#### **Only in America No One Dies**

Road map to dealing with a serious usually fatal disease

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#### Amazing time in medicine

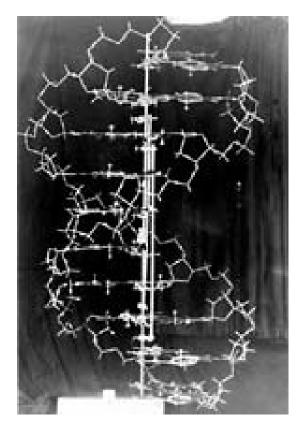
- Better understanding of the biology
- Better management for a range of diseases

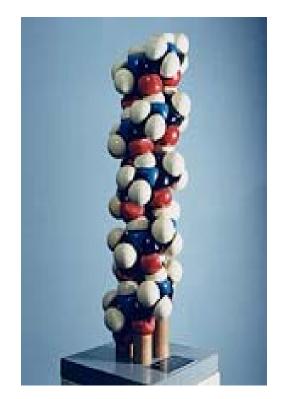
## BIOLOGY

## Crick and Watson discover the "secret of life" in 1953

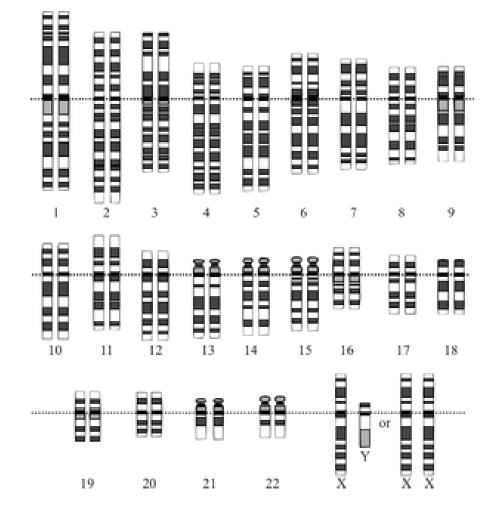


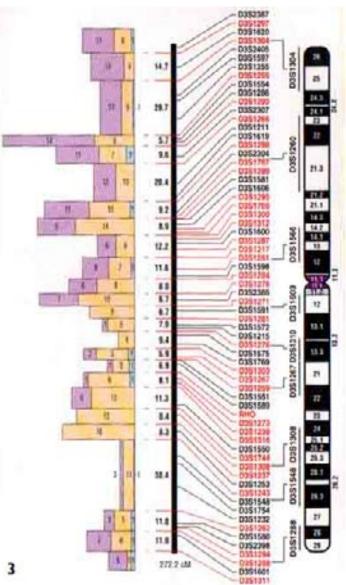
#### **DNA and double helix**



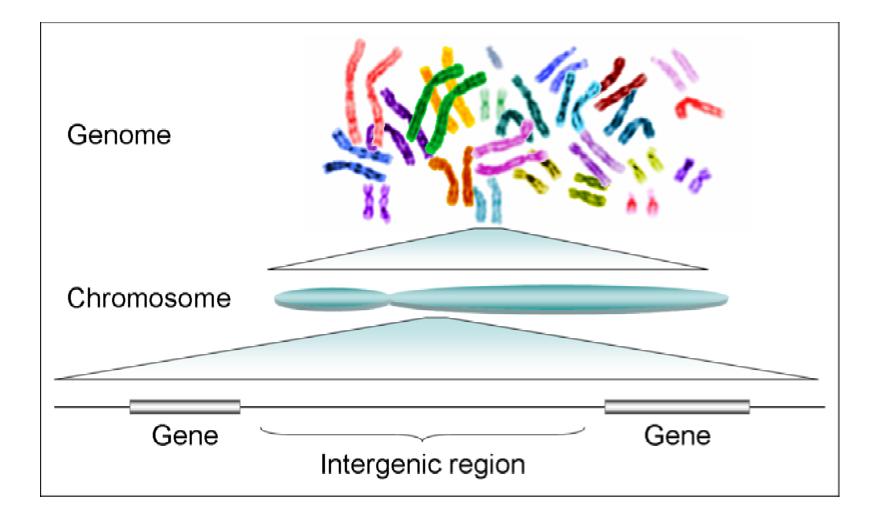


#### **DNA** is the structure of chromosomes





#### Human genome is mapped in 2003



#### Human Genome: Many reactions

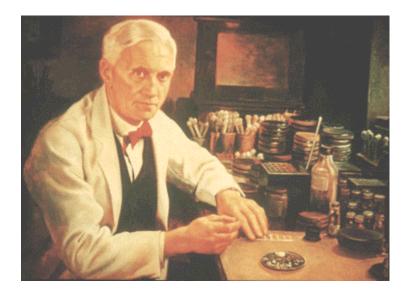




#### THERAPEUTICS

### **Development of antibiotics as an example**

• Sir Alexander Fleming discovers penicillin in 1928, now over 160 antibiotics



## Now many therapeutics

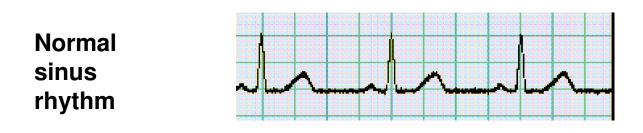
- Estimate over 6,000 different drugs
- Extensive range
  - Cardiac
  - Pulmonary
  - Gastrointestinal
  - Diabetes
  - Oncology



