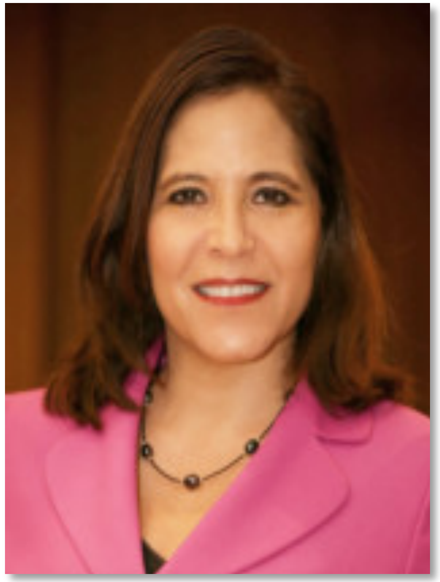
advocacy CHATS

COA Patient Advocacy Network

National Organization for Rare Disorders

Jill Pollander, RN, MSN
Vice President of Patient Services
National Organization for Rare Disorders (NORD)



Rose Gerber, M.S.
Director of Patient Advocacy & Education
Community Oncology Alliance

advocacy CHATS COA Patient Advocacy Network

Today's Chat Agenda

- **Updates: Community Oncology Alliance (COA) and COA's Patient Advocacy Network (CPAN)**
  - Save the Date: CPAN Virtual Advocacy Summit – September 28, 2022
- **Overview of the National Organization for Rare Disorders (NORD)**
- **Insight into NORD's Rare Cancer Coalition**
- **Patient Resources and Assistance**

Learn more:
COA's Patient Advocacy Network: www.coaAdvocacy.org
Community Oncology Alliance: www.communityoncology.org
National Organization for Rare Disorders: www.rarediseases.org

Save the Date!

Don’t miss our Virtual Community Oncology Advocacy Summit – Wednesday, September 28, 2022

