Disrupting the Biomedical Landscape with Patient Driven Research

Corrie Painter, PhD

Associate Director of Operations & Scientific Outreach, Cancer Program

BROAD INSTITUTE

The Internet as a Patient-Scientist

Diagnosed with Angisosarcoma 6 years ago while writing my dissertation in biochemistry

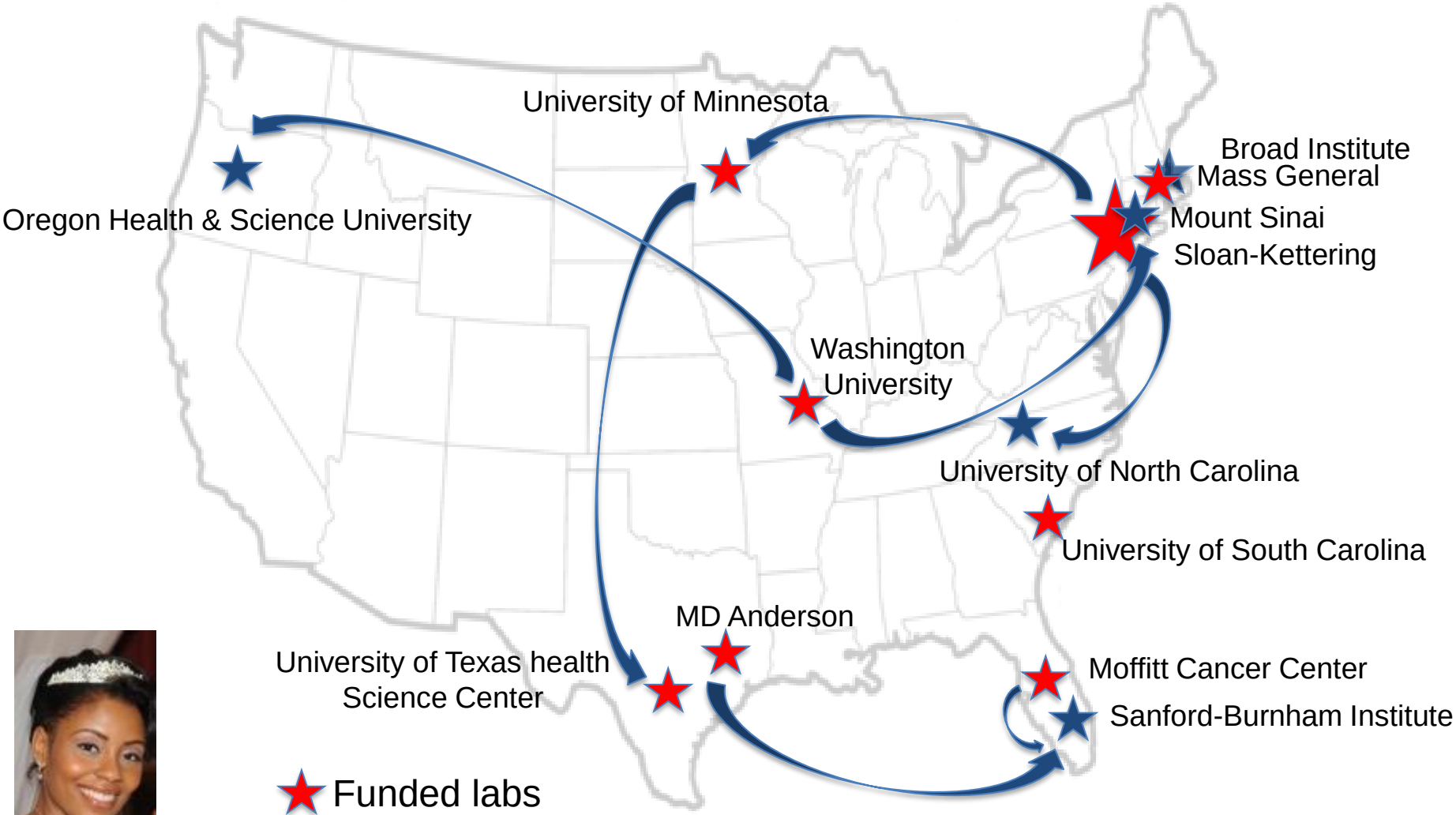
- PubMed
  - Single case studies & retrospectives with low numbers
  - *NO BASIC RESEARCH*
- Google
  - No online forums with survivors
  - Few hints of people who were looking for other survivors
- Facebook?
  - Angiosarcoma Cancer group started by Lauren Ryan
  - 10 people in the group with more collective information than PubMed + Google!

