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Subj: Cystinosis Patient Survey Coming Soon/Request for Contact Info

**Cystinosis Patient Survey Coming Soon/Request for Contact Info**

For the Cystinosis Research Network, understanding and addressing the challenges associated with cystinosis is a top priority. As such, we are gearing up to send out a survey designed to help us learn more about important areas affecting our community. You know better than anyone the challenges that come with the diagnosis, insights we hope you'll share by completing a quick and easy survey.

**But we don't have all your contact information!** We hope you'll help fill in the blanks by sharing your phone number – that way we will be able to reach you to ensure we capture your responses. Of course, all of your personal and contact information will remain confidential.

Please help us update our records by clicking on the following link and entering your first and last name, phone number and zip code. <http://www.surveymonkey.com/s/VY9YZGR>

And keep an ear out for our call! We look forward to speaking with you then.

Thanks!

Christy

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*The Cystinosis Research Network's vision is the discovery of improved treatments and ultimately a cure for cystinosis. The Cystinosis Research Network (CRN) is a volunteer, non-profit organization dedicated to supporting and advocating research, providing family assistance and educating the public and medical communities about cystinosis.*