METAVIVOR

# A Metastatic Patient Perspective

Presentation by

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# The METAvivor Mission

- Patient-founded non-profit 2009
- Priority Mission: Award metastatic breast cancer (MBC) research grants to benefit the stage IV patient
  - Thus far: 27 grants awarded at almost $2 million
- 100% of every donation goes into our research grants
- Secondary Missions
  - Increasing stage IV awareness
  - Building patient support
    - 28 support program nationwide

# Life in the Pink
# ...how the world sees BC

# ... what the world doesn't even know

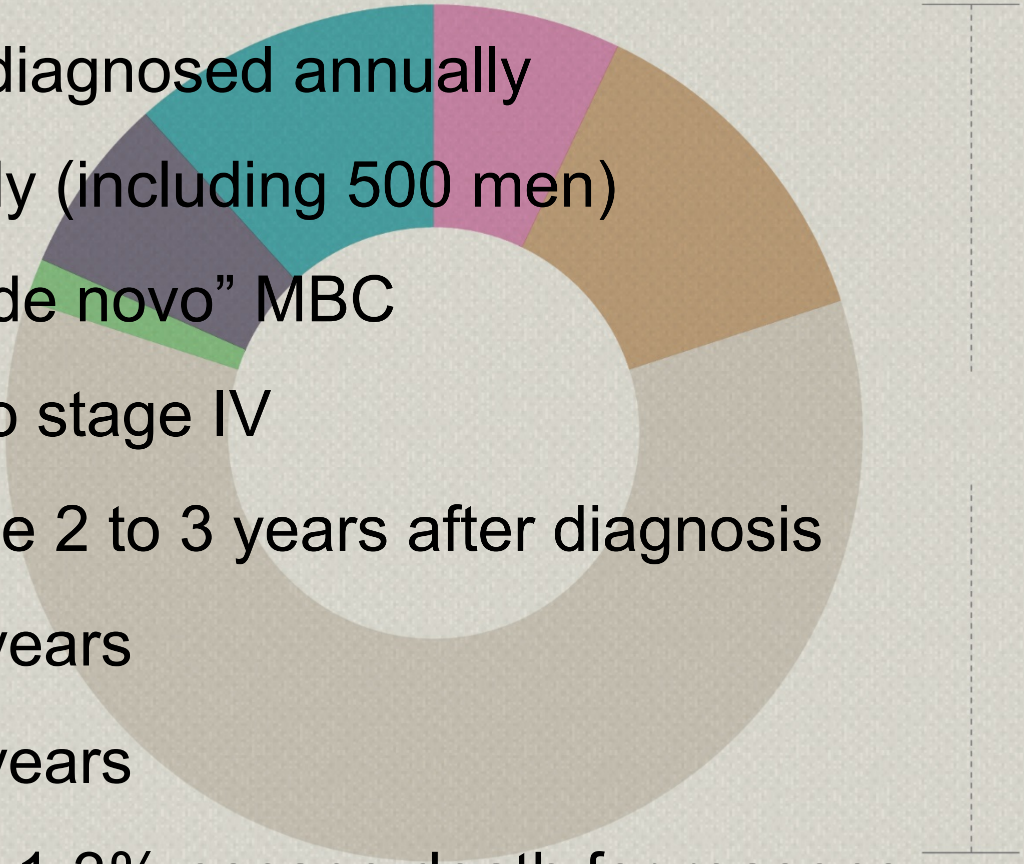
- “Pink” is behind us
- Prevention and early detection are irrelevant
- Awareness is lacking
- Support is rare
- Research is scarcely funded
- Patients are not acknowledged

5%

ONLY AN ESTIMATED 5% OF CANCER RESEARCH FUNDS IN THE WESTERN WORLD GO TOWARD METASTATIC CANCER RESEARCH.