From Bench to Bedside to Broad

- Graduate student of Biomedical Sciences
  - May 2010: Diagnosed with primary angiosarcoma of the breast.
- Co-founded 501c3 Angiosarcoma Awareness Inc.
  - August 2010: With fellow patient, Lauren Ryan
- PhD in biochemistry
  - June 2011
- Cancer Research Institute fellowship
  - July 2012: Investigating the adaptive immune response to melanoma
- PI or Advocate?

More impact as an Advocate: Patient Driven Angiosarcoma Research

Online support group + Non-Profit



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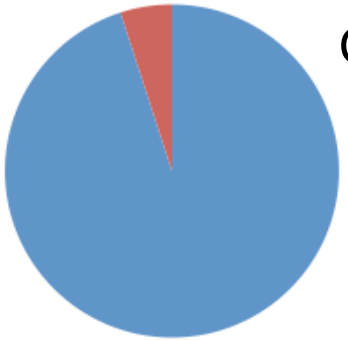
- PhD in biochemistry
  - June 2011
- Cancer Research Institute fellowship
  - July 2012: Investigating the adaptive immune response to melanoma
- PI or Advocate?
  - Faculty position at MD Anderson, or leave the tenure track to focus on the interface between patients and biomedical science
  - **January 2015: Started at the Broad as the Associate Director of Operations and Scientific Outreach, Cancer Program**

Working directly with patients to accelerate genomics research

Can the Broad work directly with patients to obtain unused tumor samples?



Only 5% of U.S. cancer patients are enrolled in clinical trials

85% of U.S. cancer patients are treated in community settings

Working with organized patient groups could transform the genomic landscape of both rare and common cancers

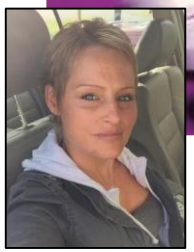
Technology, social media, and cultural changes now provide a new opportunity to engage cancer patients and directly partner with them in this research

How can we speed Metastatic Breast Cancer Research?

- **Ultimate goal:** To understand what drives metastatic breast cancer so that we eventually can interpret every patient's cancer genome, identify the optimal treatments, and anticipate and preempt resistance before it arises

- There's been a lot of progress, but we are still far from the goal

- What will it take to get there? Detailed molecular and genomic characterization of thousands of tumor and germline samples along with medical information



Some questions we are trying to answer in metastatic breast cancer

- What are all changes at the molecular level that can lead to MBC?
- Why do some patients show extraordinary responses to a particular treatment?
- Why do some tumors never respond or develop resistance to a particular treatment?
- What leads to developing MBC at a young age?
- What genes are involved in MBC for underrepresented and understudied groups?
- How can we improve the use genomic information in the treatment of MBC?
- ***How can we develop better treatments for MBC?***

Approach for patient driven genomics

IRB Approved Research Protocol

ONLINE CONSENT	Electronic consent form asks for permission to obtain tumor tissue and medical records.
MEDICAL HISTORY	Medical records are obtained and centrally reviewed
TISSUE	Tumor blocks requested from local pathology departments. Patients sent a saliva kit for germline DNA
GENOMICS	Molecular characterization includes whole exome and RNAseq
ANALYSIS	Clinically annotate genomic findings
REPORTING	Aggregate data shared with researchers. Generalized findings communicated to patients

A Collaboration with Patients and Advocates

More collaborations in the works

Patients and advocates have been involved for day 1 in conceiving, designing, implementing, testing, and refining this project.

The Metastatic Breast Cancer Project

MBCproject.org

Metastatic Breast Cancer Project

Learn More

count me in

Do you want to help transform our understanding of metastatic breast cancer?

If you have metastatic breast cancer, join a nationwide movement of patients, doctors, and scientists by sharing your tumor samples, your medical information, and your voice. Together, we can speed the development of future therapies.

BROAD INSTITUTE

HARVARD MEDICAL SCHOOL

DANA-FARBER CANCER INSTITUTE

Your tumor and medical records could unlock discoveries.

The unique genetic information in your cancer could hold the key to rapid advances in cancer treatment. By looking at the DNA in your samples (using "genomic sequencing") , researchers can make discoveries to identify new ways to treat metastatic breast cancer. This information will be securely shared with researchers around the world. It will be invaluable to cancer research for years to come — and ultimately lead to a better understanding and faster advances in the treatment of metastatic breast cancer.

