

Effective Advocate Participation in The Clinical Trial Process

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Learning Objectives

- ❖ **WHY** it is important to be involved
- ❖ **WHAT YOU** can do once involved
- ❖ **HOW** to get involved
- ❖ **Summary**

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CISN: who we are / what we do

Mission Statement: A Non profit which seeks to:

- ❖ **Provide cancer patients with information and support.**
- ❖ **Build bridges between all groups involved with cancer research, treatment, care and advocacy**

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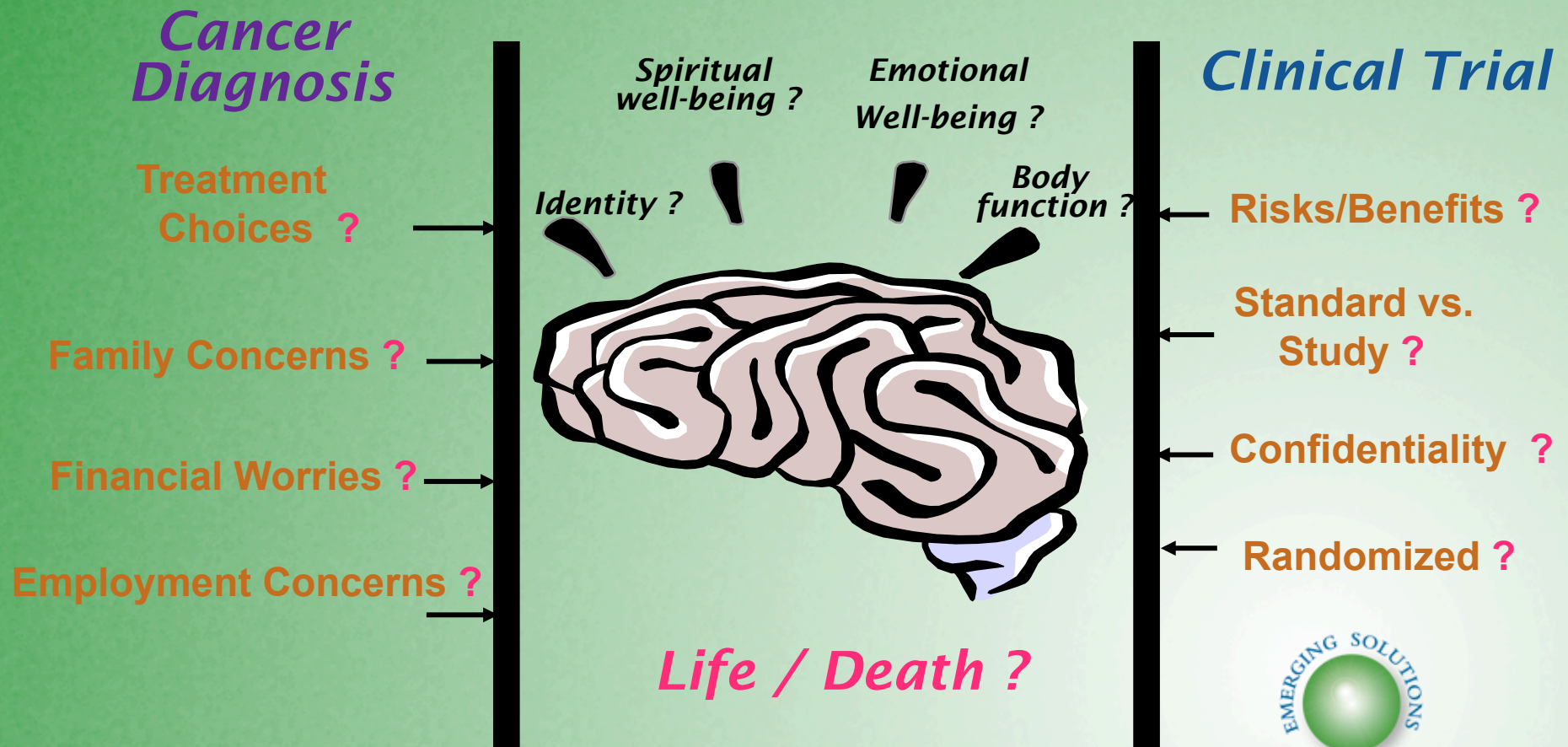
WHY it is important

- ❖ **Critical to have a seat at the table as trials are designed:** All new treatments must come through the clinical trial process
 - ❖ **YOU** Know the patient experience: can explain “overload” & its implications
 - ❖ **YOU** are the “in-house” market research team:
 - ❖ **ALL** products need to be market researched, especially clinical trials
- ❖ **Once at the table, bring patient perspective to all discussions:**
 - ❖ Not about funding or turf battles for you: no vested interest
- ❖ **Provide both general clinical trial information & study specific info**
- ❖ **Network:** Build further community partners

