



## **Cure Cystinosis** International Registry

### CCIR Committee

**Clay Emerson, PhD, PE, CFM**  
**Jill Emerson, CPA**  
**Stephen L. Jenkins, MD**  
University of Utah Health and University Hospital  
**Nancy J. Stack, MPA, JD**  
Cystinosis Research Foundation

### Researchers and Clinicians

**Natalie A. Afshari, MD, FACS**

Shiley Eye Institute  
La Jolla, California

**Corinne Antignac, MD, PhD**

Imagine Institute (Inserm U1163)  
Paris, France

**AVROBIO**

Cambridge, Massachusetts

**Bruce A. Barshop, MD, PhD**

University of California, San Diego  
La Jolla, California

**Stéphanie Cherqui, PhD**

University of California, San Diego  
La Jolla, California

**Ranjan Dohil, MD**

University of California, San Diego  
La Jolla, California

**Francesco Emma, MD**

Bambino Gesù Children's Hospital  
Rome, Italy

**Morgan V. Fedorchak, PhD**

University of Pittsburgh  
Pittsburgh, Pennsylvania

**Anthony W. Gannon, MD, FAAP, FACP**

Alfred I. duPont Hospital for Children  
Wilmington, Delaware

**Laurence Greenbaum, MD, PhD, FAAP**

Emory School of Medicine  
Atlanta, Georgia

**Paul C. Grimm, MD**

Stanford University School of Medicine  
Stanford, California

**Julie R. Ingelfinger, MD**

Massachusetts General Hospital  
Boston, Massachusetts

**Robert Mak, MD, PhD**

University of California, San Diego  
La Jolla, California

**Kathleen Rickert, MD**

University of California, San Diego  
La Jolla, California

**Reza Seyedsadjadi, MD**

Massachusetts General Hospital  
Boston, Massachusetts

**Doris Trauner, MD**

Rady Children's Hospital  
San Diego, California

### CRF Community, Family and Patients

**Marcu Alexander**

Hearts for Hadley  
Boise, Idaho

**Denice Flerchinger**

Tina's Hope For A Cure  
Clarkston, Washington

**Kurt Gillenberg**

Patient Advocate  
Santa Clarita, California

**Shannon Keizer**

Patient Advocate  
Caledonia, Michigan

**Teresa Partington**

Jenna & Patrick's Foundation of Hope  
Sacramento, California