Metastatic Breast Cancer Project

Learn More

count me in

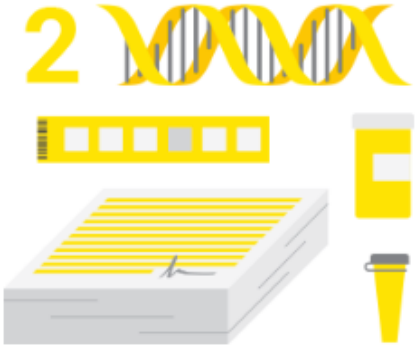
Become part of the research movement. Have a direct impact on the future.

By saying "Count Me In", you will partner with leading research institutes, hospitals, and patient advocacy groups by sharing part of your stored tumor tissue and copies of your medical records.

Here's how you can participate

Step 1. Tell us about yourself

Click "Count Me In" and complete a simple online form to tell us about yourself and your ur goal is to perform many different ithin the metastatic breast cancer ty, so allowing us to know a little bit r experience will help us design future



Step 2. Give us permission to collect your samples and data

When we start a study that matches what you have told us about yourself, we will ask you to fill out an online consent form that requests your permission to obtain copies of your medical records and some of your stored tumor tissue. We will do the rest - we'll contact

Step 3. Learn with us along the way

We are excited to learn with you! Throughout the project, we will provide you with regular updates about the status of the project and share any discoveries that you have enabled us to make. We also may ask you additional questions about your experience to help with

Metastatic Breast Cancer Project

Learn More

count me in

Join the Movement: Tell Us about Yourself

Complete the form below to tell us about yourself and your cancer. Our goal is to perform many different studies within the metastatic breast cancer community, so allowing us to know a little bit about your experience will help us conduct our current projects and also to design future studies. We will be starting with some focused studies in metastatic breast cancer, and expanding over time based on what we learn from you. We are asking all patients with metastatic breast cancer to say Count Me In and fill out the form so that we can use the information you provide to plan our next studies.