**2-3% in the US**

# Who are we?



- 73,000 to 86,000 diagnosed annually
- 41,000 die annually (including 500 men)
- 6% to 10% have “de novo” MBC
- 30% progressed to stage IV
- On average, we die 2 to 3 years after diagnosis
- 23% make it to 5 years
- 9% make it to 10 years
- Only an estimated 1-3% escape death for reasons unknown

# Prejudice and lack of knowledge are widespread

- Cancer organizations
- Family and friends
- Public
- Media
- Medical personnel
- Non-metastatic breast cancer patients and advocates

Popular positive messaging

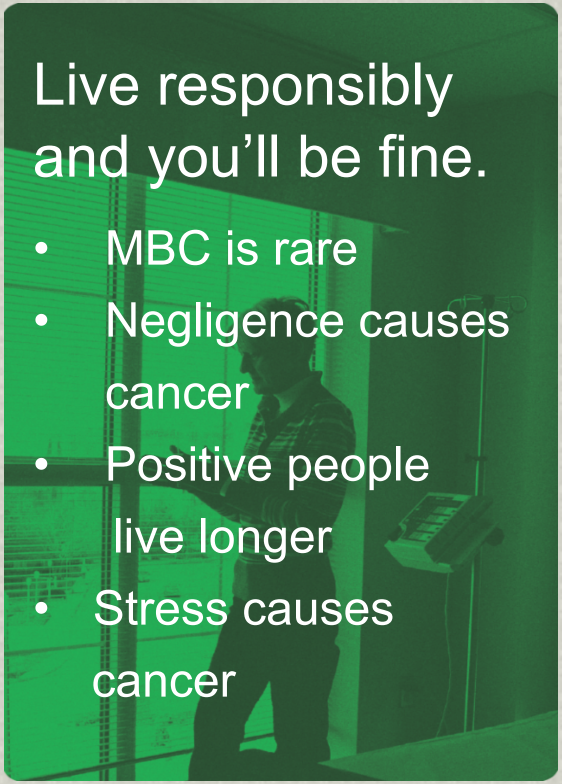
is damaging and has

far reaching consequences

# Doctors, Departments of Health, Cancer Organizations, Advocates and more mislead the public

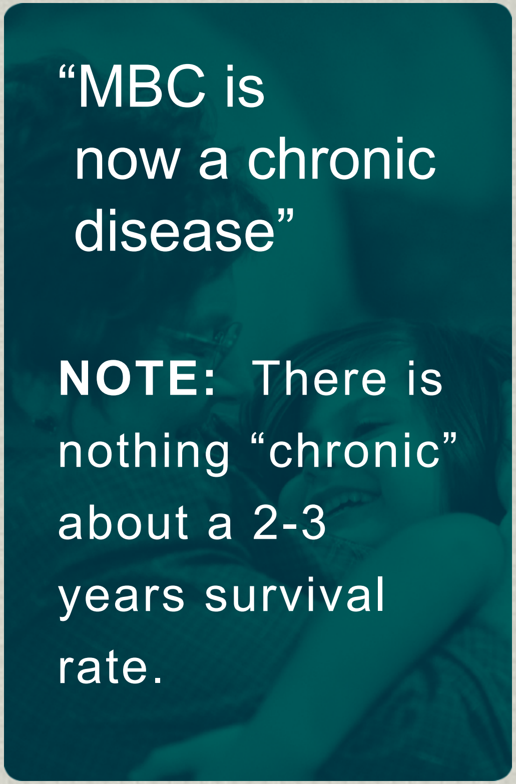
There is protection in …

- Regular mammograms and self-exams
- Early detection
- Healthy lifestyles
- Excellent medical care



Live responsibly and you'll be fine.

- MBC is rare
- Negligence causes cancer
- Positive people live longer
- Stress causes cancer



"MBC is now a chronic disease"

**NOTE:** There is nothing "chronic" about a 2-3 years survival rate.

“While you can’t change being female or your family history, you can still do a lot to help reduce your breast cancer risk.  In a word: lifestyle.”

EXERCISE MORE

EAT HEALTHIER

DON’T SMOKE

LITTLE OR NO ALCOHOL

ELIMINATE STRESS

“Being responsible about your health can go a long way.”

