

THE CYSTINOSIS Advocate

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JOIN US!

2025 CRN Family Conference

Amway Grand Hotel | Grand Rapids, Michigan
Friday, July 11 - Sunday, July 13

Connect with each other, **learn** the latest,
meet experts in research and treatment!



CYSTINOSIS SYMPOSIUM A Rare Disease Model for Comprehensive Care

The CRN hosted an event focused on the importance of building multidisciplinary healthcare teams. Learn more on pages 3 & 12.

A Heartfelt Collaboration: Cards2Warriors and Cystinosis Warrior Steve

By Dawn Veselka, co-founder Cards2Warriors

Have you heard about Cards2Warriors? If not, it's time to get acquainted with this inspiring Central Florida-based non-profit. Their mission is simple yet powerful: to spread love and cheer through the art of snail mail. They're reaching out to warriors, caregivers, siblings, and medical professionals with heartfelt messages designed to inspire hope and perseverance in the face of life's toughest challenges. Their goal? To send 100,000 messages filled with love to those who need it most.

One of the unique aspects of Cards2Warriors is that all their card designs are created by artists who live with illness. This not only adds a personal touch but also brings diverse perspectives and energies to their work. Earlier this year, thanks to their partnership with Amgen Rare Disease, they teamed up with Cystinosis Warrior and Adult Leadership Advisory Board (ALAB) member, Steve Schleuder, to create a special multi-purpose card.

The card features a vibrant sunset design on the front, perfect for any encouraging sentiment or life event. On the back, you'll find a photo of Steve, a bit about his journey, and a QR code to learn more. Steve, beloved throughout the rare disease community, is known for his warm demeanor, graphic design skills, and his genuine heart for helping others. His contribution to this project adds a layer of authenticity and hope that resonates deeply with recipients.

Collaborating with artists like Steve is a core part of Cards2Warriors'

mission. It's not just about sending cards; it's about sharing stories, spreading awareness, and creating connections that uplift both the senders and the receivers. Steve was a joy to work with, and his unique artistic style shines through in this collaboration. We're excited to send these special cards to his fellow Cystinosis warriors and their care teams (while supplies last).

If you enjoy receiving mail, we encourage you to sign up on their website: <https://cards2warriors.org>. The programs are completely free, and your information will never be shared. Cards2Warriors sends cards throughout the year, so you never know when one might land in your mailbox!



When signing up, be sure to mention that you were referred by the Cystinosis Research Network (CRN). And for those who might hesitate to sign up, thinking that someone else might need a card more, please reconsider. Everyone deserves a little love and encouragement!

Cards2Warriors is on a mission to send out 100,000 cards, and they'd be delighted if one of them found its way to you. Life with illness is full of challenges, but through all the ups and downs, Cards2Warriors wants you to know that you are seen, cared for, and loved. So go ahead, sign up today — you deserve it!

JOIN OUR Happy Mail Program



WE SEND CARDS OF HOPE AND CHEER TO ILLNESS WARRIORS AND THEIR CARE TEAMS!

Our programs are *FREE* and
we *NEVER* share your information. Ever.

 **Sign Up Today!** 

www.Cards2Warriors.org