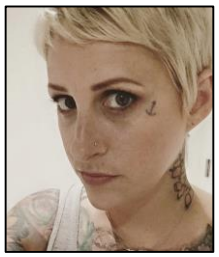
Contact Info

First Name

Last Name

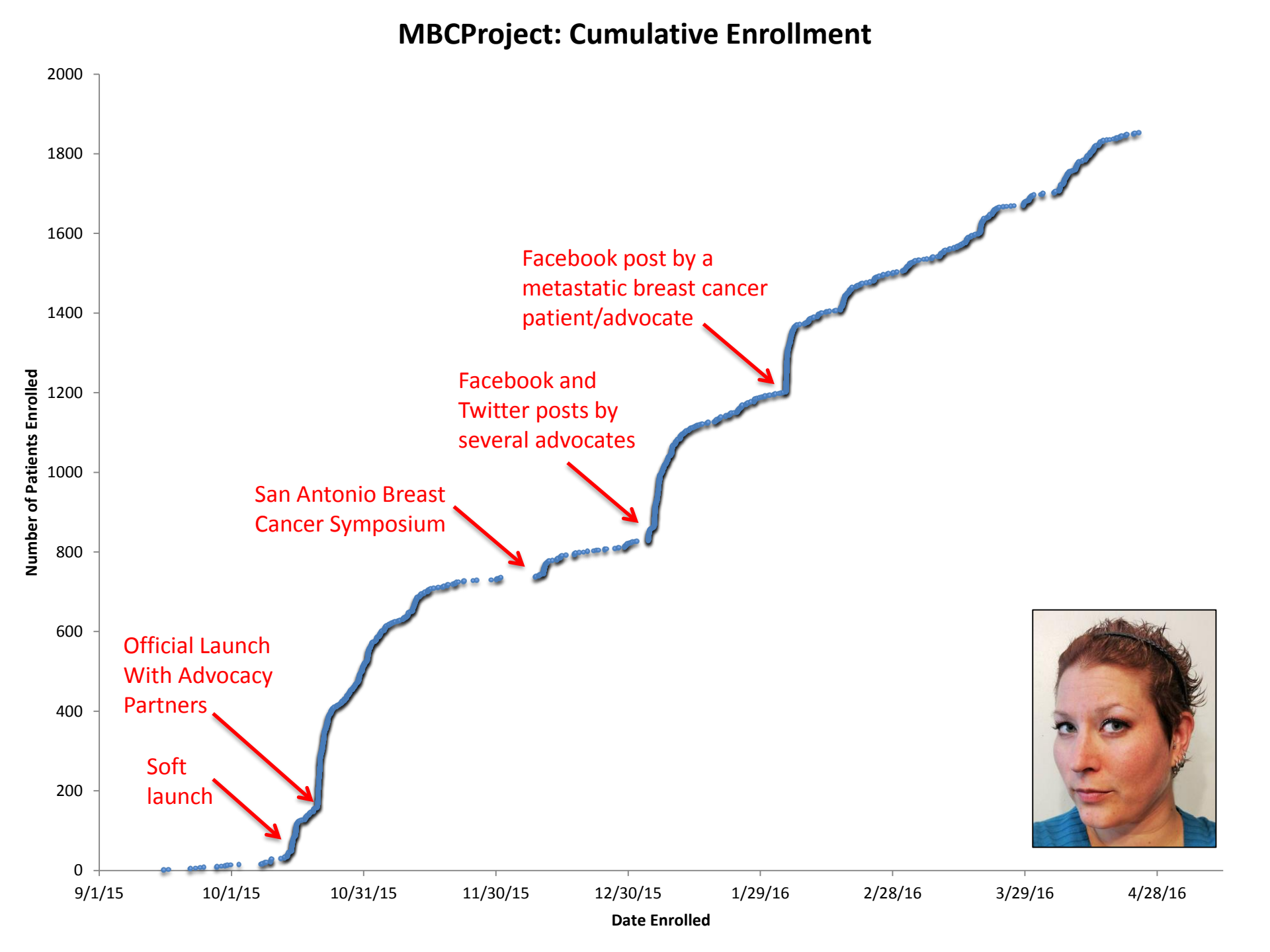
Email Address

The Metastatic Breast Cancer Project
MBCproject.org



Over 2100 women and men with MBC from all 50 states have joined the MBCproject in the 7 months since our launch in October 2015

MBCProject: Cumulative Enrollment



How do we interact with participants?

- **Regular updates** through the website and email about status of the project, progress to date, and any discoveries that have been made
- **Educational information** and videos about metastatic breast cancer research, approaches we are using, and explanations of new discoveries
- **Notifications** when we are starting to study new groups of patients with metastatic breast cancer
- **Feedback** about questions and suggestions we receive through the surveys and direct emails – *we're committed to listening to and learning from our patient-partners*

We are not at present returning individual genomic results - but this being worked on

Patients driving the MBCproject in Social Media

MBC Project and 1 other liked

Litlbee @litlBee · Apr 9

@corrie_painter the ability to do something to help in future, helps me #opendata **#MBCproject**

Catherine Ormerod and 1 other Retweeted

April Hines @owlchick_april · Apr 8

"Taking research and putting it in the hands of patients to drive it." We're ready; let's go! #Thriving2gether **@MBC_Project** @Nikhilwagle

Catherine Williams and 4 others liked

judy erdahl @jerdh · Apr 23

Amazing how happy that little box makes you feel! I felt like a 2 yr old. Let me help! **#mbcproject** #countmein

Patients driving talks

Fred Hutch
May 24 at 6:23pm ·

Like Page

Dr. Corrie Painter of the Broad Institute of MIT and Harvard came to Fred Hutch to talk about the The Metastatic Breast Cancer Project — a new model for using social media-powered, patient-driven research to speed cancer cures.

Photo by Bo Jungmayer / Fred Hutch News Service

A new handle on research ← Pun

Dr. Corrie Painter first turned to Facebook to find others who sha
aggressive cancer. It was her first step on a path from the bench
Broad Institute of MIT and Harvard, where as a…

FREDHUTCH.ORG

Like Comment Share

Beth Caldwell, Janet Freeman-Daily and 278 others

46 shares 8 comments

Beth Caldwell; MBCproejct Patient; METup Co-Founder

Dr. Corrie Painter from the Broad Institute talks with Fred Hutch writer Diane Mapes about why researchers should embrace social media. Video by Bo Jungmayer / Fred Hutch News Service

Facebook Live.. What?