Information taken from the American Cancer Society website

# Incomplete messaging is unacceptable ... Part 2 must always be included

1. ***People should strive to live healthy and do their self exams and mammograms***

2. ***HOWEVER, plenty of people do everything right and still metastasize***

# The consequences of misleading messaging

**"In keeping with our focus of Wellness, we have tried to stay away from reminders of people who, unfortunately, were unsuccessful in their fight against cancer. While not seeming to put our heads in the sand when it comes to the realities of cancer, we want our guests to always be focused upon successfully beating this disease."***

* Email semt to METAvivor by a cancer Wellness Community in rejecting a request to put a symbol on their property in honor of persons living with and dying of metastasis.

# Patients are tired of trying to explain their disease ... or even what metastasis is

- 95% report the public does not understand their disease
- 59% say this is a significant problem for them
- Over 70% of the public reports MBC patients should keep their disease to themselves

# Interaction with family and friends

- 25% can freely discuss topic with family/friends
- 54% have family and friends who are uncomfortable with the topic
- 21% rarely talk about it

**Result: Patients are strongly drawn to each other – people who understand**

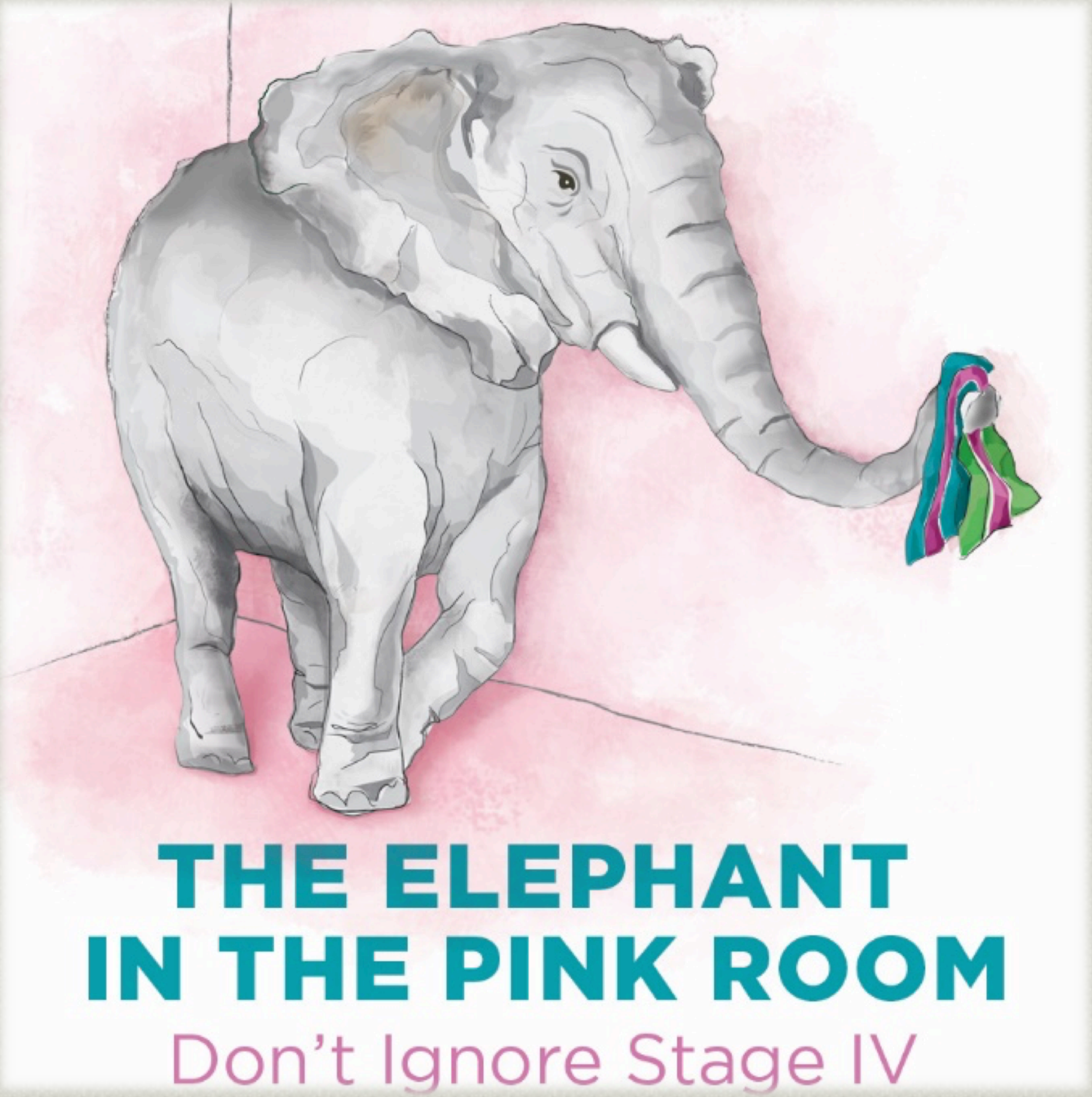
* Results are from a 2014 METAvivor survey.

