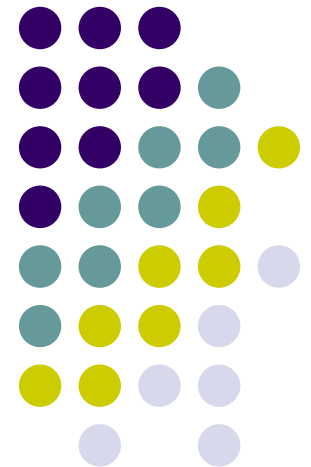


The SPORE PART Program

**An Introduction to the Patient
Advocate/Research Team
(PART) Program**



What Is the PART Program?



SPORE Patient Advocate/Research Team Program to:

- Enhance SPOREs' ability to translate effectively
- Help SPOREs & patient advocates work effectively together
 - Based on successful models
- Solicit feedback from SPORE investigators & patient advocates
- Program will develop, based on needs
- Voluntary participation (not a SPORE mandate!)

● **How is it Funded?**

- Through an InterSPORE supplemental grant, funded by AVON & NCI

● **Who is Involved?**

- Joe Gray, PI
- Deborah Collyar, co-PI & Program Director
- PART.core
- PART Advisory Team

Why Does PART Exist?



Internal Challenges to SPOREs

- Promote ongoing interdisciplinary research
 - Connect disciplines & researchers to common goals & collaborations
 - Instill the “team” concept
- Help resolve traditional barriers if they impede SPORE results

External Challenges to SPOREs

- Develop actions to resolve endemic SPORE issues, e.g.
 - HIPAA barriers +
 - Moving to preclinical & beyond
 - Intellectual property
 - IRB inconsistency
- Discussions w/key stakeholders (e.g. government, companies, institutions, associations)

Why are Patient Advocates Interested?

- Patient advocates think translationally!
- Recognize SPORE’s potential to get better answers to people more quickly



A Special Kind of Advocacy...



- **PART Program = Research Advocacy**

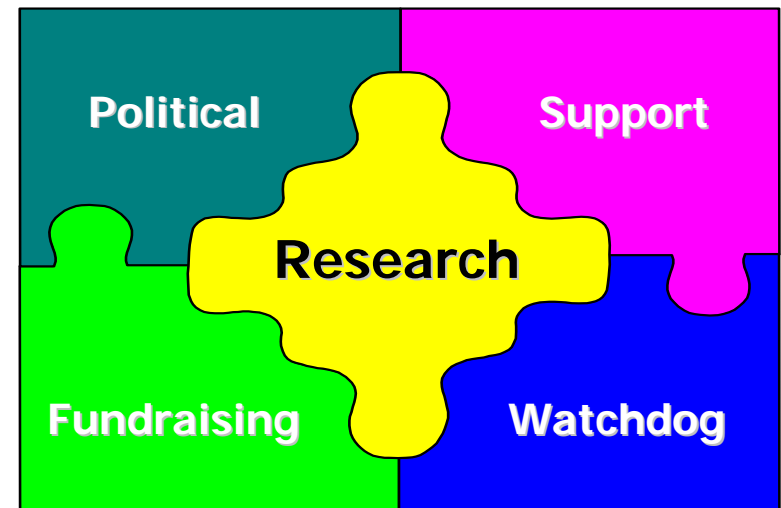
- Help SPORES translate more effectively
- Patient experiences/viewpoints into research discussions
- Activities that help many aspects of each SPORE
 - Basic
 - Epidemiology
 - Clinical

- **Remember...**

- In order to help, advocates must know what's happening in your SPORE!

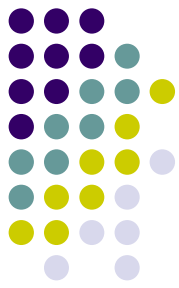
- **NOT in the PART Program***

- Fundraising
- Lobbying/political initiatives
- Watchdog advocacy
- Direct patient support



* Can only be done as individuals, not as SPORE advocates

PART Program Goals



- 1. Help SPOREs develop local Patient Advocate Research Teams**
 - Each SPORE is unique, models of successful teams as a guide
 - Proven steps to build successful teams
 - Onsite support includes orientation for investigators & for advocates
- 2. Connect local teams together to share information**
 - Share ideas & issues, moral support
 - Training and resources for scientific & advocacy concepts
 - Categories: global (all SPORE advocates), by cancer type & by topic
- 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)

Examples of SPORE Patient Advocate Assistance*



✓ SPORE Projects & Cores

- Input on strategic direction, patient experience to help create tighter focus
- Grant reviews (developmental, SPORE renewals, other mechanisms, etc.)

