

# How caHUB connects to people (if we let it)

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- PAIR: Patient Advocates In Research
- CALGB CARE: Committee on Advocacy,  
Research Communication, Ethics, and Disparities
- UCSF: Center for Translational Research

# Why do we care about biospecimens for research?

- Mice & cell lines get cured.
- People don't.
  - Biospecimens → targeted care
    - Bench → bedside → beyond



**Where** do biospecimens come from?

**PEOPLE**



# What do biospecimens mean to treatment & care?



- Traditionally: diagnosis
  - Blocks, keeping wax factories solvent
- Today, clues about subgroups who might be:
  - At higher risk for a subtype of cancer
    - (But what can we do about it?)
  - Helped or harmed by certain therapies
- Tomorrow: great potential, don't overpromise
  - Fresh/frozen/paraffin samples are of finite use
    - The REAL goldmine is turning it into useful information
  - Many changes needed to reap rewards
    - Science, systems, pathology, social/cultural, rationing



# What do biospecimens mean to people?

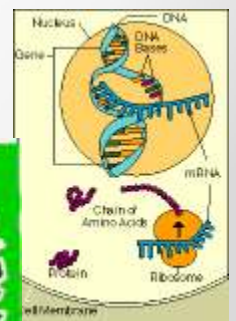
Many things....

- Nothing
- Hope
- Pain
- Diagnosis
- Vulnerability
- Fear
- Scientific hopes
- Loss of privacy
- Spiritual connection
- Loss of self, family, community

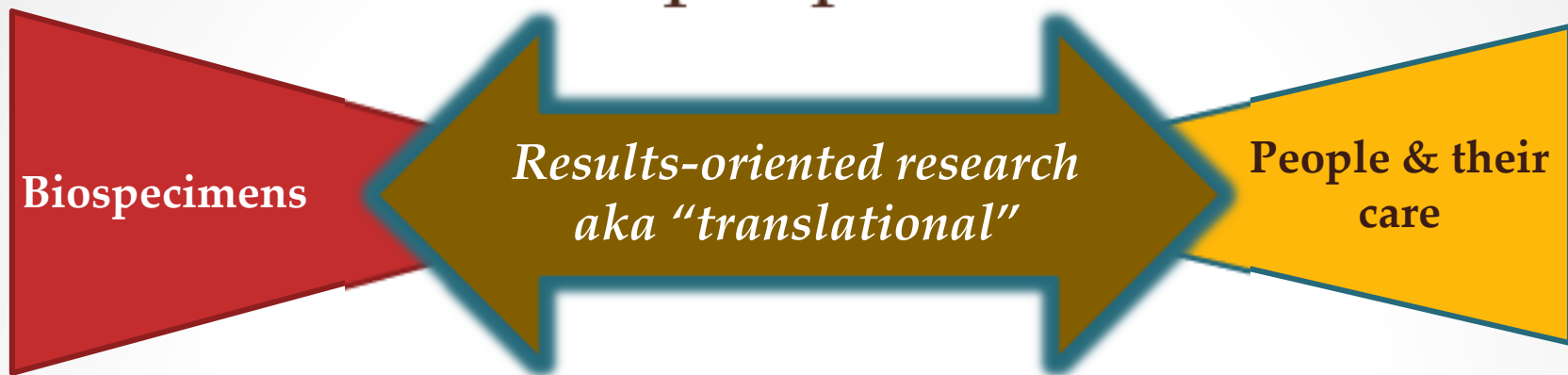
Could mean “tailored care”...

- ◉ For cancer (or not)
- ◉ “The right treatment/person, given in the right way, at the right time”
- ◉ Total care
  - ◉ Screening to post-treatment, even hospice

So, how do we get there?



# How to connect biospecimens to people



## 1. caHUB has potential to help through

- Top quality biospecimens (goal: ensure discoveries are really relevant to people)
- Essential DATA that can grow (sharing is good, misuse isn't)
- Remembering where they came from, and why people let us use them!

