One More Thing...

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The last issue of *Healthcare Transformation* stirred a group of responses. Our interview with EPIC founder **Judy Faulkner** was picked up by *Politico*. And *Becker's Hospital Review* picked out nine things: “9 things **Judy Faulkner** said when she sat down with **Dr. Stephen Klasko**.”¹

Our article on **EMILY'S ENTOURAGE** struck home for many. **Emily Kramer-Golinkoff** found what many people with rare diseases find: that a clear path of scientific discovery is often interrupted by bureaucratic trivia. Her goal is to raise the funds and target her form of cystic fibrosis (CF). She's found Scientists to be approachable—indeed warm and caring.

And it's easy to understand how **Emily** builds her amazing worldwide network—she is herself remarkable.

Below is one reaction to **Emily's** story from the co-founder of another patient action organization, **Darren Sudman**. His response is perfect:

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 mind-set 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 31 years old. She has advanced stage CF. 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 2 years into our mission that hospitals were just as competitive as Big Ten 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 a dish. This is where 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 oftentimes comes from the outside.

Three years ago, 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 were 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. ■■■

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► Reference

1. Dietsche E. 9 things Judy Faulkner said when she sat down with Dr. Stephen Klasko. December 6, 2016. Available at <http://www.beckershospitalreview.com/healthcare-information-technology/9-things-judy-faulkner-said-when-she-sat-down-with-dr-stephen-klasko.html> (last accessed March 15, 2017).