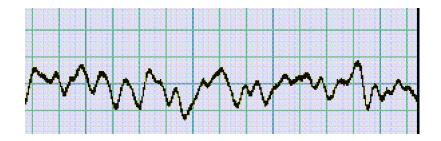
#### DEVICES

#### MANY EXAMPLES

# A complication of heart attacks: ventricular fibrillation



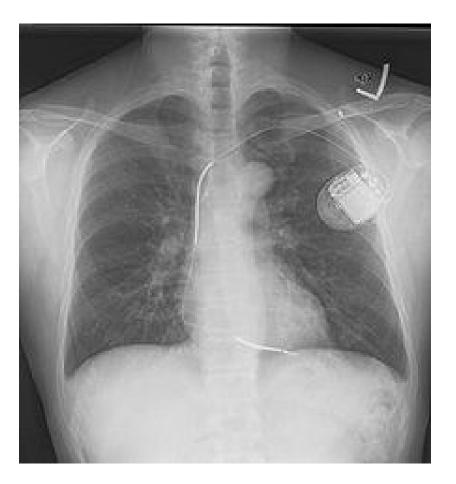
Ventricular fibrillation



#### Implantable defibrillator



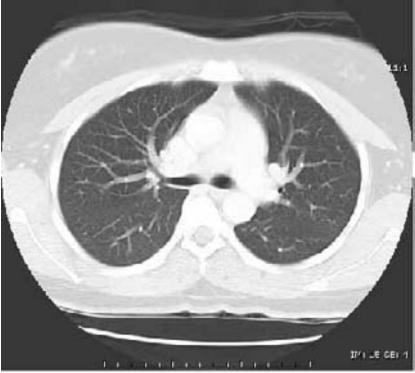
#### Patient with an implantable defibrillator



#### **BETTER DIAGNOSTICS**

## **Beatles and CAT scan technology**





## **PET Scan: Evaluation of physiology**



## Magnetic Resonance Imaging (MRI)

- Use radio frequency
- Does not use radiation
- Enclosed and noisy



## MRI of the breast: an improvement over mammography for select circumstances



## **CANCER MEDICINE**

- Earlier diagnosis
- Better therapeutics

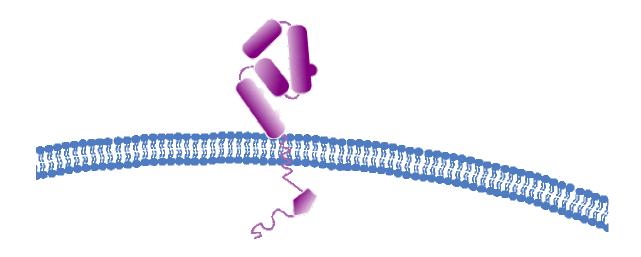
#### **Breast Cancer**

- Better Outcomes
- Early diagnosis
  - Mammograms
  - Breast MRI
- Better therapeutics
  - Local management
  - Systemic management

# Discovery of HER2 biology and breast cancer management

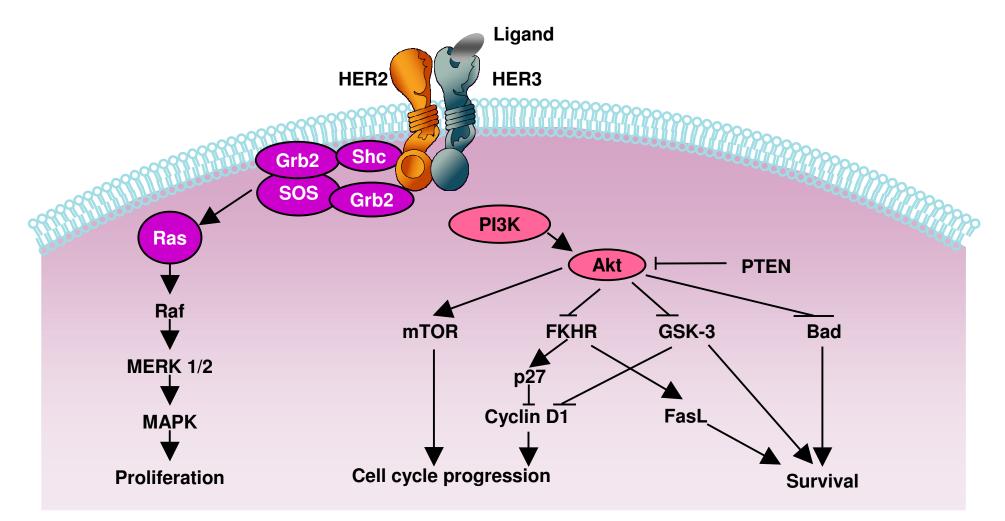
• Taking a poor prognosis breast cancer situation to now potentially curable situation