Participants, not samples

Online to real life engagement

The San Antonio Breast Cancer Symposium 2015

BC Consortium @BC_Consortium · Dec 10

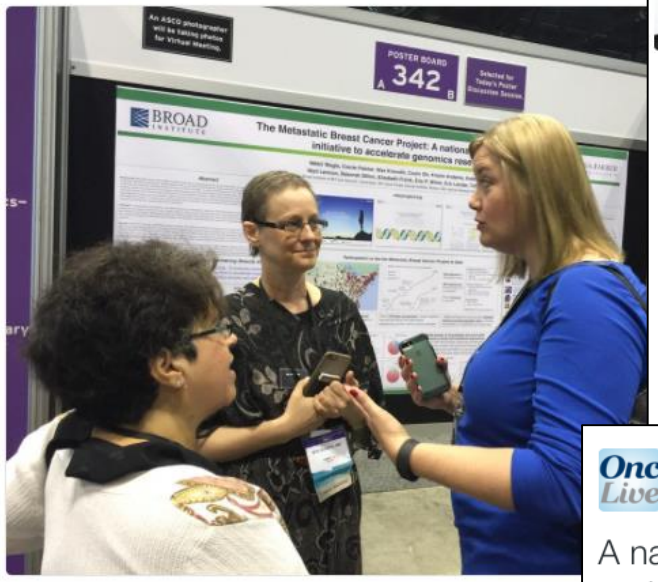
Researchers & activists negotiate the future of metastatic BC research @corrie_painter @Nikhilwagle @metup #SABCS15

MBCproject patient panel and lunch 2016

One of the most important days of my life. Thank you MBC Project.~ Jill Haagenson

Best Of ASCO 2016

It's @BBethJo presenting the #MBCproject at the #asco16 poster session



RETWEETS 12 LIKES 24

Eric Topol @EricTopol · Jun 7

The surpising power of smartphone apps to help patients w/ #cancer thrive & survive on.wsj.com/1ZskHBH #ASCO16

WSJ Health News, WSJ Science, Ron Winslow and 2 others

HEALTH & WELLNESS

Studies Rely on the Internet to Help Cancer Patients

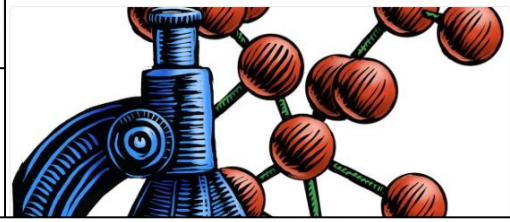
People with lung cancer lived longer when using an app to report symptoms

BBeth Jo @BBethJo · Jun 6

@bethfairchildnc @summar_breeze @Judit_Saunders @ihatebreastcanc @catbrennan Count us in!!!! #ASCO16 #mbcproject

7 11

Patients Are Contributing to Breast Cancer Research curetoday.com/articles/count… #ASCO16



OncLive.com @OncLive

Follow

A nationwide effort could lead to new discoveries and better treatments for patients with breast cancer onclive.com/conference-cov… #asco1

Patient-Driven Research Project Aims to Advance Metasta

Researchers are hoping that a new nationwide effort to encourage patients to share their tumor samples and clinical information will lead to new discoveries and better treatments.

onclive.com

RETWEETS 10 LIKES 11

11:15 PM - 4 Jun 2016

10 11

Male Breast Cancer @MBCC2014

Following

He wouldn't talk about his breast cancer dx at first. Now look @Bronxborn409! #malebreastcancer #ASCO16 #MBCproject

Corrie Painter, PhD @corrie_painter

It's @Bronxborn409 representing @MBCC2014, a stellar advocacy partner of the #MBCproject #asco16 #bcsm

RETWEETS 5 LIKES 10

6:32 AM - 6 Jun 2016

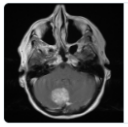
5 10

Lisa M Guzzardi, RN @LguzzardiM

Following

'Incredibly Rapid' Enrollment in @MBC_Project Study. Why? #bcsm #ASCO16 @Nikhilwagle @corrie_painter

Via @Medscape



'Incredibly Rapid' Enrollment in Breast Cancer Study. Why?

Many oncology clinical trials fail to complete enrollment, but a new study of metastatic breast cancer has patients signing up in droves. What is going on?

medscape.com

RETWEETS 28 LIKES 28

12:33 PM - 6 Jun 2016

28 28

Patient-Reported Data

95% submitted the 16-question survey

98% response rate to each question (all are optional)

