

# PREOPERATIVE THERAPY IN INVASIVE BREAST CANCER

Reviewing the State of the Science and Exploring New Research Directions

## Role of Advocacy in Preoperative Trials

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# Role of the Advocate

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- Provide the patient perspective
- Support the “good” science
- Translate the science for the patient
- Support patients in their decision-making
- Influence policy

# Advocate or patient... is there a difference?

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## Patient

- May know a little or a lot about their disease
- Focus is on self, family
- Main concern is treatment
- Emotions play significant role in decision making

## Advocate

- Has more in depth knowledge about disease
- Focus is on the healthcare system/research
- Main concern is influencing research and healthcare delivery
- Emotions are channeled into working for larger community

# The Patient Perspective

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- It is not about the science
- It is about the patient
- The needs and concerns of the patient in making an informed decision about preoperative therapy

# What Patients Think and Hear

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- Get it OUT!
- Cancer Cells even in a small tumor can migrate to other locations through the blood stream
- “Aunt Minnie didn’t have preoperative therapy”

# Options – lots of

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✓ Doctors are able to offer patient options

✓ Patients want the “best” treatment

✓ Doctors are fascinated by the science

✓ Patients are frightened by the word cancer

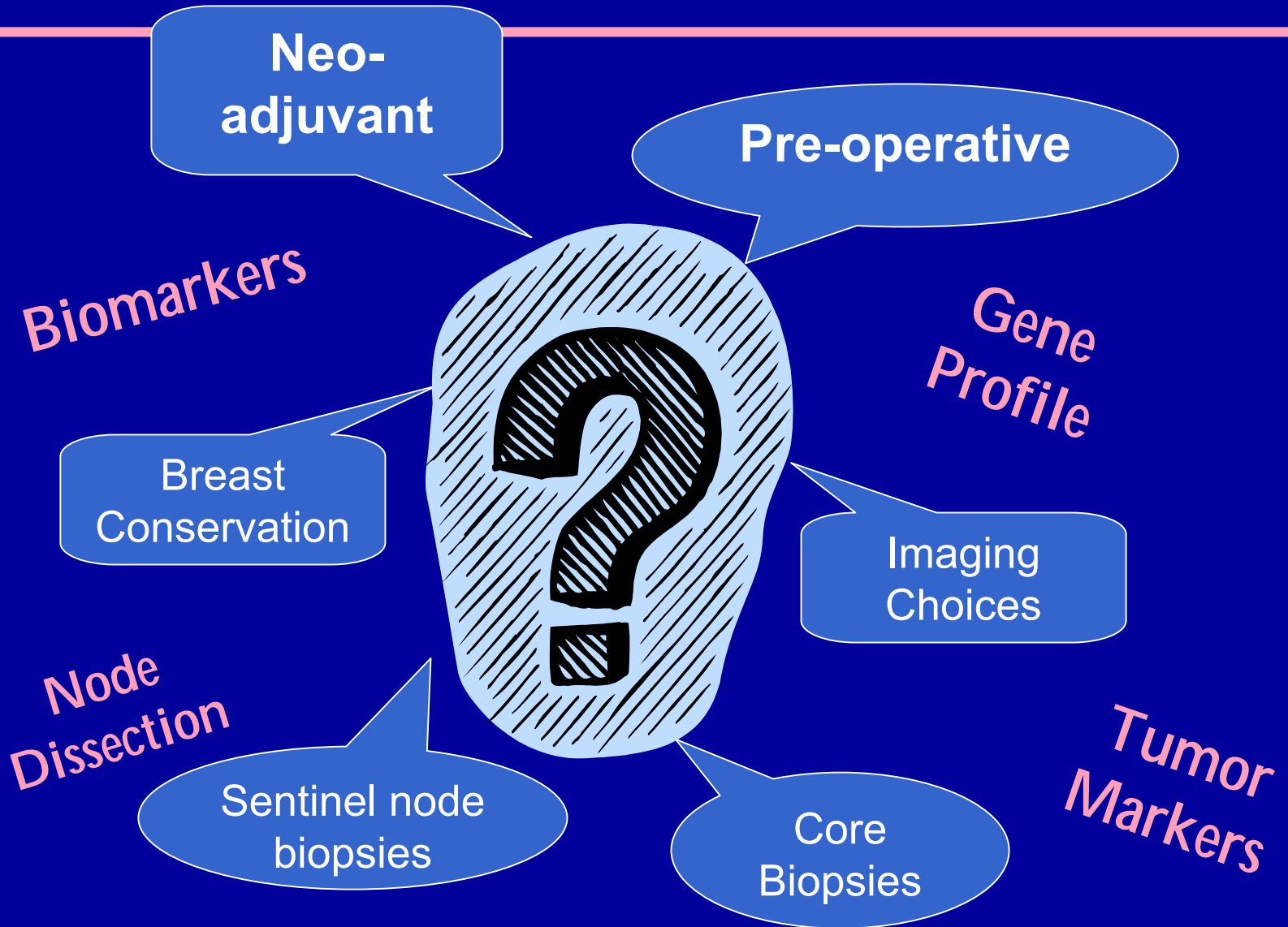
✓ Doctors don't have a lot of time

✓ Patients need time to absorb what is happening

✓ Doctors think they have explained EVERYTHING

✓ Patients say they understand but.....

# The Words Don't Help



# This is a Life Decision

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- Not just a medical decision
- Are there extra costs – even those insured may have a 20 or 30% co-pay?
- Are there extra treatments – pain and suffering?