## 2. Support other translational research efforts too

- E.g. SPOREs, NExT, STRAPs, all clinical trials, cooperative groups, etc.

# Targeted care means targeted biospecimens and...

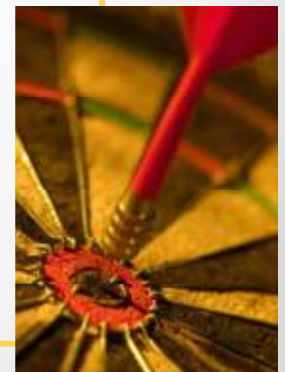
- **Targeted patients**

- How do we find & interest them?
- How will we respect cultural differences?
- What messages have they received about
  - Targeted therapies?
  - Medical misconduct?
  - *The Immortal Life of Henrietta Lacks* (book)?
  - Clinical trials?
  - “Personalized medicine”? (misnomer)
  - Genetic tests/ risks?

- **Targeted partners**

- Who sees these patients?
- Who will you work with?
- Who will work with you?
- What barriers exist
  - For them?
  - For you?
  - For your patients?

**New therapeutic goals REQUIRE new ways to study them.**  
**Time to create new connections!**



# New standards are critical

- ***Biospecimens/data***

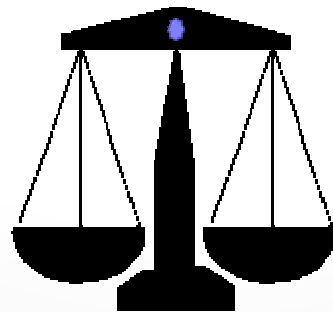
- How many are there, and does processing affect them?
- How many names are there for microarrays?
- How to change research culture to share data?

- ***Privacy/confidentiality***

- What is “genetic” research?
- When will we be able to identify people from 2-3 SNPs?

- ***Communications/connections***

- How to create new teams in an overworked system?



Protect

Progress

# Other examples of important efforts

- Susan G. Komen for the Cure Tissue Bank (IU)
- caBIG Knowledge Centers (KC)
  - Data Sharing and Intellectual Capital, TPBT, CTMS
- NCI Group Banking Committee
  - Consent for future use
    - Form, patient brochure, IRB sheet
- CALGB CARE Ethics
  - Mandatory biopsy position paper (in press)
    - Coalition Patient Advisory Board also doing survey
  - Recommendations on GWAS and data sharing
- UCSF Center for Translational Research
  - Process/materials to identify new collaborators and help them set a workable collection process



# caHUB areas that still need a plan

- **Communication loops**
  - Internally
  - Pathology community
  - Research fields
  - Medical community
  - Global connections
  - Advocacy groups
  - Patient community
- **Education program**
  - Internally
  - Pathology community
  - Research fields
  - Medical community
  - Globally
  - Advocacy groups
  - Patient community

**NOTE: these are different than marketing!**

# We need to get research right

***Data/information ≠ Knowledge ≠ Results***

- The **good** news
  - More survivors
  - More discoveries
  - More expectations
- The **challenges**
  - Shrinking budgets/  
higher costs
  - More regulation

## ***Dangers of not doing this well....***

- False +/-, other inaccuracies affect millions
- Un-validated biomarkers ≠ commercial products
- Leaves some groups behind
- **Wastes time, \$\$\$, erodes trust, and costs lives**
- Business as usual won't work anymore

# Thank you...



- Patient Advocates
  - In PAIR (~200)
  - In SPOREs (~220)
  - In NCI CARRA (~170) and DCLG (15)
  - In Cooperative Groups (~80)
  - In FDA (~20)
  - Many others
- Experienced:  
for creating new opportunities
- New:  
for fresh ideas & energy
- And to those who made a difference before their death

- Research teams for
  - Dedication
  - Efforts
  - Collaborations

***Thanks for all you do for  
cancer patients  
and their  
families***

- For more information,  
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