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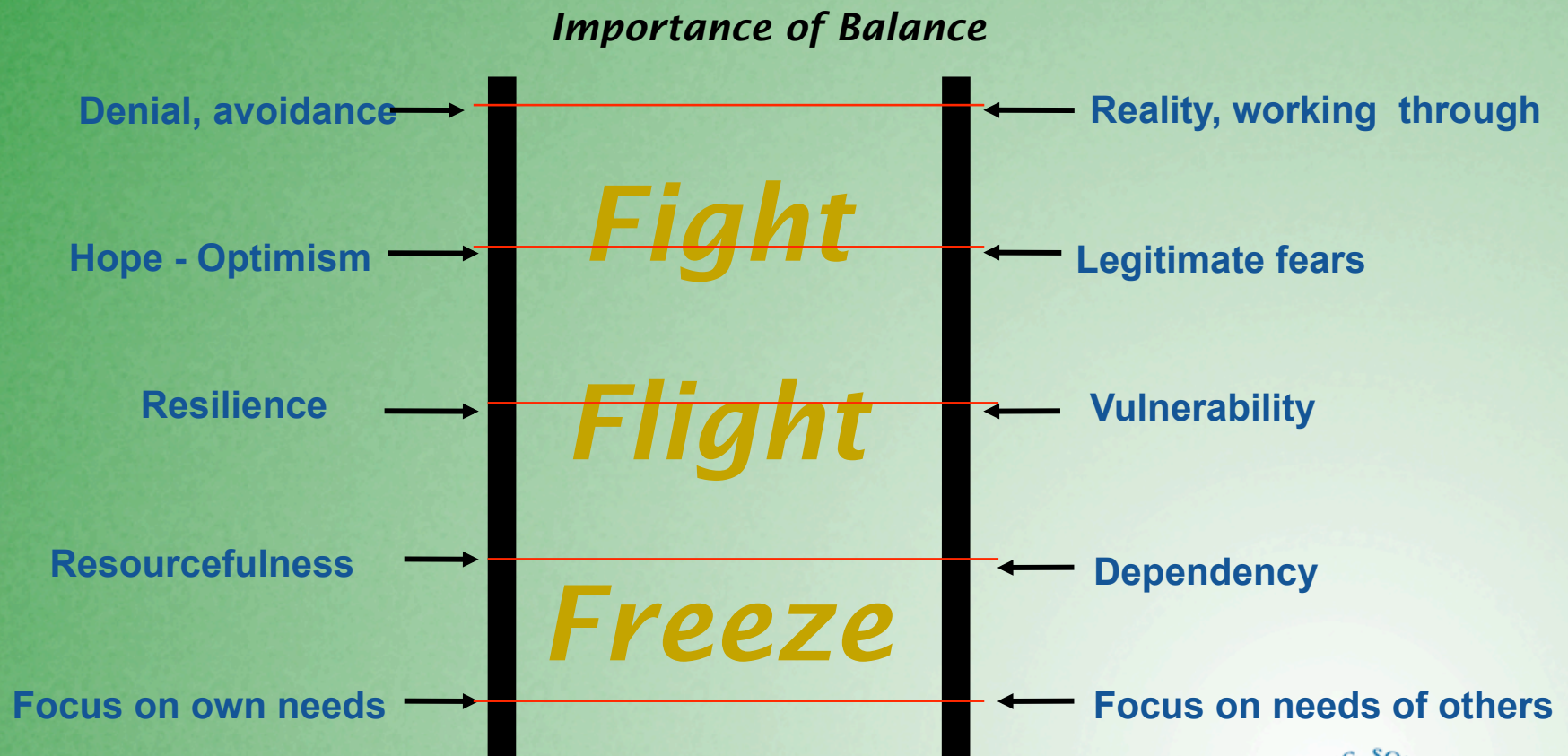
Patient Perspective at diagnosis: Overload



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Patient Perspective: Overload Implications



Probability of enrolling in clinical trial low

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Examples of what you can do

- ❖ **Assist during all stages of study design:** “market research”
- ❖ **Help write the consent form:** patient friendly language
- ❖ **Help design educational materials:** communication plan
- ❖ **Help with minority outreach:** you know the Community