✓ Tissue

- Consent forms, collection processes, usage, patient follow-up procedures

✓ Clinical Trials

- Development: input on design, informed consents, IRB representation
- Accrual: letters on clinical trials, presentations to patient groups
- Adherence: Support/guidance for patients, input for amendments

✓ Education

- Forums and “training days” for patient advocate community
- Presentations in professional training courses (to scientific staff)
- Newsletters

✓ Patient Flow

- Better clinic procedures to create more receptivity to clinical trials

* Representative, but incomplete list

Example #1

SPORE Projects & Cores



- **UCSF BOP survey (n=27): Scientist view of advocates**
 - Offer patient experience & perspective
 - **Facilitate multiple communications**
 - Focus discussion on **relevance**
 - **Won't tolerate "turf" wars**
 - Put a "face" on breast cancer
 - Give a sense of purpose
 - **Ask questions others won't**
 - Support non-status quo ideas
 - Foster community/public/national support
 - **Influence research into more translatable direction**



Example #5: Genetic Privacy A Reality Check(point)

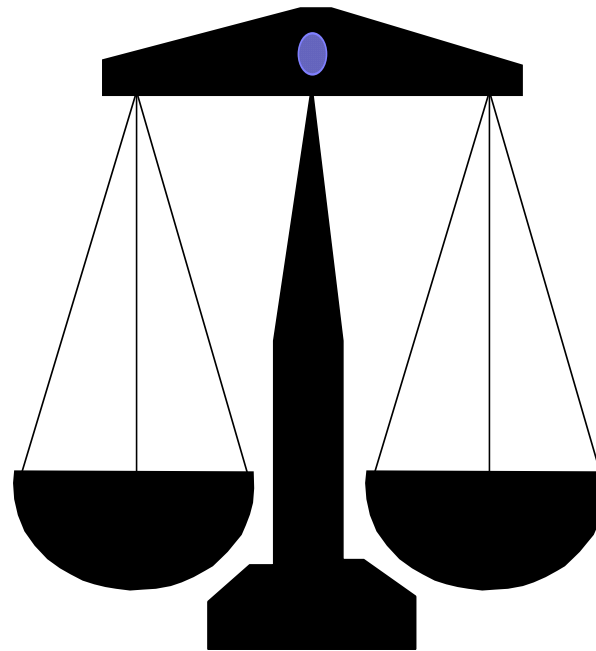


DNA = Human Bar Code

➤ Everybody wants it, Affects Everyone, even Family

Pros:

- ✓ Medical “miracles”



Cons:

- ✓ Others knows all

How Do We Protect People & Still Do Research?

So, What IS the PART Program?



- A program to help SPOREs translate effectively
- Will develop around issues that need to be tackled
 - Locally & nationally
- A “problem-solving” engine to help build a coherent development system
- High priority on keeping it interesting & fun!
- **Communication Methods**
 - SPORE website: public side & private side (coming soon!)
 - InterSPORE meetings & Working Groups
 - Annual SPORE Investigators’ Workshop
 - SPORE PI discussions (~2/year)
 - Task forces
 - Onsite assistance
 - Conference Calls
 - Emails



Starting Places Even WITHOUT an Advocate Program



- **Help us identify HIPAA impact on SPORE research**
 - HIPAA-IRB Project
 - Analyze successful & troublesome studies, develop tools
- **Help us gather clinical trial tools from your site(s)**

Send info to Deborah at deborah@sporeadvocates.net

- (925) 736-8155, fax: (925) 736-2836, cell: (925) 260-1006
- We'll post on private SPORE website
- See if patterns start to emerge!

And If You Have Patient Advocates...

- **Share advocate successes with others**
 - Send to information@sporeadvocates.net



Thank You's to...



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