COMMUNITY ONCOLOGY
VIRTUAL
ADVOCACY
SUMMIT
’22

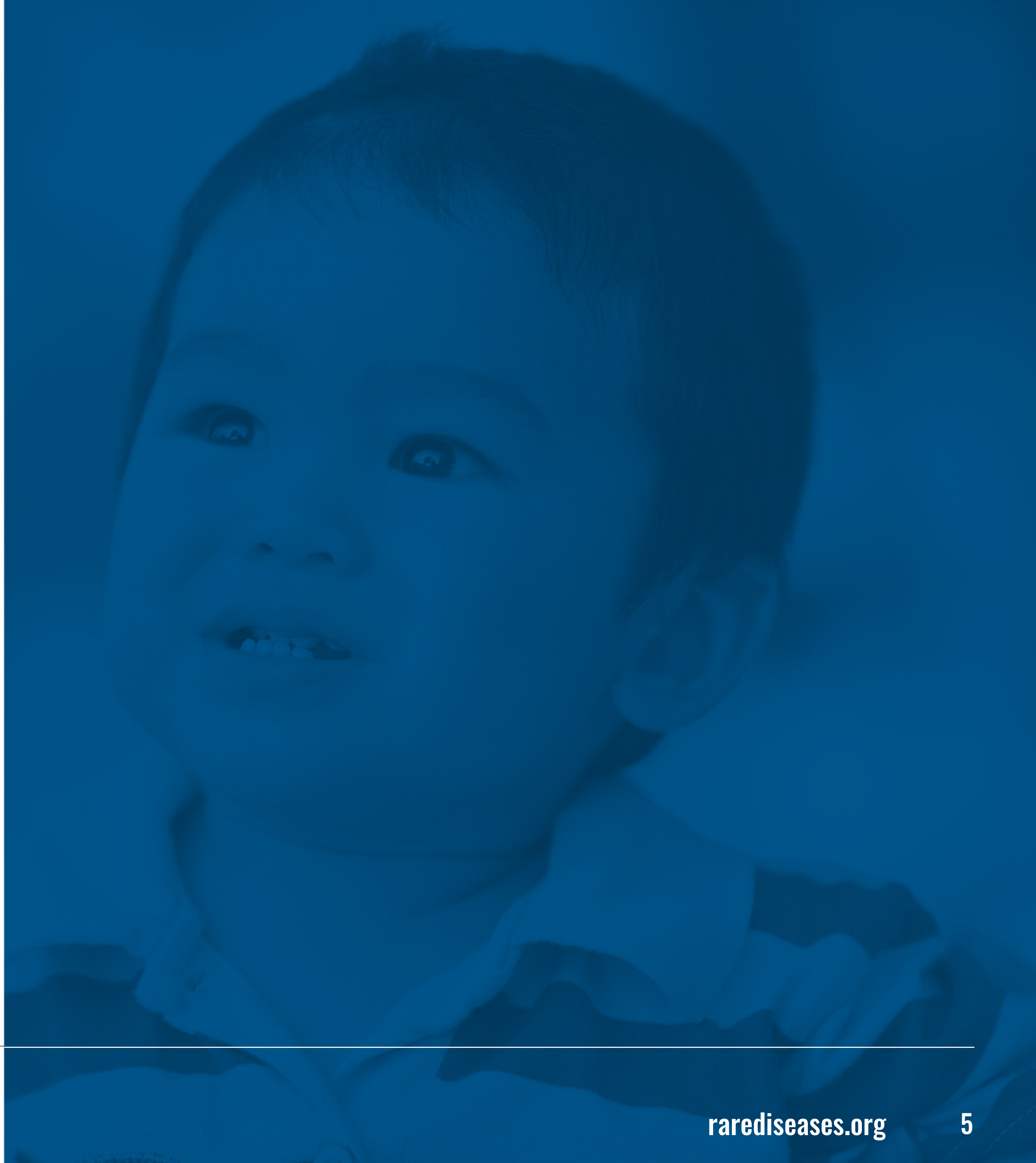
NORD: SERVICES & SUPPORT

Jill L. Pollander

Vice President of Patient Services

NORD® MISSION STATEMENT

NORD, a 501(c)(3) organization, is a patient advocacy organization dedicated to individuals with rare diseases and the organizations that serve them. NORD, along with its more than 330 patient organization members, is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and patient services.



PATIENT SERVICES & SUPPORT

- Dedicated Patient Services Team understanding of the nuanced needs that accompany a rare diagnosis:
    - Patient Assistance Programs
    - Information & Resource Services
    - Clinical Trial Support

PATIENT SERVICES & SUPPORT
800-999-6673

- NORD's Communication Center enables seamless communication via phone, email and fax.
- Dedicated Patient Services and Information Services Team
- Communication Center

  Mon-Thurs 8:30am-7:00pm EST

  Fri 8:30am-6:00pm EST

- High-touch, caring, concierge-level service

$35,642,186 awarded across all NORD assistance programs in 2020

9,951 patients with 265 rare diagnoses assisted

959 patients assisted with medical expenses not covered by health insurance

7,636 patients assisted with health insurance premiums and/or copay expenses

68,718 calls answered

65,983 emails answered

Travel and lodging assistance provided for 11 clinical trials

7 new assistance programs opened

Webpage views of NORD's RareCare® programs increased over 155% from 2019

Assistance provided to rare patients and families in 50 states and 5 US territories

