Trials, Tribulations and Triumphs: Our Journey Through Rare Disease Clinical Trials

Wednesday, May 26, 2021
5:30—8:30 pm

Zoom Meeting
Log in from the convenience of your home or office—Zoom link will be provided.

Speakers:
Donna Appell, RN
Executive Director
Hermansky-Pudlak Syndrome Network Inc.
Oyster Bay, NY

Pamela Johnson, MPH, CCRC
Research Education and QI Specialist
Hartford Healthcare
Hartford, CT

Program Description:
A rare disease, as defined by the Rare Diseases Act of 2002, is any disease or condition that affects fewer than 200,000 people in the U.S., or about 1 in 1500 people. However this definition does not encompass the trials, tribulations and triumphs a patient with a rare disease or their loved ones go through in trying to find a treatment. Join us in hearing about the personal experiences of our speakers in their rare disease journey. The program will include a viewing of the documentary “RARE” on the challenges of recruiting for a rare disease drug trial.

At the end of the program, attendees should be able to understand the:
- challenges patients with rare disease face in finding a diagnosis and in finding a treatment.
- orphan disease designation and its implications.
- importance of clinical trial participation, in particular the need for a collaborative effort.
- importance not only of self-advocacy, but of combining effort within the rare disease community.

Agenda:
5:30-5:45 Welcome and Icebreaker
5:45-5:50 Receiving Contact Hours
5:45-8:30 Educational Program and Q & A

Target Audience: All clinical research professionals

Cost: Complimentary for ACRP NY Metro and Philadelphia Chapter Members/$25 for all others.

Registration: Register at Eventbrite until Tuesday, May 25, 2021, 12 pm. No refunds after May 25, 2021. Log in information will be sent after registration ends. Only one registrant per email.

Dual Registration to the session is required. After purchasing your ticket on EventBrite, you will receive an email with a Zoom registration link 1 day before the event. You MUST register on that Zoom link to confirm your identity in order to be sent the Zoom link for the actual event.

After registering on Zoom, you will receive a confirmation email containing the link to join the session.

Contact hours: 3.0 Contact hours are pending approval by ACRP. Membership is not required for online registration of contact hours.

Contact Hour Cost: Complimentary for Chapter Members/$15 ACRP Members/$30 Non-Members

To receive contact hours: Purchase the contact hours on the ACRP NY Metro Chapter website up to two weeks after the event. Between 1 and 30 days after attending the program, go to https://acrp.digitellinc.com/acrp/login to complete the evaluation. You can also get to it by going to the “My Courses” link and clicking on the button for Chapter Events (the button on the left side). Once you are on the platform, click on Chapter Events on the left, click on the correct event, select the CE Information tab and click on the “Take Evaluation” button. It takes one business day for the information to refresh in your account.