## What the media wants ...

- Success stories
- A rare, isolated heartbreaking story

## What organizations want to fund

- Patient support ... NOT research

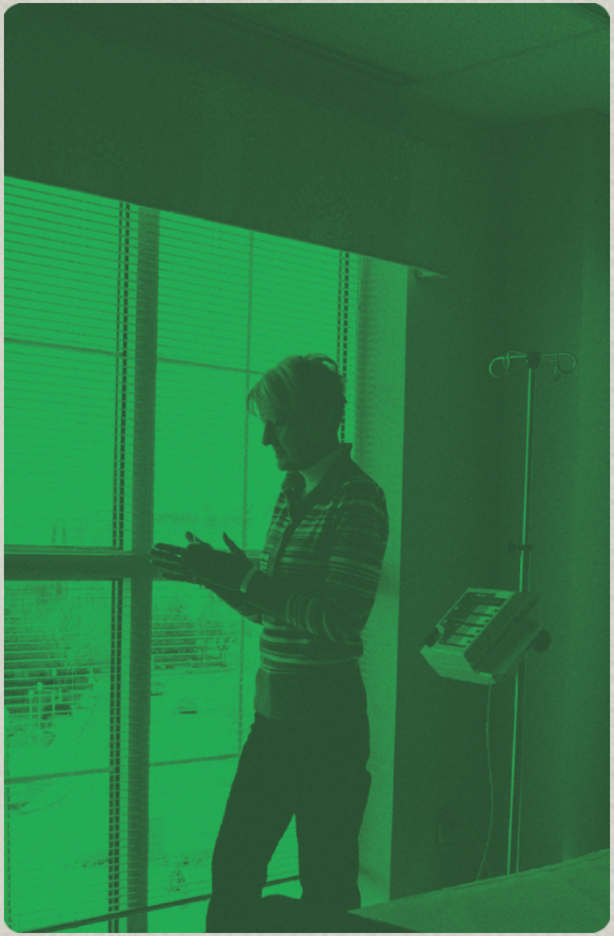


# Our 2012 Awareness Campaign

# The problem is pronounced in the medical world

- Metastatic patients see their condition as urgent ...
- Medical personnel see us as the patients no effort – urgent or otherwise -- will save

# Doctors .... Naïve? .... Or in denial?



- Those under 40 often denied tests, including mammograms
    - Metastasis rate for 25–39 year old’s has more than doubled since 1972*
- Concerned survivors are considered paranoic
    - Patients turn to GPs, GYN and others to get testing

*The number has quadrupled. The reasons are unknown.

# Oncologists and bad news avoidance*

72%: told by an MD – but not necessarily their own

- “I kept bugging the PA until he told me”
- “My breast surgeon asked what treatment I was on – my onc had known for a month
- “I finally went in and got a copy of my records – there it was”

26%: by phone or answering machine

1%: by email

1%: by text

* Results are from a 2014 METAvivor survey.

# Many doctors avoid clarifying metastasis at diagnosis*

- 25% understood at diagnosis
- 45% learned from staff what it meant
- 28% learned it was fatal on the internet
- 2% learned from family or friends

* Results are from a 2014 METAvivor survey.

# Many also avoid the Hospice discussion

- 43% told in person (72%) 14% by phone (1%)
- 28% by email (26%) 14% by text (1%)

* Results are from a 2014 METAvivor survey.