6 minutes to complete

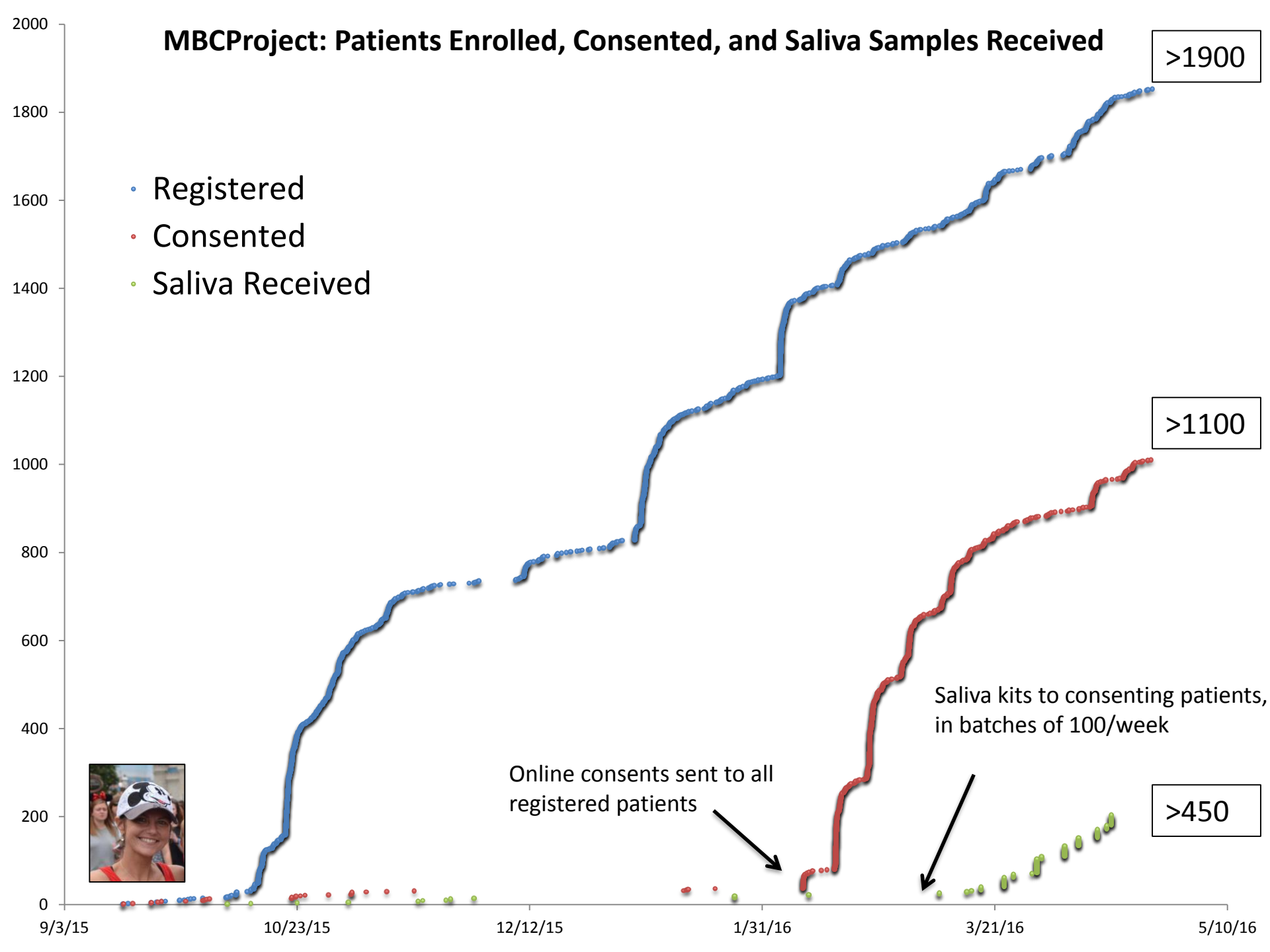
Detailed patient reported data from >1750 patients

Disease Characteristics:
- *Dates of initial diagnosis*
- *Date of diagnosis with metastatic disease*
- *ER+, PR+, and HER2+ status*

Treatment Response:
- *Questions about extraordinary responses*
- ***Free text** about treatments*
- *Date of most recent biopsy*

Demograpgics:
- *Year of birth*
- *Race and ethnicity*

***Free text** about anything additional*


MBCProject: Patients Enrolled, Consented, and Saliva Samples Received
>1900
>1100
>450
Registered
Consented
Saliva Received
Online consents sent to all registered patients
Saliva kits to consenting patients, in batches of 100/week
2000
1800
1600
1400
1200
1000
800
600
400
200
0
9/3/15
10/23/15
12/12/15
1/31/16
3/21/16
5/10/16

Metastatic Breast Cancer Project: Patient groups to study

- **Patients with Extraordinary Responses to Therapies**
- **Patients who present with advanced disease**
- Young People with Metastatic Breast Cancer
- Underrepresented Populations
- Patients who develop resistance to therapies

Each of these groups is readily identifiable based on the screening questions on the MBCProject.org website

6. Since your diagnosis with metastatic breast cancer, have you been on any of your cancer therapies for more than 2 years?

