

CCG Clinical Trial US and Global Case Studies

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CLINICAL TRIAL RARE DISEASE PATIENT ADVISORY BOARD MEETING



What

Convene a group of HLH patient advocates including disease specific, family foundations and rare disease groups.

GOAL: Drive greater understanding of HLH patient and carer experience, obtain relevant insights to better design clinical trials to insure recruitment and endpoint data success.

How

- Explore challenges from point of diagnosis, treatment, survivorship and beyond
- Identify unmet needs and gaps in disease education
- Discuss evolving HLH treatment landscape
- Understand obstacles for clinical trial participation, i.e. travel, carers, access to trial sites, financial, etc.
- Brainstorm a vision for what improvements in HLH awareness and support is needed
- Create a forum for on-going dialogue around shared priorities for structuring trials to ensure recruitment and sustained participation

Outcomes

- Full day meeting at company headquarters uniting advocates and appropriate cross-function staff
- Gained critical insights to align with clinical trial design and trial access points
- Appreciation from all participates to being brought in early
- Consensus to continue bi-directional discussions



















CLINICAL TRIAL SURROUND SOUND THROUGH INNOVATIVE COLLABORATIONS

The ARISE-HF trial is evaluating the effectiveness and safety of an oral investigational drug called AT-001 in adults with Diabetic Cardiomyopathy.

ARISE-HF



Florida Medical Association RESULTS

- Leveraged PI Trial presentation video shared directly via email with 18,000 FMA members
- CT web banners ads and leaderboard featured on FMA's website with click-through rates for members at 28-30%
- CT information reached FMA 25,000+ members in Florida



- 95k views
- **2,500** followers
- f 11,200 followers

Florida Nurse Practitioner RESULTS

- Pre-recorded PI presentation shared with 125 attendees during FNPN's virtual conference.
- Clinical Trial web banners ads and leaderboard featured on ENPN's website – four months
- CT info reached 13,000+ NPs throughout Florida and over 26 advanced practice registered nursing (APRN) groups statewide



Diabetes Sisters RESULTS

- Virtual DbCM education on YouTube with a pre-recorded segment by PI
- Instagram "Did you Know" segments ran daily in mid-September
- Diabetes Sisters has half-million website visitors per/year





SICKLE CELL CLINICAL TRIAL EDUCATION ALIGNED TO U.S. MULTI-STATE & UK TRIAL SITES

The Situation

 Difficulty enrolling patients in trials due to stigma, lack of trust due to historical issues within black communities.

CCG Engagement:

- Identified PAOS and KOLs and opportunities for engagement based on country regulations
- Designed patient-friendly materials and information to help promote patient enrollment and retention in compliance with ABPI Code
- A clinical trial education congress was hosted by stakeholders & KOLs in conjunction PI.

Results:

- There was 100+ patients in attendance and the program/materials shared
- Dramatic increase in enrolment
- Stakeholder feedback supporting our client was impressive
- 1:1 Trial Coordinator onsite discussions to further reinforce and encourage enrollment

Approach: Community Patient Engagement Meetings (Pem)*

Based on comprehensive advocacy landscape assessments, established a framework in US & UK priority markets for patient engagement and clinical trials educational meetings, in collaboration with state chapters of the National Sickle Cell Disease Association of America and the Principal Investigators of client-sponsored trial.