# Research – we know your challenges are in some ways much like ours

**Metastasis**

**Research**

- Funding focuses on early stage
- Awareness of mets research is lacking
- Mets research rarely makes headlines
- Hard to make a living
- Few understand your choice

# The Patient’s Bottom Line

- What the patient wants most is to live
- Without significantly more research our death rate will not change
- Research has our full support
  - We donate and advocate
  - We gladly give blood and tissue
  - We participate in trials and mores to science
  - Just tell us how we can help

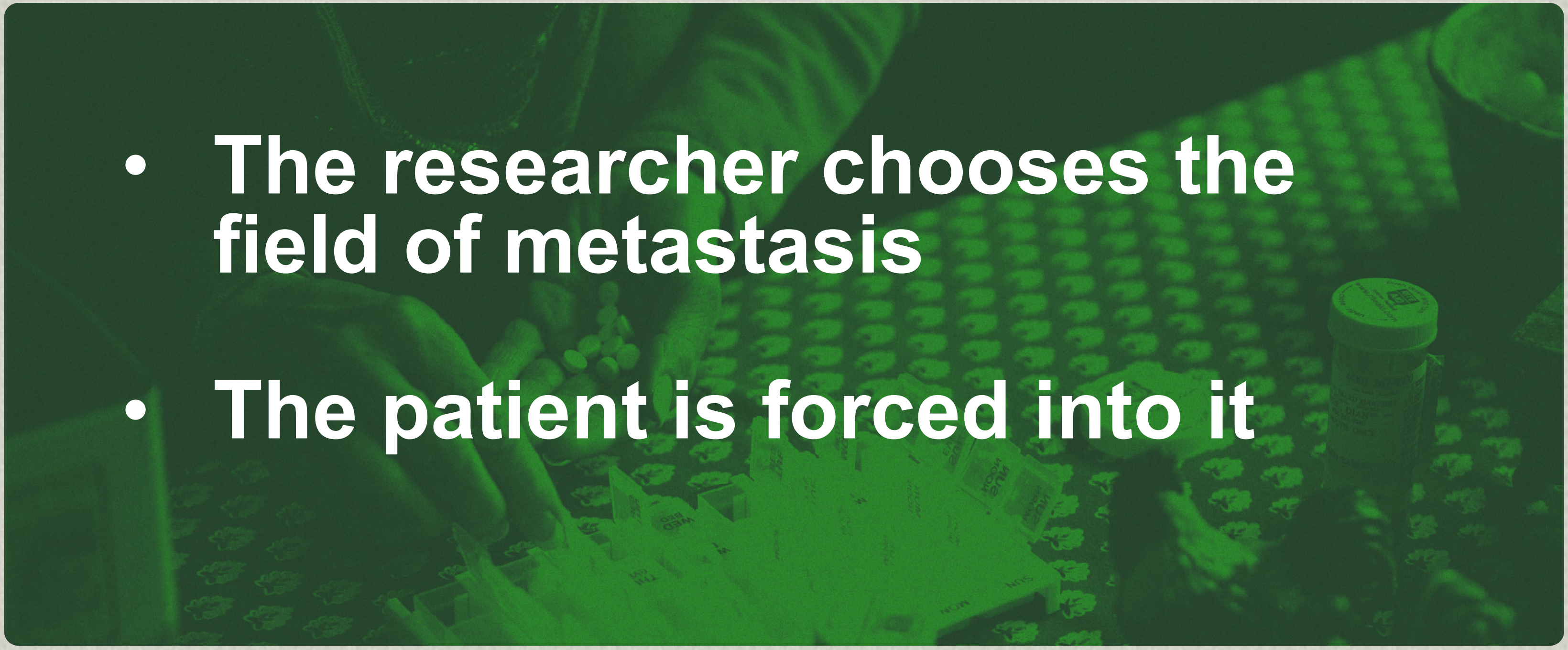
Living with a metastasis is very  difficult ... both physically and psychologically