- ○ Yes
- ○ No
- ○ Don't know

6a. OPTIONAL: please list the cancer therapies have you been on for more than 2 years, if you know their names:

Describe treatments

_____

7. Have any of your therapies worked extraordinarily well – made your cancer disappear completely (resulting in no evidence of disease, NED) or result in a dramatic reduction in tumor size -- for any period of time?

- ○ Yes
- ○ No
- ○ Don't know

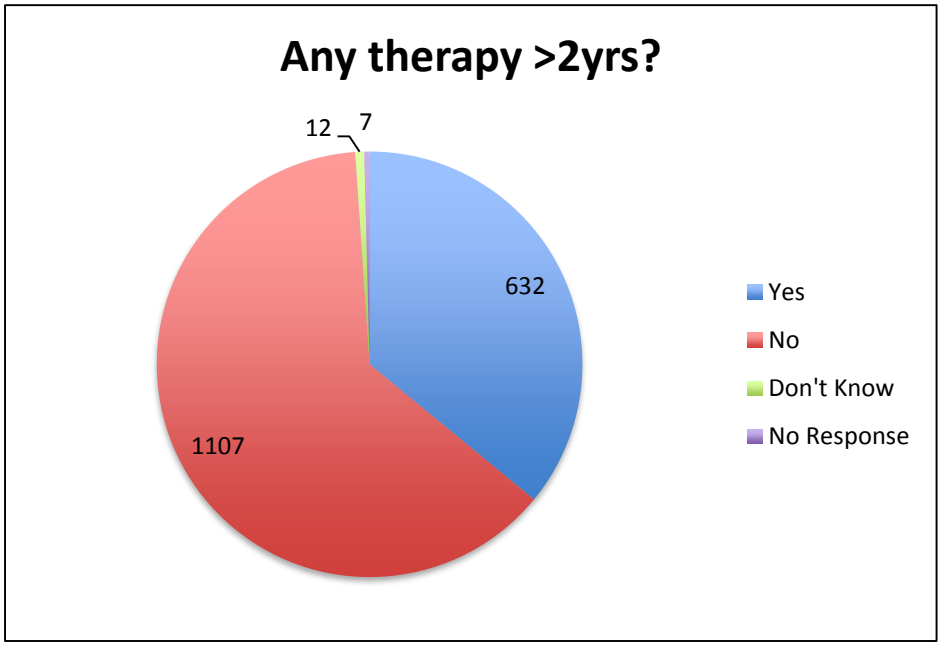
7a. OPTIONAL: please list the cancer therapies that have worked extraordinarily well, if you know their names:

