

Reaction to our story on Emily's Entourage and other patient groups striving for targeted research:

Is Competition Among Hospitals Hurting Patients?

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I met Emily Kramer-Golinkoff and her mother Liza for coffee earlier this year. A mutual friend connected us. She thought that we could help each other out. I knew little of Emily's personal story going into the meeting. In the words of Jerry Maguire, she had me at hello.

Those of us who suffer a hardship or tragedy are usually advised not to compare grief. I think that advice exists so that we don't fall into the mindset of "woe is me." However, I never play that way. I always play for inspiration, and when I heard Emily's story, I was in awe.

I lost a three-month old son in 2005 to an undetected heart condition. After his passing, we started Simon's Fund to raise awareness about conditions that lead to sudden cardiac arrest and death in children. That's my backstory.

Emily is thirty-one years old. She has advanced stage CP. She spends hours every day for treatments. Then she gathers up the strength and courage to change a system that has perplexed CEOs, lawmakers and bureaucrats for years. She is fighting for her life and the lives of others too. Awe is really the only word.

I was glad to see Emily's story appear in this month's *Healthcare Transformation*. She has so much wisdom to share with all of us. I was especially interested in her recipe for success where the key ingredient is collaboration.

That is what brought us together for coffee - the desire to help one another. That is also what has historically plagued the field of medicine - the lack of collaboration, or to put another way, fierce competition. I remember coming to the realization about two years into our mission that hospitals were just as competitive as BIG10 Football teams. Competition is good. It challenges people to work hard and fast for a desired outcome. However, that's not a good formula for research, particularly when data and money are scarce, and time, as in the case with Emily, is limited.

Consider an alternative. Are you familiar with the Bravo hit reality show Top Chef? A group of chefs are given the same set of ingredients. They have a limited amount of time to create dish. This is where the creativity, training and experience play a role. The judges pick the best dish. It is a pretty simple concept, like research.

Aren't data just like ingredients? It would be a very boring reality show, but what if we gave the same good data set to three academics. Couldn't they produce a variety of outcomes? Could we end up with a few valuable findings?

Like Emily, Nicole and Mark, we believe that innovation and collaboration are essential to medicine and research, and as the article suggests, it often times comes from the outside.

Three years, Simon's Fund developed and launched HeartBytes, a digital cardiac registry of seemingly healthy kids. We recognized that there was tremendous value in the data that was being gathered at our heart screenings and others around the country. **We also found it curious that researchers wasted so much time raising money and gathering data. They're not good at that. They're good at research. Therefore, we created a "free public library" model for research.** We would gather the data, de-identify it, and make it available to qualified researchers. We want more chefs in the kitchen.

Hopefully, this article will lead to the identification and collaboration of more disruptors. When their passion and perseverance is coupled with the expertise found in our country's medical institutions, there are no limits.