Getting Others Involved: How To Be An Effective Advocate for Research Participation By Seniors

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Researcher Background: "I have..."

• Understood the importance of patient advocacy since I was a child (through family example)

• Served as a medical and community educator since 1986

• Successfully advocated for inclusion of a Community Liaison Council at the CFAR

• Personally experienced age discrimination when trying to volunteer for research studies

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Why research advocacy matters

• The general public thinks that research trials are intended to answer the question: “Does this drug/intervention work?”

• But what trials actually ask is: “Does this drug/intervention work on the study subjects?”

• Drugs and interventions don’t work identically on every age group ... so every age group needs to be included in clinical trials
Who can be an advocate?

Anyone:

• Who cares about seniors
• Who would be trusted by seniors
• Who wants to prevent or minimize suffering
• Who is concerned about health equity
• Who believes in scientific research
What does an advocate do?

• Helps scientists:
  ➢ Think about the importance of including seniors in research
  ➢ Ask the right questions
  ➢ Recruit the right subjects for the study

• Helps your peers:
  ➢ Think about the importance of participating in research
  ➢ Ask the right questions
  ➢ Agree to participate in the right studies
What does an advocate say?

• To help your peers:
  ➢ Think about the importance of participating in research
  ➢ Ask the right questions
  ➢ Agree to participate in the right studies

• Phase I trial ...
  of an experimental AIDS Vaccine
  ➢ Healthy volunteers
  ➢ Low risk for HIV
  ➢ Checking
    ✓ Safety & Side Effects
    ✓ Optimum Dosage
What does an advocate say?

• To help your peers:
  ➢ Think about the importance of participating in research
  ➢ Ask the right questions
  ➢ Agree to participate in the right studies

• Phase II trial ... of an experimental AIDS Vaccine
  ➢ Medium Risk for HIV
  ➢ Checking
    ✓ Unexpected side effects
    ✓ Does it work under optimal conditions?
What does an advocate say?

- To help your peers:
  - Think about the importance of participating in research
  - Ask the right questions
  - Agree to participate in the right studies

- Phase III trial ... of an experimental AIDS Vaccine
  - High Risk for HIV
  - Checking
    - Unexpected safety or side effect issues
    - Does it work in the real world?
Where does an advocate work?

• Develop the study concept:
  ➢ Discuss with researchers what is important to the community

• Secure funding:
  ➢ Assist in writing and reviewing grants

• Prepare the study protocol:
  ➢ Provide input on study design such as barriers to recruitment and/or participation
Where does an advocate work?

• Create study procedure:
  ➢ Help finalize eligibility criteria within the study protocol
  ➢ Assist in creating the informed consent protocol

• Implement the study:
  ➢ Assist with study recruitment
  ➢ Serve as a peer advocate during the informed consent process
Where does an advocate work?

• Monitor the study:
  ➢ Join a Data Safety Monitoring Board
  ➢ Provide recommendations for change, if needed

• Analyze data and Interpret results:
  ➢ Provide feedback on how the community will view the study results

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Where does an advocate work?

• Disseminate study information:
  ➢ Write newsletter articles or blog about results
  ➢ Co-present results at a conference or support group
  ➢ Work with research team to ensure that study participants get feedback from the study
Where does an advocate work?

• FDA review and approval:
  - Apply to be a consumer representative to an FDA advisory committee
  - Attend FDA hearings and give comments

• Post-approval studies:
  - Advocate with physicians for continued tracking of drugs, devices, an therapies
What interests you?

• Talk to the person sitting next to you about the information on these slides and discuss what YOU would like to do
• Write down the questions that come up during your discussion
• In 10 minutes we will meet as a group again to talk about your questions