



CPAG:

Perspective from an RDCRN Consortium
PAG as Research Partner

Partners
for a
Healthier
Future

WHAT IS CPAG?

- The Coalition of Patient Advocacy Groups or 'CPAG' is the collective representation of patient groups affiliated with the consortia of the Rare Diseases Clinical Research Network (RDCRN), a program of ORDR/NCATS.
- CPAG is composed of representatives from each patient group in the network who are tasked with being FULL PARTNERS in the research undertaken by their RDCRN consortium



WHAT IS CPAG?

- CPAG members influence the direction of the Rare Diseases Clinical Research Network as a whole. They participate in network-level discussions and meetings. The CPAG coalition, through its leadership, is a voting member of the RDCRN Steering Committee.



WHAT IS CPAG?

- 100+ voluntary health/patient advocacy organizations representing a variety of rare disorders
- Extremely diverse in resources, experience, name recognition and infrastructure (see “snapshot” slide)
- All committed to rare disorders research through the RDCRN



WHAT CPAG IS NOT

- CPAG is not an independent patient representative group
- CPAG as an entity exists only in the context of the RDCRN
- CPAG's focus and activities are limited to (and only to) issues related to the RDCRN



CHALLENGES FOR CPAG

DIVERSITY CHALLENGE

- The member groups that comprise the entity collectively known as “CPAG” are incredibly diverse and range from “Kitchen Table” organizations with no staff and little revenue to multi-million dollar non-profit corporations with professional staff and access to consistent funding sources.
- Many of the PAGs associated with the RDCRN are operating with extremely limited financial and human resources.

How can we meet the needs of such a diverse coalition of member groups and fulfill our commitment to be partners with RDCRN investigators?



CHALLENGES FOR CPAG HAT CHALLENGE



- The member groups that comprise the entity collectively known as “CPAG” are dedicated professionals with a laser focus on their individual diseases

As CPAG representatives, we must wear several different hats and be sure we are considering the needs of the RDCRN as a whole, in addition to our individual consortia and groups



ADDRESSING THE CHALLENGES

- CPAG leadership

Chair: Chuck Mohan (UMDF/NAMDC)

Co-Chairs: Janet Hieshetter (DRF/DC)

Joyce Kullman (VF/VCRC)

Cynthia LeMons (NUCDF/UCDC)

- Work closely and receive guidance from ORDR staff



OPPORTUNITIES FOR CPAG

1. Face to Face Meetings
2. Monthly Calls
3. Working Groups of CPAG
4. Committees of the Steering Committee



CPAG MISSION AND VISION

■ CPAG Vision

Through collaboration, patient advocacy groups and researchers can make faster progress toward new treatment options and cures, which can improve the lives of all persons and families affected by a rare disease.

■ CPAG Mission

The Coalition for Patient Advocacy Groups will promote collaboration between rare disease advocacy organizations and the Rare Diseases Clinical Research Network in order to facilitate better access to, and earlier benefit from, research conducted on rare diseases. As the patient advocacy arm of the Rare Diseases Clinical Research Network, CPAG members will use their position to advance the cause of rare disease research and improved patient outcomes through the network.

PCD Timeline

----- Indicates start of RDCRN/GDMCC