- Will preoperative treatment compromise my functioning or future treatment choices?
- Will more time be required?
  - Away from work
  - Away from family



# What Educational Tools are Out There?


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- Tissue Research
  - NCI Booklet
  - RAN Booklet
  - Success story of advocates and NCI working together
  - Outcome
    - more information for patients

# Patient Education Materials

National Cancer Institute

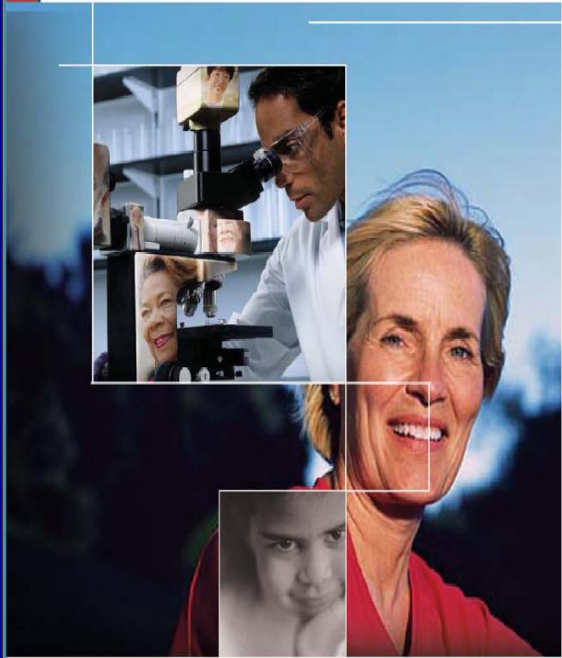
Providing Your Tissue for Research: What You Need To Know



LEARN MORE ABOUT  
CANCER RESEARCH AND  
TREATMENT SERVICES

Why is it important for me to consider donating my tissue for research?

A booklet for prospective donors



Research Advocacy Network  
*Advancing Patient-Focused Research*

# Advocate Questions

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- What does this add to the treatment?
- Longer life, more certainty?
- What does this add to the science?
- Is this a proven therapy?
- Is this ready for prime time?
- How is it being used in the community?

# Is This Replicable in the Community?

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- Are patients at academic medical centers the same as those in the community?
- ECOG found average age of women in their breast cancer trials was 51
- The SEER data shows the average age of breast cancer patients is 65
- Patients at academic medical centers who enter trials are also white, better educated and higher socio-economic status

# Research and Advocate Interests

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Example – ACOSOG Z1031 (AIs Preoperative Study)

- Advocate Interest
  - What AI is best?
  - What patient population?
  - How to educate patients?
- Research Interest
  - All of the above and how to combine AI and chemo in preoperative therapy?

# What You are Doing is Important!

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- Advocates
  - Can inform the process
  - Need Information
  - Want the opportunity to ask questions
  - Will provide patient with information
  - Get the word out!!!!