## Human Epidermal Receptor 2 (HER2)



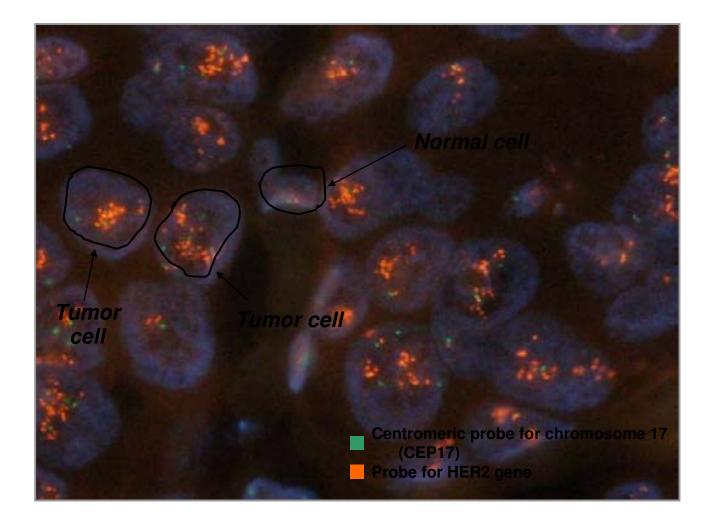
Inside of the cell

## HER Family Proliferation and Survival Signaling Pathways

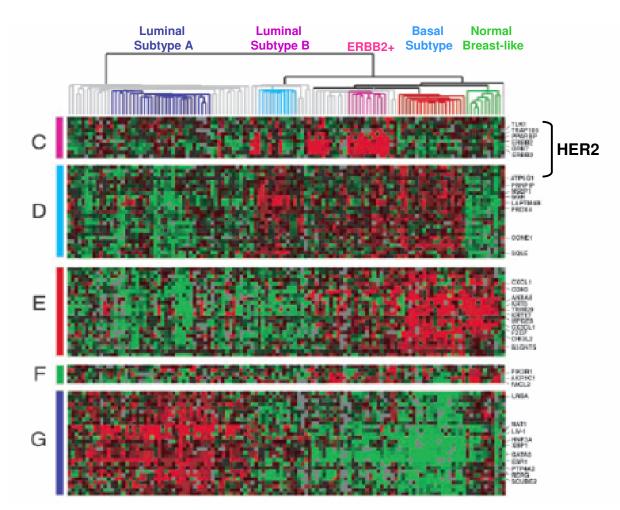


Lin and Winer. Breast Cancer Res. 2004;6:204.

### **HER2 Gene Amplification**

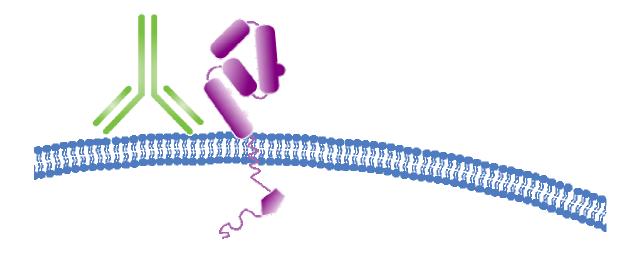


#### **Breast Cancer Subsets**



Ménard et al. *Clin Cancer Res.* 2002;8:520. Sørlie et al. *Proc Natl Acad Sci U S A.* 2003;100:8418.

#### **Trastuzumab binds to HER2**



• Continually suppresses HER2 activity

So when we are diagnosed with a serious potentially fatal disease, so why should we not be able to beat it and do well?