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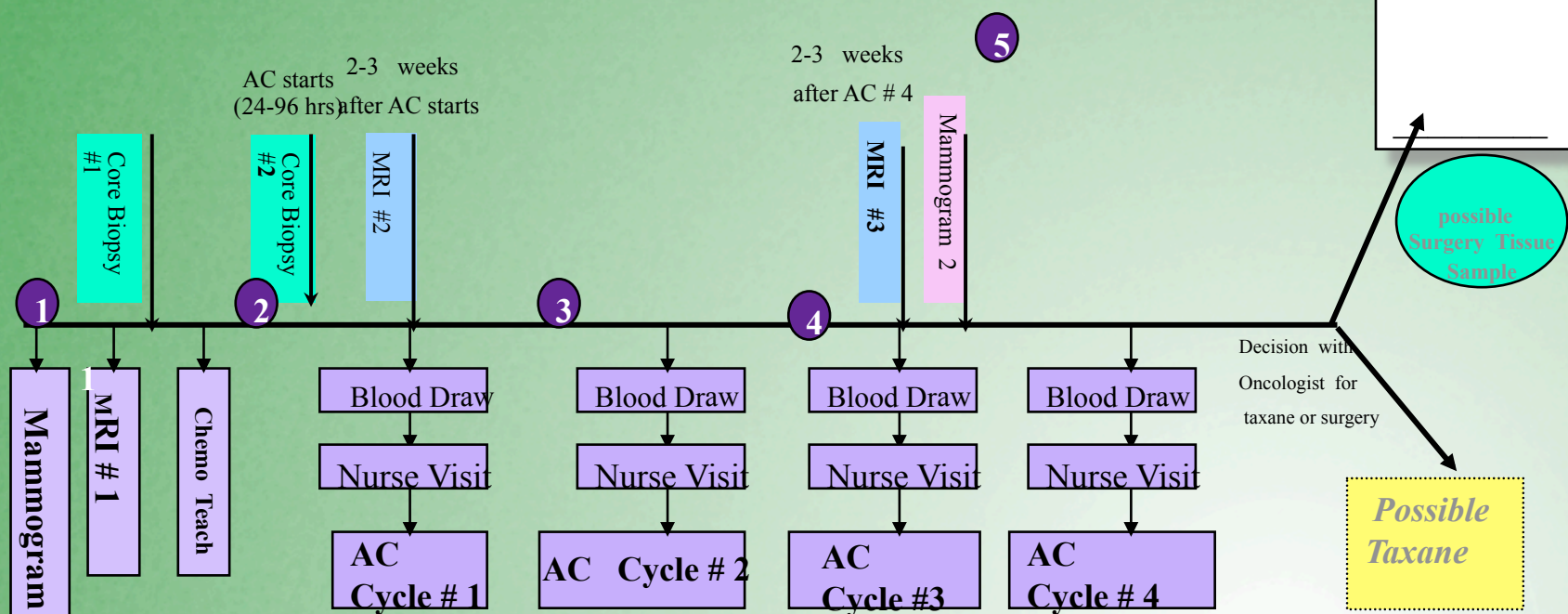


"I SPY Trial"

Standard treatment vs. Study Procedures

Advocate
Calls

Patient



Sponsored by UCSF Breast SPORE

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Pre & Post CISN help

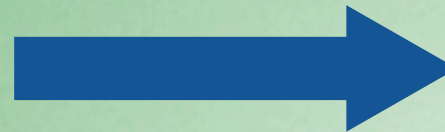
MRI of the Contralateral Breast

ACRIN Research Study 6667

An ACRIN Research
Study for Women
with a
Recent Diagnosis of
Breast Cancer

*Information for
Participants*

acrin American College of Radiology
Imaging Network



Breast MRI Study

Imaging your cancer-free breast



Are you a breast cancer
patient with concerns
about your healthy breast?

acrin American College of Radiology
Imaging Network

Thanks to ACRIN

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EMERGING SOLUTIONS
cisn
cancer information
& support network

HOW to get Involved

❖ Know your Local Community:

- ❖ **Cancer Centers:** pay a visit, volunteer (<http://www3.cancer.gov/cancercenters/public.html>)
 - ❖ **IRB:** all Institutional Review Boards must have community members
 - ❖ charged with protecting participants
 - ❖ **Protocol Review Committee:** all protocols must come through this process
 - ❖ **Cancer Resource Centers**
- ❖ **Local Hospital:** same as above
- ❖ **Department of Public Health:** Work directly with patients
- ❖ **Advisory Boards:** ask at your hospitals, Industry, State and local

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HOW to get Involved

❖ Be involved at the National Level:

❖ Training & Conferences

❖ OCNA Conference

❖ AACR: Scientist <-> Survivor Program: (www.aacr.org - survivors)

❖ ASCO <http://www.peoplelivingwithcancer.org/> training: www.RAN.org

❖ NBCC Project LEAD: <http://www.stopbreastcancer.org/> (click on education link)

❖ Coalition of National Cancer Cooperative Groups: <http://www.cancertrialshelp.org/>

❖ Summit Series on Cancer Clinical Trials: <http://www.cancersummit.org>

❖ Trials Central: <http://www.trialscentral.org/>

❖ Clinical Trial Support Unit: <http://www.ctsu.org/>

❖ NCI, FDA, CARRA: <http://la.cancer.gov/CARRA/index.html>

❖ Industry: get on email advocate lists, leave a card at conference booths

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Summary

- ❖ **Get a seat at the table:** volunteer
- ❖ **Bring the patient perspective to all discussions**
- ❖ **Make sure you are well trained:** stay current
- ❖ **Make clinical trials a priority for your Organization**
- ❖ **Find future Collaborators:** ask

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Thank You

❖ **OCNA**

❖ **Genentech**

❖ **All of my collaborators**

❖ **Federal:** ACRIN; ACOSOG; Coalition of Cooperative Groups, CARRA, Summit on Clinical Trials

❖ **State:** SFGH, UCSF, UCDAVIS

❖ **Coalitions:** Genetic Alliance, NBCC

❖ **Non Profits:** C3, RAN, CABCO, EMPACT

❖ **Industry:** Genentech, Genomic Health, Pfizer, GlaxoSmithKline

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