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An Open Letter to the CRN Community

Our family cystinosis journey began roughly 15 years ago. Like many of you, I'm sure, when we finally received a diagnosis that our daughter, Kacy, had cystinosis, we experienced a wide range of feelings and emotions. I recall a young doctor sitting with us and saying "you are in for a long and difficult journey". Fortunately he also said "and I have been watching how you care for your daughter and I know you are up to the challenge". My wife, Jen, and I really needed to hear both of those messages. Yes, cystinosis is a difficult journey AND yes we can handle it.

CRN and the caring people that make up CRN have helped us meet the challenge over the years. Fortunately before the initial daze of the two week hospital stay that lead to Kacy's diagnosis, we found CRN. Wow, cystinosis is such a rare disease but we actually found a place, a community to help us. We remain grateful to the founders of CRN, going back to 1996, as well as all of the hard working volunteers since then.

Until there is a cure for cystinosis CRN is committed to its three pronged mission dedicated to: supporting and advocating research, providing family assistance and educating the public and medical communities about cystinosis.

Current board members of CRN include: Jen Sexstone, Ina Gardener, Christy Greeley, Jen Wyman, Marybeth Krummenacker, Jonathan Dicks, Carol Hughes, John Maccarone, Gail Potts, Herberth Siegler, and Melanie Vachon.

Over the last few months, 6 board members have chosen to resign from serving the CRN Board. This is disappointing. This is sad. This weighs on my mind and heart. The individual reasons for their resignation is their story to share, not CRN's. This isn't about the organization's transparency, it's about respect.

CRN is in a healthy financial position thanks to the commitment from the entire community including individual donors and industry partners. The website (cystinosis.org) contains both financial information as well as the organization's By Laws. My sense is that if you compare this transparency to other organizations that you will find CRN as a leader in this area.

CRN By Laws and operating processes are consistent with other nonprofits and best practices. CRN is organized with a Board providing overall policy, an Executive Committee, and Executive Director.

CRN is managed by the Executive Director who is primarily responsible for the overall operations of CRN. This is both common and a best practice. There are decisions to be made each day and it is not practical or a best practice for a full board to vote on every decision. For example, before I was interim president, I did not get involved or vote on signing a standard contract with a hotel for the conference; nor did I expect to. This didn't involve policy or a change in the direction of CRN. This decision was best managed by the Executive Director and Executive Committee along with a professional and experienced meeting planner.

CRN is fortunate to have the support and expertise of a Medical Advisory committee and Scientific Review Board made up of many of the world's experts in cystinosis. We are blessed as a community to have their generous support and guidance as we execute on our core mission. We are excited that they will be participating in the CRN Virtual Conference coming up on July 16-18.

Speaking of the conference, like most organizations, CRN made the difficult decision to move to a virtual format in 2021. This process started many months ago. CRN is fortunate to have the volunteer services of Dana Marshall. Dana is a professional and experienced meeting planner. As in years past, Dana assists with determining our needs with the conference venue including common and standard legal agreements for events of our size. Near October 2020, it became evident that holding an in person event was not possible given the uncertainty of the pandemic at the time and its effect on the safety of our community and the ability for our speakers and advisors to travel and we began working with the hotel venue on an agreeable separation from the contract. Discussions continue to this day and we have outside legal counsel assisting us in the process at this time. While CRN firmly believes based on counsel of hospitality law experts that it was legally impossible to hold the event due to COVID19, as you might imagine conference venues looking at losing significant revenue do not necessarily share that opinion. CRN has the right experts (non Board members) working on its behalf. As someone whom has contributed and/or raised significant dollars for CRN, please know that financial stewardship is very much on my radar.

Cystinosis has brought us together as a community. Whether you support CRN or another organization, we are a community. And, until there is a cure for cystinosis, we need to work together.

Respectfully,

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