

4th Annual Medical Research Summit
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The Role of Patient Advocates in Research

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- PAIR: Patient Advocates In Research
- InterSPORE Patient Advocate/Research Team
(PART) Program

Why Advocates In Research?

Bridging the Research Gap

- Scientists: experts on letter “Q”
- Patients: whole alphabet
- Offer new approaches to old problems



PAIR Goal: Better Answers Quickly

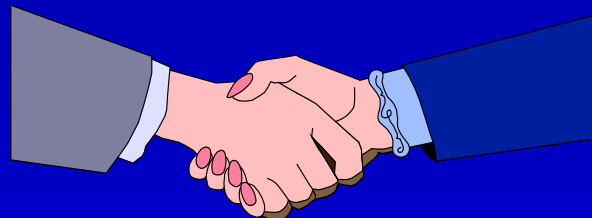
Transforming medical research into better results for people

Activities:

- Policies & Programs
NCI, FDA, OHRP, CSR, DoD,
ASCO, DoE
- Clinical Trial Issues
Design, Informed Consent,
IRBs, Accrual
- Genetic Protections
- Drug Development
- Tissue Issues
- Insurance Coverage
- Education

With...

- ✓ Federal Agencies
- ✓ Institutions & Clinics
- ✓ Cooperative Groups
- ✓ Industry Players
- ✓ Scientists
- ✓ Patients
- ✓ the Public



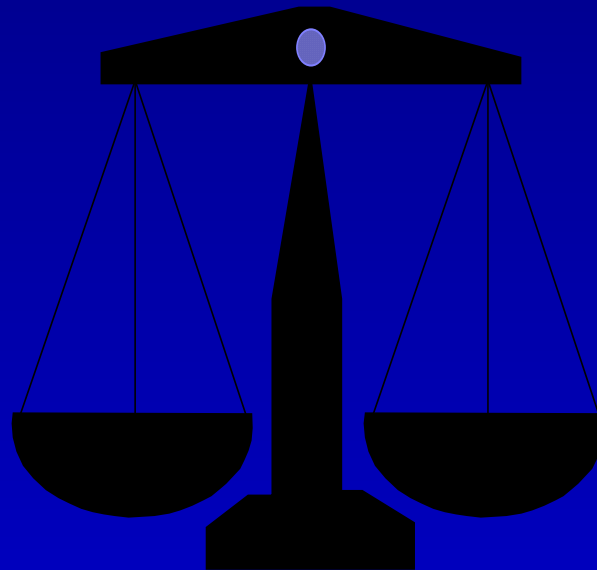
PAIR Example: A Reality Check(point)

Genetic Privacy

- DNA = Human Bar Code
 - ☒ Everybody wants it, affects YOUR family members

➤ Pros:

- Medical
"miracles"



➤ Cons:

- Everyone
knows all

How Do We Protect People & Still Do Research?

What Do Patients Want?

Patients ⇒ Public ⇒ People

A Cure. No? Then:

1. Best Treatment & Care
2. Medical Staff Who Cares
3. Information on Their Best Options
4. Good Quality of Life
5. Control over Something
6. Settle for Manageable Disease if Lengthens Life
7. To Die Painlessly

In Clinical Research:

- Protection, not coercion
- Choice, not paternalism
- Participate, not subject
- Truth, not rosy pictures
- Targets, not shotgun
- Leapfrogs, not step stones
- Outcome information
- CAM, Immunology, etc.
- To Be Treated Fairly

PAIR Example: Advocates in CALGB



Activities:

15 Core Patient Advocates
Diseases & Modalities
Advocate training
Trial design
Genetic policies
Help conduct trials
Newsletter & Outreach
Participant Communication

- *Ask "why?"*
- *Protocol review*
- *Bring in new ideas*
- *Tackle treatment fallacies*
- *Correlative science partners*
- *OPRR/DoD policy change*
- *Informed consents*
- *Increase accrual*
- *Sanity check*

InterSPORE

PART Program Goals



1. Help develop local Patient Advocate/Research Teams
 - Each SPORE is unique, models of successful teams as a guide
 - Proven steps to build successful teams
2. Connect PART teams together to share information
 - Share ideas & issues, moral support
 - Training and resources for scientific & advocacy concepts
3. Identify common SPORE issues & help resolve them
 - Regular SPORE polls to identify national priorities
 - Task forces to address them with action plan
4. Help build resource banks for clinical trial delivery
 - E.g. Collection of HIPAA experiences, IRB experiences, etc.
 - E.g. Collection of clinical trial delivery resources (consent & accrual)

Ex: InterSPORE PART Team...