- We have all these medical advances in diagnosis and therapies
- We are a "can do" nation
- And yes we are stubborn

#### **Cultural ethos in the United States**

"That it's hard to believe that a disease can get the better of us with such great technologies available"

Lowell E. Schnipper, MD Harvard Medical School



# Lance Armstrong Phenomena: who did it, so why can't I?



"Do not go gentle into that good night Rage, rage against the dying in the light"

**Dylan Thomas** 

### **Cancer Statistics in US 2009**

- 1,479,350 new cancer cases
- Age of patients
  - Median age 67
  - 25% ages 65-74
  - 22% ages 75-84
  - 7.5 % 85 and older
- 562,340 cancer deaths
- Gender
  - One of two men will die from cancer
  - One of three women will die from cancer

## **Road Map**

#### How to deal with the diagnosis of a FATAL disease

## **Initial phase**

- Diagnosis
  - What is it?
  - Confirm and verify
  - Start a personal medical folder/note book
- Prognosis
  - Is it fatal?
  - What is the expected survival: weeks, months, years?

### Your role

- Identify your medical team
- Identify your support team
- Develop ownership of the treatment plan
- Expect a "roller coaster" ride of emotions ranging from disbelief to anger to fight to acceptance

#### Putting your teams together

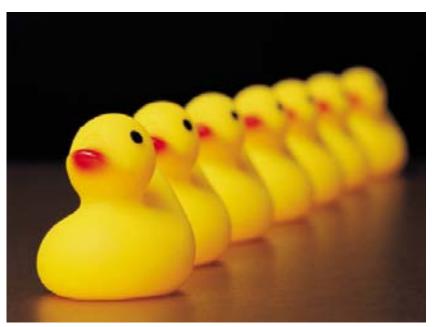
- Multidisciplinary medical team
- Supportive team

## Criteria for your medical team

- Knowledge
- Skills
- Communication
- Collaboration
- Compassion

#### **Multidisciplinary medical team**

• Get your docs in order



- Make sure they work well together
- Identify a team captain (may have co-captains)

#### **Patient Doctor Relationships**

- Paternalistic
- Autonomous
- Shared Decision Making

#### Identify your support team

- You need a chief advocate usually your spouse/ significant other/family member/close friend
- Family
- Friends
- Other support groups
  - Support groups (e.g. Life with Cancer program)
  - Faith related support

#### **Treatment options**

- Benefits
  - Response rate
  - Progression free survival
  - Over all survival
- Side Effects
  - Short term
  - Long term
- Goal: quality of life and prolongation of life

### **Clinical Trials**

- Is there something better than standard therapy
- Hopeful
- Benefits/side effects are not well defined
- Types
  - Phase I: identifying side effects of new therapy
  - Phase II: evaluating benefit of new therapy
  - Phase III: comparing new therapy with standard therapy

#### **Second Opinion**

- Good idea for rare or complicated diagnosis
- Treatment options vary
- Just not sure about your team

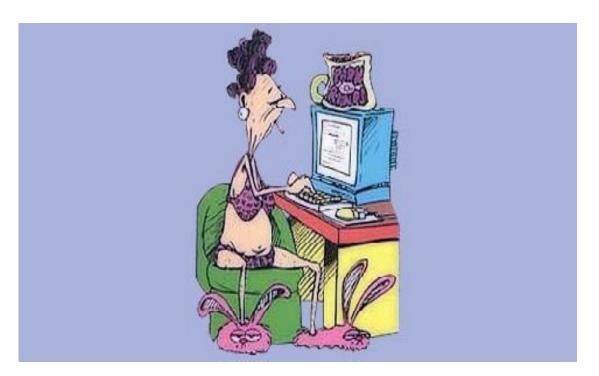
#### **Doctor appointments**

- Plan for these meetings
- Develop a list
- Most initial appointments are one hour
- Most f/u appointments are 15 minutes
- If you need more time, ask for it but ahead of time

#### **Check list**

- Treatment details
- Tests for monitoring
- Medical costs
- Nutrition
- Sex
- Travel
- Is this genetic?
- Complimentary care
- Advanced directives

## **A Living Will**



Last night, my husband and I were sitting in the living room and I said to him," I never want to live in a vegetative state, dependent on some machine and fluids from a bottle. If that ever happens, just pull the plug."

He got up, unplugged the Computer, and threw out my wine.

#### **Treatment phases**

- Initial phase
  - Benefits/risks
- Second line phase
  - Benefits/risks
- Beyond second line
  - Benefits/risks
- Each major treatment decision is a "fork in the road" with a change in the benefits/risk ratio and needs a reevaluation

# White knight syndrome

Make things better Solve the problem Be the "good guy"



#### **HOPE versus TRUTH**

- Not mutually exclusive
- Patients do better with the truth
- Avoid false hope

#### **Terminal phase**

- Am I there yet?
- Palliative care
- Hospice
- Exercise control over this process

#### CONCLUSION

#### It ain't over till it's over.

Yogi Berra



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