



# Talk NERDY



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## Executive Summary

The primary goal of the Talk NERDY program is to empower the over 65 population to learn about and engage in clinical research in meaningful ways. Researcher teachers work with Alliance staff to create interactive curricula that include a broad overview of the roles of NIH, FDA, and pharmaceutical companies, teach PICOTS through reading and evaluation of research articles, and include breakout sessions with direct interaction with researcher teachers. Questions and substantive discussion are actively encouraged.

Participants: Individuals with chronic conditions in Heart Valve Disease, Atrial Fibrillation, Alzheimer’s Disease/Other dementias, Age-related Macular Degeneration (AMD), and Chronic Pain and/or their caregivers

Takeaways:

- 1) Do not assume medical literature is too hard to understand but be willing to discuss nomenclature,
- 2) Small Breakout groups with good facilitators is key to productive discussion, and
- 3) Recruit researcher teachers that believe in patient engagement, are willing to address challenging topics, and are accessible in the moment.

**Patient access to researchers who listen and engage is the #1 priority for Talk NERDY attendees.**

## Patient Engagement Strategy: Structure and Partnerships

In-person training that migrated to Zoom, Google classroom, and email

- Attendees complete an application form and interview, participate in an orientation session with introductions, complete homework, participate in (6) training sessions, and complete a follow-up lessons learned interview
- Partnership organizations recruit attendees from their membership; other organization participate as observers
- Current alumni (over 150 people) recruit new participants
- Researcher teachers involved have a background in one of the 5 diseases, gerontology, or statistics

## Successes

Talk NERDY graduates have served in numerous research advocacy roles:

- Consumer reviewers for the Congressionally Directed Medical Research Programs
- PCORI Ambassadors
- FDA Advisory Committee members/FDA/Clinical Trials Transformation Initiative Patient Engagement Collaborative
- Presenters at large scientific conferences such as AAIC (Alzheimer’s Association International Conference)
- Presenters to Congress as official disease representatives for increased research funding, and
- Founders of disease-specific non-profit advocacy organizations.

## Findings/Lessons Learned

Recruitment challenges for Heart Valve, AMD, rural and minority populations for all conditions:

- Increased partnerships (including invitations to observe the training)
- Switching from the use of organizational social media to alumni-based social media

Communication/Trust and Engagement

- Web-based platforms were not successful; familiar tools such as email, phone and zoom work best
- Hands-on availability is key
- Audio and visual aids for teaching (articles plus a video interview) are key

Finding research programs with an understanding of true patient engagement, and how to implement and fund that, is extremely challenging.

- More research organizations Talk the Talk than Walk the Walk
- Funding for patient engagement is not built into grants
- Institutions need buy-in, not just individual investigators
- Better training needs to be provided so that patient partners understand the conversation in the room
- IRBs need to be better educated about the importance and value of monetary reimbursement

## Long-term Goals

Continued growth of the Talk NERDY Program includes:

- Ongoing educational classes on Clinical trial safety (AEs, SAEs, DSMB, IRB), the Importance of Randomization and Blinding in Clinical Trials, and Co-morbidities Common in the Over 65 population: what they are and how they can affect clinical trial participation and format
- Ongoing webinars and guest speakers on research-specific topics
- Connecting Talk NERDY graduates with researchers and clinicians to create concrete opportunities for collaboration that result in positive contributions to the research process