Learning how little funding goes into research is devastating

Having promising researchers leave the field destroys all hope

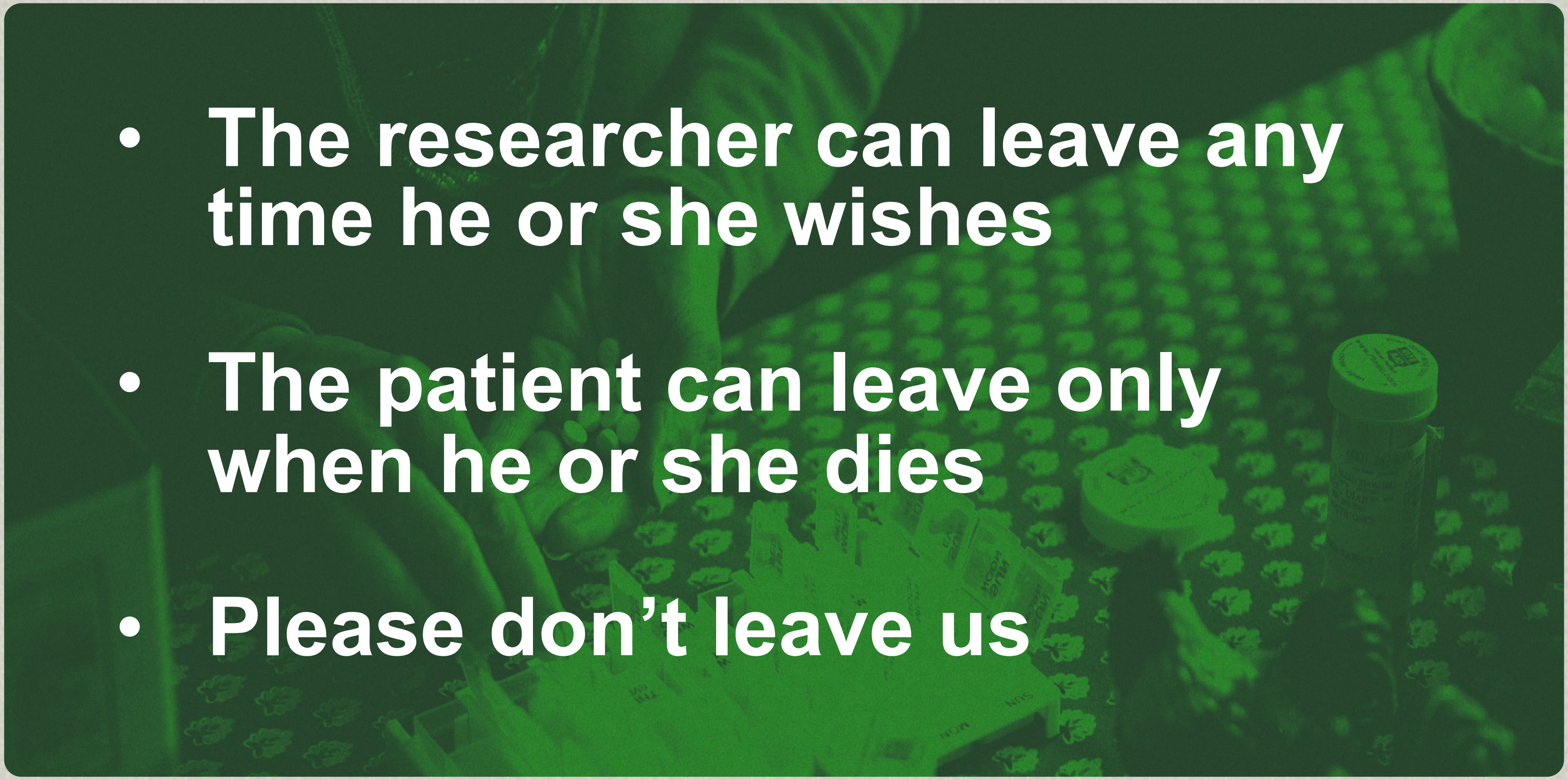
We need a cadre of young researchers ready to take over when our senior researchers retire

# Major Point #1



- The researcher chooses the field of metastasis
- The patient is forced into it

# Major point #2



- The researcher can leave any time he or she wishes
- The patient can leave only when he or she dies
- Please don’t leave us

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