers. Onward.

Balance - Family, exercise, music, work. In that order

Caregivers - I do the work I do for caregivers - Honor the caregivers, help the helpers. We couldn't exist without them.

Onward - Moving stuff an inch that has 10 miles to go, requires one foot in front of the other.

Overall, I'm satisfied with my accomplishments. Balance is never ending, you're never *there*. I'm in awe of the continued advocacy work ahead of us. Mostly, I've been a content machine - producing while I still can. Writing helps me think and then contribute while feeding and growing my social network. Thanks to the many of you who have included and educated me. The discipline of weekly blogging keeps the grey cells firing despite my MS. I started a [YouTube channel](#). Multi-media. What a hoot! Something else where I'm good enough to be dangerous. I've written seven guest blog posts. You can access them on my [Portfolio web page](#). Two major publications came out this year, [What Your Patient is Thinking,](#)

[Learning Together](#) in the **British Medical Journal** and [Communication at Transitions: One Audacious Bite at a Time](#) in the **Journal of Participatory Medicine**. I was interviewed on Radioactive Broadcasting URGENT CARE radio: [Building a Team and Getting What You Need](#) and [Kistein Monkhouse's #PatientOrator](#).



I've become the Newsletter Editor for [Society of Participatory Medicine](#) and a patient reviewer for the [British Medical Journal](#).

Thanks to [Danny McGinnist, Jr.](#) for creating my logo while we drove from DC to Cinderblocks in May.

Conferences attended

- Coalition for Compassionate Care of California Annual Summit in Sacramento as an ePatient Scholar
- International Conference on Communication in Healthcare and the Health Literacy Annual Research Conference in Baltimore as a panel member and PCORI Ambassador
- Patient Centered Clinical Decision Support-Learning Network Annual Conference in Washington DC as planner and Steering Committee member
- PCORI Annual Conference in Washington DC as speaker and Steering Committee Member



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An e-patient, caregiver, nurse, informaticist, and leader living and working where health care and technology intersect

Empowering people as they travel together toward best health

Patients, Caregivers, Clinicians, Direct Care and Support Staff, Communities

- National Caregiving Conference in Chicago as a panel member and PCORI Ambassador
- Cinderblocks in Grantsville, MD, as me

Pound for pound, dollar for dollar, the best were Cinderblocks, Caregiving, and Compassionate Care. Small, diverse participants, attendee-focused (not vendor) with practical lived experience shared.

The most fun

Collaborating with a design studio, Involution Studios, on [Precision Prism](#) expanded my mind. Design thinking for people: function AND beauty. Thanks, Juhan and Edwin.

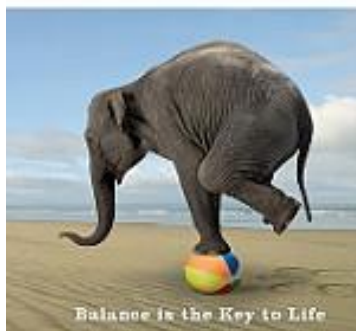
Consulting with [WEGO Health Solutions](#) as a user-tester lets me contribute to their mission to support and grow the network of paid patient and caregiver experts.

Kayla Nelson has been tutoring me on website design and social media. What a gas! Besides a complete remodeling, I've added [Portfolio](#) and [How Can I help You?](#) pages. My blog/web hits have increased dramatically. In 2017 almost 3,000 unique website users (more than 75% new visitors) spending almost two minutes per view while viewing an average of two pages. Between 30% and 40% of my subscribers open and read their weekly email. I understand this is a great number. You can subscribe to my blog [here](#). My most popular posts were [Paying Patient Experts](#), [100th Birthday](#), [Cinderblocks](#), [Medical Advocacy](#), [CMS Quality Measures for People](#), and [Golden Rule](#). The most popular portfolio item was [Calling All Advocates Interview](#) with Mary Sue Schottenfels. Most people access my work through LinkedIn. Consistently more than 100 views, as high as 1,000, mostly not my followers. Jeesh.

Building on my PCORI, Communication and Dissemination of Research, adventure, I'm learning more about making choices on the health journey (informed decision-making) especially in treatment of MS, pain management, and end-of-life.

2018

I'm excited to be consulting with [two AHRQ funded initiatives](#): CDS Connect and the Patient-Centered Clinical Decision-Support Learning Network. I'm committed to developing my web Resource Center (no link yet). I'm already scheduled to speak in 2018 at the [Beryl Institute Conference](#) in Chicago, the [MGMA Operations Conference](#) in Phoenix, and [the International Waldenstrom's Macroglobulinemia Foundation \(IWMF\)](#) conference in Chicago. I will be a member of the Editorial Review Board for [the Journal of Participatory Medicine](#).



My priorities for 2018: support the caregiver community, focus on learning what works as we make health choices, improve communication during transitions, advocate for patient experts, and balance for me and as always, keep blowing my horn – ONWARD!