UCSF Breast SPORE Advocacy Core

- Identify barriers that thwart translation to people
- Identify issues & solutions for patients in the scientific process (i.e. clinical trials, biospecimens, policies, & education)

WHAT?

- Help scientists speak English
- Represent patients
- Put people & ideas together
- Understand concepts
- Ask simple questions
- Blow up boundaries
- Focus on ultimate goal

HOW?

- Scientific meetings
- Exec Committee
- Vote on grants
- Protocol review comm.
- IRB member
- Trial/Instrument design
- Unique projects



UCSF BSAC Results:

Translational Barriers

Tissue Issues

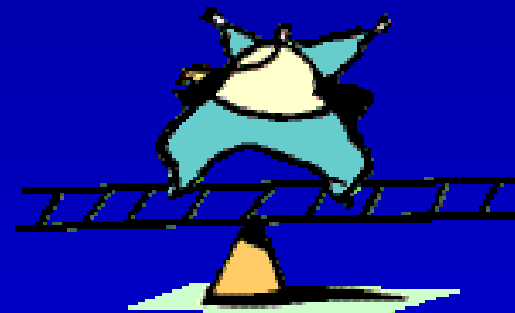
- UCSF Tissue Use Committee
- Input in consent process
- Tackle national challenges
- New ways to help collection

Accrual Issues

- Created clinical letters for UCSF patients
- Partnering with clinic
- Improving design
- Informed consent project
- Increased enrollment

Drug Development

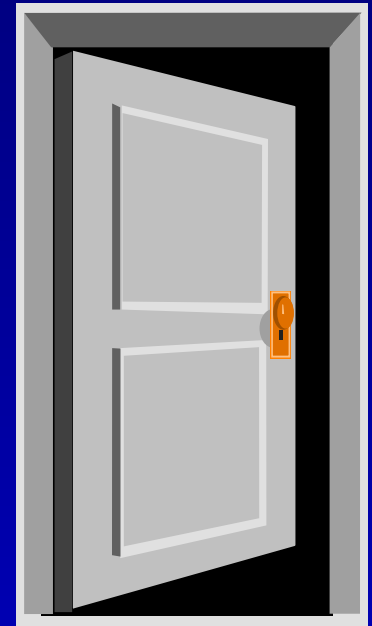
- Helped with NCI DN
- Strategize on industry ties
- Help w/Intellectual Property
- Activate PAIR advocacy network when needed



Why Advocates In UCSF BOP?

Scientist Survey said...

- ✓ Offer patient experience & perspective
- ✓ **Facilitate multiple communications**
- ✓ Focus discussion on **relevance**
- ✓ **Ask questions others won't**
- ✓ Put a "face" on breast cancer
- ✓ Give a sense of purpose
- ✓ **Won't tolerate "turf" wars**
- ✓ Support non-status quo ideas
- ✓ Foster community/public/national support
- ✓ **Influence research into more translatable direction**



Some Questions for YOUR Field...



1. Why do we try to fit medical research & its protections into 1 shoe size?
2. How are the medically underserved helped by being left out of the research genomic age?
3. What kind of steps are you taking to educate all patients on research protections that are in place?
4. How are you striving for balance between the pros & cons of medical research?

Thank You's!



- You for your interest & for listening to a patient
- UCSF Breast SPORE & Advocacy Core for support, insights & patience
- SPORE Patient Advocates for time & commitment
- SPORE PIs for openness to include patient advocates
- AVON & NCI for the SPORE opportunity