NORD®

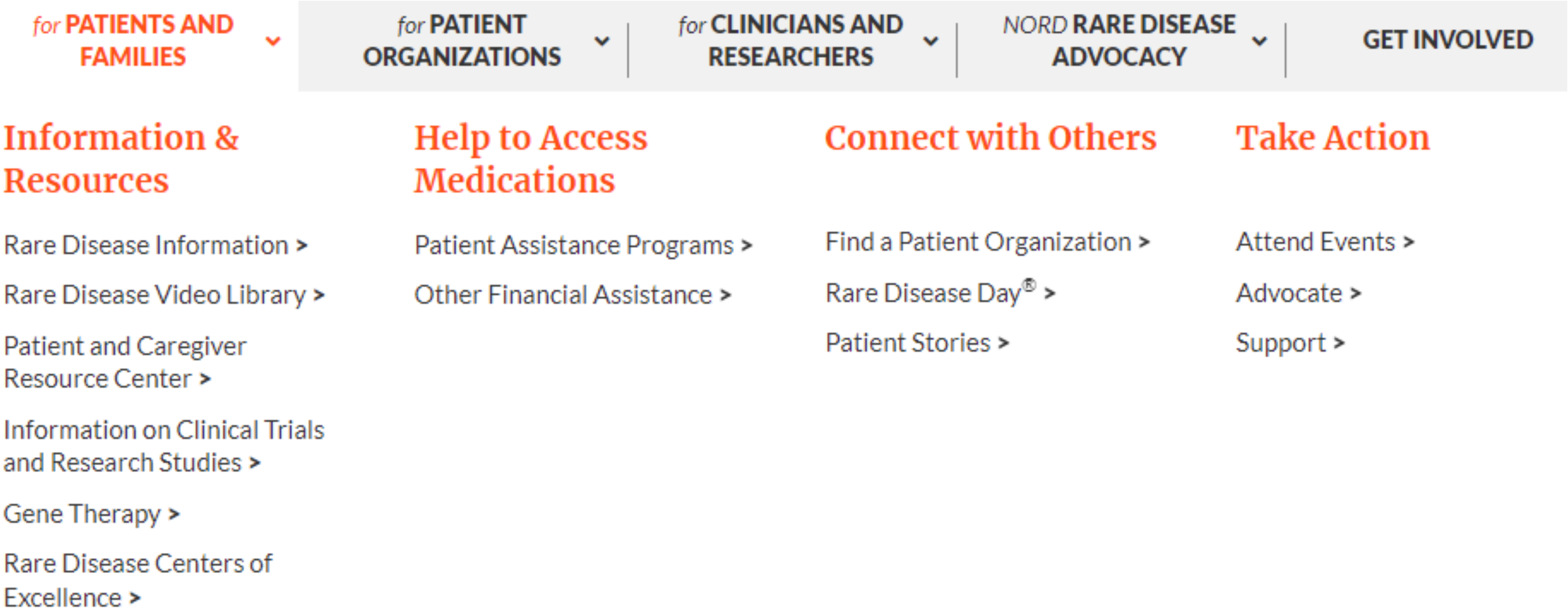
OUR WHY

NORD’S RARE CANCER COALITION (RCC)

- NORD’s Rare Cancer Coalition™ (RCC) is comprised of more than two dozen rare cancer patient advocacy organizations collaborating on issues facing the rare cancer community.
    - RCC collaborations:
        - Department of Defense (DoD) Peer Reviewed Cancer Research Program (PRCRP)
        - National Institutes of Health (NIH)
        - Global Drug Development (World Orphan Drug Congress)
        - Rare Cancer Day
        - FDA – Oncology Centers of Excellence
        - Rare Cancer Congress
        - and more…

RESOURCES

- RareDiseases.org



for PATIENTS AND FAMILIES

for PATIENT ORGANIZATIONS

for CLINICIANS AND RESEARCHERS

NORD RARE DISEASE ADVOCACY

GET INVOLVED

Information & Resources

Rare Disease Information >

Rare Disease Video Library >

Patient and Caregiver Resource Center >

Information on Clinical Trials and Research Studies >

Gene Therapy >

Rare Disease Centers of Excellence >

Help to Access Medications

Patient Assistance Programs >

Other Financial Assistance >

Connect with Others

Find a Patient Organization >

Rare Disease Day® >

Patient Stories >

Take Action

Attend Events >

Advocate >

Support >

RESOURCES

- rarediseases.org/get-involved/rare-cancer-coalition/

NORD's® Rare Cancer Coalition® (RCC)

Address
1779 Massachusetts Avenue NW
Ste 500
Washington, DC 20036 USA

Phone
202-545-3971

Email Address
Membership@RareDiseases.org

Website
https://rarediseases.org/get-involved/rare-cancer-coalition/

NORD® RARE CANCER COALITION


NORD
National Organization for Rare Disorders
Rare Impact Award
June 22, 2019

Thank you.

Thank You to Jill Pollander & Our Listeners!

Don’t miss our next advocacy chat

Wednesday, August 10, 2022, 12:00 PM – 12:30 PM ET

Lauren Chatalian, MSW, LCSW
Director of Advocacy
CancerCare