Clinical Research Discussion in Support Groups

Another important role for the HD Social Worker
To HDSA 2008, CHDI, and all HD Social Workers . .
Thanks for all you do ..

• Triage in times of crisis.
• Provide counseling and support for patients, families and caregivers.
• Support Groups
• Advise, refer, and advocate for services.
• Participate in activities and fundraisers.
• And much more ..
So . . with all you already do . .

Why this topic about clinical research?

Why in support groups?

And why me?
Because ..

- Participation needs are huge.
- The time is right.
- The support group is a right place.
- Members want more discussion, and learn from it.
- AND bottom line, it is successful for recruitment.
A Look at the Numbers

Nearly 800 needed now:

- 2-CARE: 600 participants at 43 study locations
- PRECREST: 80 in Boston
- Memantine: 60 participants at 3 study centers
- Citalopram: 36 in Iowa
And within the next year . .

Nearly another 1000

- CREST: Will need another 650 participants.
- ACR-16: Will need another 100.
- Dimebon: May need several hundred more for PHASE 3.
- PREQUEST
Nearly another 1000

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- PREQUEST
And . .
that’s just the beginning . .

Several CHDI drugs are anticipated ready for clinical trials in near future (2 to 5 years), . . with more to follow.

*Bottom line: Long-term and on-going need for thousands, within and outside of usual trial centers.
Not just Numbers . . .

Pace of Recruitment

- Minocycline: (118) 12 centers, almost 2 years
- Dimebon: (90) 15 centers, 10 months.
- Memantine (60), 3 centers, still recruiting after several years.
- Citalopram: (36) 1 center, still recruiting after several years.

Suggests that the message is not getting out far enough quickly enough.
To best succeed:

We need every willing hand, lay and professional at all points of contact . . .

And engagement of “grass root” lay community efforts in recruiting process.
Why the Support Group?

• Most frequent community outreach.
• “Hands on” learning.
• Trusted supportive environment.
• Extended family reach.
Why Add the Lay Community?

• Fewer restrictions: Not constrained by IRB regulations, or organizational liabilities.

• History of success in aiding recruitment and retention (Breast Cancer best example).
The Northwest Project

• Grew out of my own (positive and negative) support group experiences.

• Modeled on successful community outreach in STAR breast cancer prevention trial.
To attend Northwest support group meetings to survey 100 members (HD and caretakers) before and after clinical research discussions.

The Reality: Due to time constraints: Survey formats differed (time constraints) among the 6 groups.
Survey Design

Assessment of clinical research:
• Interest
• Knowledge
• Factors influencing participation
Anonymous and voluntary.
Comfort with the Survey

![Bar graph showing comfort levels for HD and Caregiver groups. The graph indicates that the majority of subjects are "very comfortable" with the survey, with a small percentage experiencing discomfort with a few questions.](image)
Discussion Points

• Pace and description of drug development and introduced CHDI.

• Drugs in trial; drugs far along pipeline potentially near to trial.

• Mechanics of clinical studies and trials utilizing real-time examples; discussed criteria, informed consent, placebo, phases, safety, risk, personal issues.
The Results

The majority:

- Want more information
- Are interested in participation.
- Have little basic knowledge of clinical trials, but . .
- Learn many specifics of clinical trials.

Unanticipated Results: Recruits to TRACK-HD
HD Status
Gender

- HD
- Caregiver

Male
Female

0%
25%
50%
75%
Source of Clinical Trial Information

- Local doctor
- Center of Excellence
- Support group
- Internet

The chart shows the percentage of patients who get information about clinical trials from different sources. The highest percentage comes from support groups, followed by local doctors, centers of excellence, and the internet.
Do You Have Enough Information?

- HD before
- HD after
- Caregiver before
- Caregiver after
Interested in Clinical Trial Participation?

- HD before
- HD after
- Caregiver before
- Caregiver after

- Yes
- No
- Don't know
Preferred Mechanism to Notify you about Clinical Trials?

- Doctor
- Letter
- Email
- Phone
- Person
Would you be Comfortable with Web Registry?

- **HD**
  - Yes: 100%
  - No: 0%
  - Maybe: 0%

- **Caregiver**
  - Yes: 75%
  - No: 25%
  - Maybe: 0%
Your Most Important Reason to Participate

- Get new drug
- Help community
- Get best care

HD:
- Get new drug: 25%
- Help community: 75%
- Get best care: 0%

Caregiver:
- Get new drug: 25%
- Help community: 75%
- Get best care: 0%
Your Most Important Reason Not to Participate

- Missed work
- Distrust
- Confidentiality
- Too stressful
- Drug safety

HD

Caregiver
Factors that would Influence a Positive Decision

- Saturday assessments
- Reimbursement for travel
- Assistance from advocate
- None of the above
Can support group discussion be a successful part of recruitment?

For TRACK-HD:

• Successfully recruited 4 (5 volunteered, but did not fit criteria: 4 pre-manifest volunteers too far from onset, 1 early symptomatic on antipsychotic.

• Arranged car pools and negotiated Friday afternoon/Saturday assessments.
Literacy Results

- Baseline clinical research literacy is very low.
- Substantial learning occurred in many areas: understanding criteria, consent process, participant rights, placebo and blinded concepts.
- Substantial confusion regarding trial phases and medical care within clinical trials.
Right to leave trial

- **Correct**
- **Incorrect**
- **Don't know**

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Northwest Support Group Project

• HDSA (D. Lovecky, B. Boyle) and CHDI (R Blumenstein, D. van Kamman, J, Guiliano)
• Support groups in Ballard, Boise, Olympia, Spokane, Yakima and Snohomish/Everett
• Cindy and Amy Crossman, Donna Ross, Anne Spencer and Lael Hinds