

# *Patient Perspectives on Biospecimen Quality*

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OBBR NCI – NIH, U.S. Department of Health and Human Services

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# Across The Scientific Spectrum



Physical  
Behavioral  
Social  
Cultural  
Economic  
Political  
Spiritual  
Technological

# HOPE

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# The Art of Translation...

“ From the standpoint of medicine as an art for the preparation and cure of disease, the man who translates the hieroglyphics of science into the plain language of healing is certainly more useful.”

-William Osler, Physician



# 100 Years and Counting...

- Taken more than a century, and now biospecimens, technology, and science for patient benefit is coming of age
- Biospecimens are precious human resources filled with unique genetic information
- The privilege of using biospecimens to advance research into clinical application brings great responsibility not to be taken lightly
- Biospecimens are part of resource toolkit

# Patient Dilemma with Words and Decisions...

Invasive ? Non-invasive?

Academic Center ? Local ?

Informed Consent?

How to pick treatment?

Do my kids need genetic testing?

Where is my tissue?

Eligible ? Insurance ?

Am I Going to Live?

Personalized medicine?

Biospecimen?

Biopsy? 2<sup>nd</sup> pass?

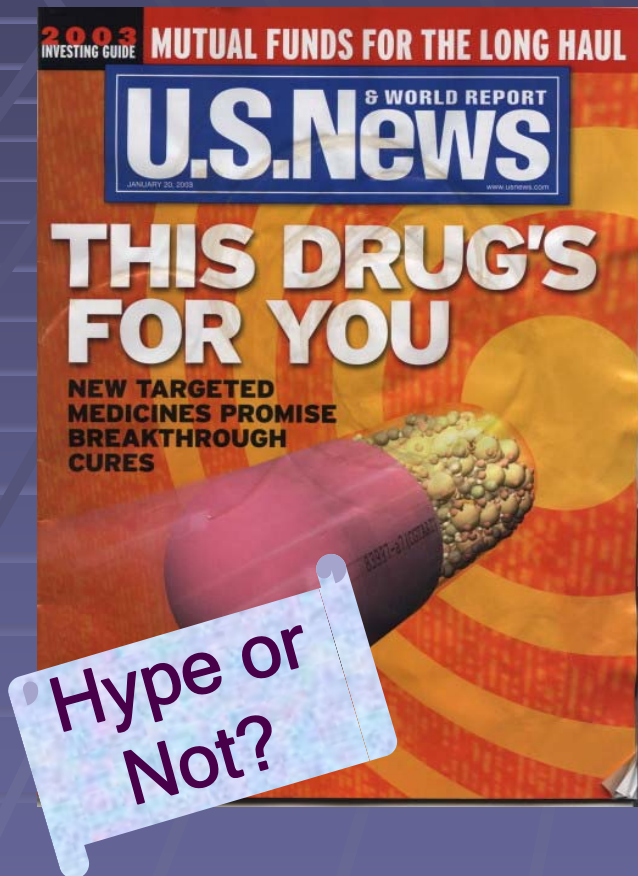
Targeted Therapies?

EGFR Inhibitor?

Proteomics?



# The Promise

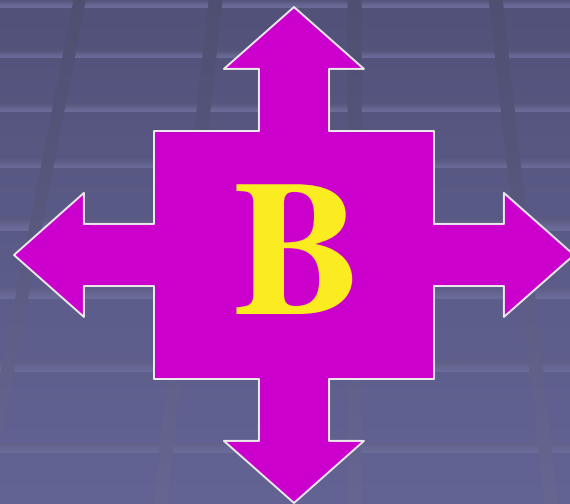


- Personal Targeted Therapies
- Seek and Control instead of Search and Destroy
- Genetic Testing
- Reduced Toxicities
- Predictive/Preventive Capability
- Reduced drug failure rates
- A CURE

# Connect The Dots

Patients, Volunteers, Groups &  
Public

Academic &  
Community



Public Agencies  
& Policy Makers

Industry & Private  
Sector

B= Biospecimen

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# Consequences of Poor Quality-

- **False + and False -**
- **Inaccuracy; non-reproducibility**
- **Erodes public confidence**
- **Wastes time & money**
- **Impedes clinical benefit**
- **Takes another 100+++ Years**



# Benefits for All

Commitment for:

Infrastructure + resources + best practices  
can yield high-quality annotated biospecimens

The Potential Upside 

Data + specimen with integrity becomes  
Information into knowledge that puts real  
discovery into real life in real time for  
patient benefit

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# Biospecimen Best Practices Are More Than Just Freezer Temperature and Hold Time

- ④ Partnering with the public and community
- ④ Privacy and patient protection, cultural sensitivity
- ④ Data Sharing and bioinformatics
- ④ Handling of biospecimens
- ④ SHARE, promote and provide research access
- ④ Balancing Intellectual property
- ④ Patient treatment and profile resource
- ④ Special populations- Ethnic, age specific, gender, familial syndromes

# Achieving Quality: Barriers or Building Blocks??

- **New frontier requires new attitudes**
- **Each sector depends on one another**
- **Patient-Clinician-Pathologist-Researcher**
- **Expectations are all over the place**
- **Translate into better care for patients**
- **Spend the time and money and do it right**
- **Financial and operational issues**
- **Have to stand tall- Do good by doing right**



# Treatment Decision Making: Outside Sources of Info for Patients

Answer Options	Greatly influences	Somewhat influences	Barely influences	Does not influence	Not applicable
Information received from a patient advocacy organization	15	63	19	7	11
Information read in the newspaper or mainstream magazine	5	37	35	27	10
Information heard on the TV or radio	1	20	41	41	11
Information retrieved on the internet	11	60	25	9	8

Source: TRAC Perspectives on Costs of Cancer Care Survey-2006

# Who is in the Biospecimen Sandbox?

## Advocacy

- ✦ Patients
- ✦ Caregivers
- ✦ Public
- ✦ Organizations

## Research and Medical

- ✦ Researchers
- ✦ Clinical Trial PI
- ✦ Community MDs
- ✦ Academic Center MDs and PhDs
- ✦ Pathologist

## P&P Agencies and Industry

- ✦ NCI
- ✦ FDA
- ✦ CMS
- ✦ HRSA
- ✦ AHRQ
- ✦ NIH
- ✦ 3<sup>rd</sup> Party Payers
- ✦ Industry



# Confidence, Public Trust, Quality

**Confidence in you and your team**

**Confidence in the reason**

**Confidence in the test**

**Confidence in the system**

**Confidence in the procedure**

**Confidence in the test results**

**Confidence in the diagnosis**

**Confidence in the recommendation**

**Confidence in the outcome**

**Confidence...period**



# Why We Must Get This Right...

**“ We must harness the scientific, industrial, and social will to accelerate discoveries into accessible and meaningful clinical applications. Patients, families, friends, and loved one are counting on us...Because in the end, it’s not about you, or me, or the science, it’s about the patient.”**

*Paula Kim - Research & Patient Advocate*

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# Patient & Advocate Perspectives

## Don't Leave Home Without Them



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