

# SUPPORT FOR THE CYSTINOSIS COMMUNITY

At Amgen, we are committed to providing support and resources to individuals living with rare diseases. With support built around the patient, we serve as a partner in their journey, providing each person with access to a range of programs, educational materials and opportunities to connect with the rare disease community.

## OUR DEDICATION TO PEOPLE LIVING WITH CYSTINOSIS



Financial assistance in place so that, where eligible, cost is not a barrier for individuals to receive our medicines<sup>1</sup>



Dedicated one-on-one support throughout the treatment journey from Patient Access Liaisons (PALs) that work directly with individuals to provide non-medical, logistical assistance<sup>2</sup>



Connection to resources that may help with disease education, meeting others in the community, self-advocacy and access to diagnostic testing

## CYSTINOSIS COMMUNITY ORGANIZATIONS

**American Association of Kidney Patients** | [AAKP.org](http://AAKP.org)

**Cystinosis Research Network** | [Cystinosis.org](http://Cystinosis.org)

**American Kidney Fund** | [KidneyFund.org](http://KidneyFund.org)

**Dialysis Patient Citizens** | [DialysisPatients.org](http://DialysisPatients.org)

**Cystinosis Research Foundation** | [CystinosisResearch.org](http://CystinosisResearch.org)

## COMMUNITY SUPPORT AND SERVICES

### FINANCIAL RESOURCES

**Bromberg & Associates** | [BrombergTranslations.com](http://BrombergTranslations.com)

Provides translation services for 200+ languages at no cost to individuals and families impacted by health conditions

**Good Days** | [MyGoodDays.org](http://MyGoodDays.org)

Provides individuals and families with financial and travel assistance

**National Organization for Rare Disorders Programs (NORD)** | [RareDiseases.org](http://RareDiseases.org)

#### Co-pay Program

Assists eligible individuals who have health insurance to cover deductibles, copayments and coinsurance costs associated with the care of rare diseases

#### Emergency Relief Program

Supports eligible individuals and families who need financial support when faced with limited resources to pay for unexpected or emergency non-medical expenses

#### Medical Assistance Program

Assists eligible individuals who are uninsured or for whom coverage has been denied, with out-of-pocket costs for medical expenses

 For more information, contact NORD Patient Services and Information and Resource Services at 800.999.6673 or by filling out their contact form at [www.rarediseases.org/contact/](http://www.rarediseases.org/contact/)

**Patient Advocate Foundation's Rare Disease CareLine** | [RareDisease.PAFCareline.org](http://RareDisease.PAFCareline.org)

Provides free and confidential assistance with financial and practical challenges that impact an individual's ability to access healthcare

**The Assistance Fund** | [TAFcares.org](http://TAFcares.org)

Provides support for adults and children with rare and chronic diseases, including financial and travel assistance

1. Assumes utilization of Amgen financial support programs

2. Available to those prescribed with an Amgen medicine

## MENTAL HEALTH RESOURCES

### **Angel AID** | [AngelAidCares.org](https://AngelAidCares.org)

Provides mental health and wellness services to rare families through transformative retreats and a connective caregiver-to-caregiver multilingual network

### **Center for Chronic Illness** | [TheCenterForChronicIllness.org](https://TheCenterForChronicIllness.org)

Provides online support groups and educational events for those living with chronic health challenges

### **Give An Hour** | [GiveAnHour.org/RareCaregivers/](https://GiveAnHour.org/RareCaregivers/)

Supports caregivers and families impacted by rare diseases through one-on-one peer support, group support, professional training and research

### **Our Odyssey** | [OurOdyssey.org](https://OurOdyssey.org)

Connects young adults impacted by rare and chronic conditions with social and emotional support

## TRAVEL RESOURCES

### **Angel Flight Northeast** | [AngelFlightNE.org](https://AngelFlightNE.org)

Provides free medical air transportation in the U.S. for individual's needing financial assistance utilizing private, corporate and airline resources

### **Miracle Flights** | [MiracleFlights.org](https://MiracleFlights.org)

Provides financial assistance to low-income families for commercial air travel to obtain special medical care

## COMMUNITY ORGANIZATIONS

### **EURORDIS – Rare Diseases Europe** | [EURORDIS.org](https://EURORDIS.org)

### **Global Genes** | [GlobalGenes.org](https://GlobalGenes.org)

### **National Organization for Rare Disorders (NORD)** | [RareDiseases.org](https://RareDiseases.org)

### **One Rare** | [OneRare.org](https://OneRare.org)

### **Remember the Girls** | [RememberTheGirls.org](https://RememberTheGirls.org)

### **The Akari Foundation** | [TheAkariFoundation.org](https://TheAkariFoundation.org)

### **The Everylife Foundation for Rare Diseases** | [EveryLifeFoundation.org](https://EveryLifeFoundation.org)

## ABOUT AMGEN

Amgen harnesses the best of biology and technology to make people's lives easier, fuller and longer. We are on the cutting edge of medical discovery, reliably inventing powerful therapies. We are focused on fighting the world's toughest diseases and helping millions of people globally.

If you would like to speak with us – or have ideas you would like to share – please send an email to [RareConnect@amgen.com](mailto:RareConnect@amgen.com).