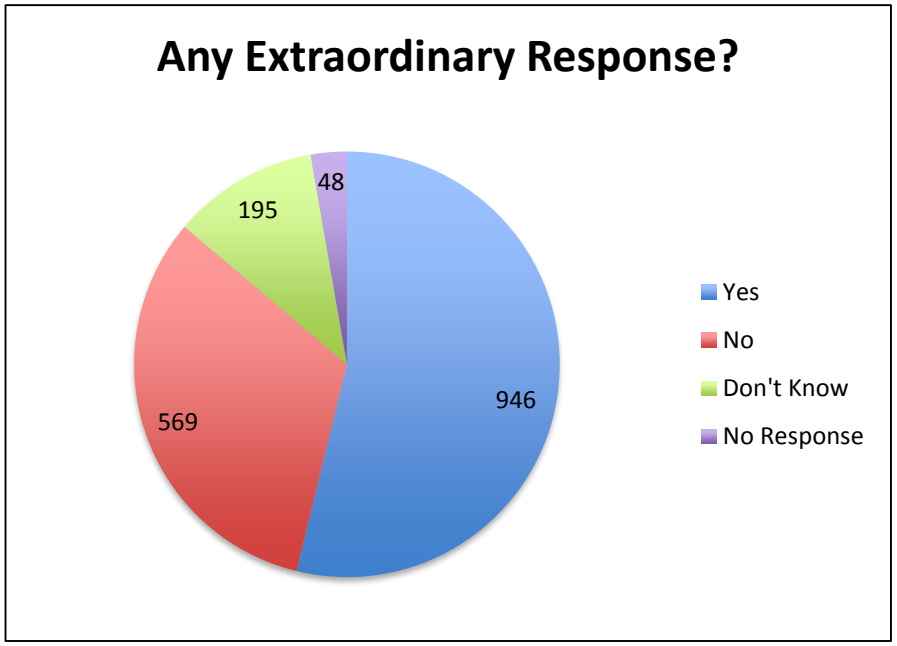
Descripe treatments

_____

Questions about extraordinary responses to therapies

Studying patients with Exceptional Responses





99% of those who responded "Yes" provided the drug names

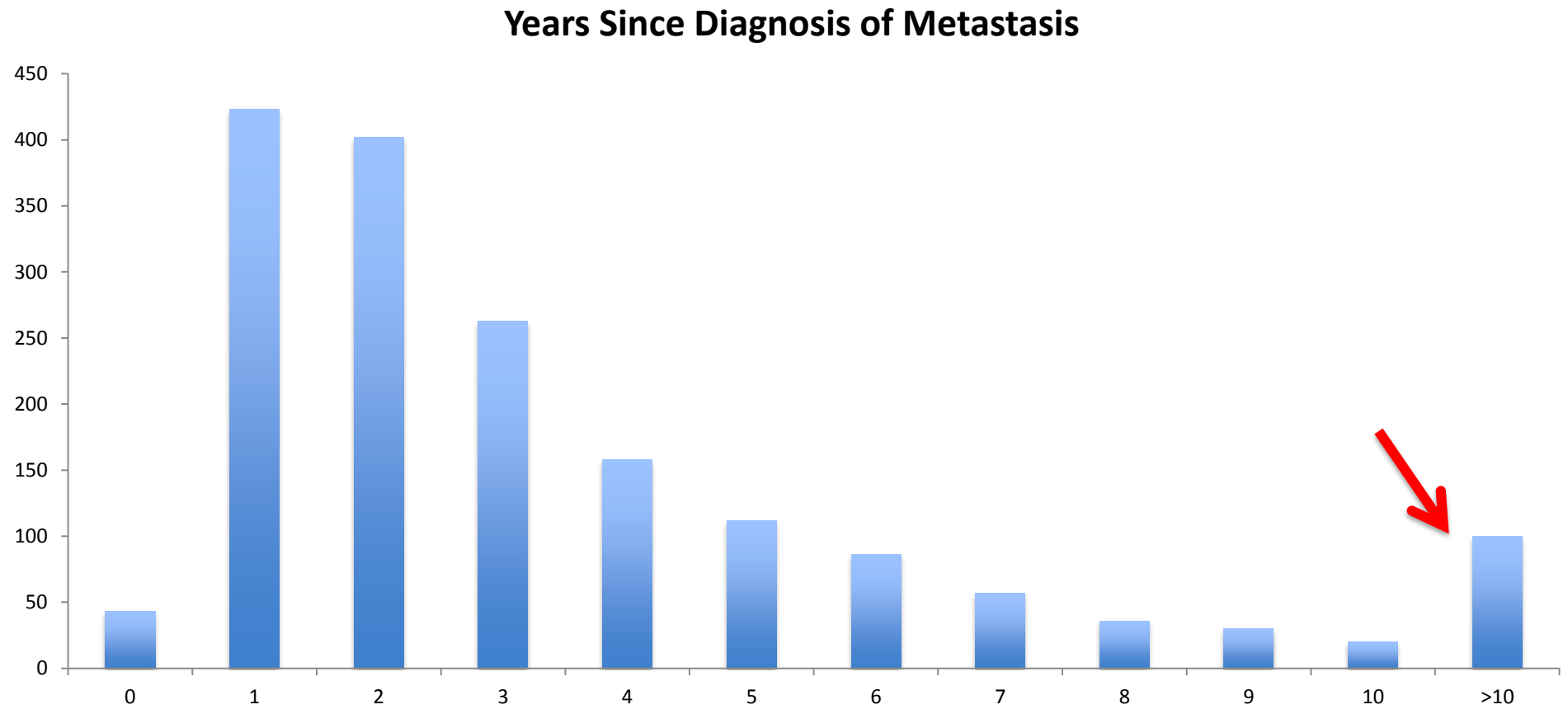
98% of those who responded "Yes" provided drug names and additional "free text" details

***EXAMPLES -** patients with self-reported long-term and/or exceptional responses to:*

- ***Capecitabine (Xeloda)**: 117*
- ***Platinums (Carboplatin, Cisplatin) and PARP inhibitors**: 63*
- ***Everolimus**: 36*

Studying patients with Exceptional Responses

100 respondents report living with metastatic disease for more than 10 years.

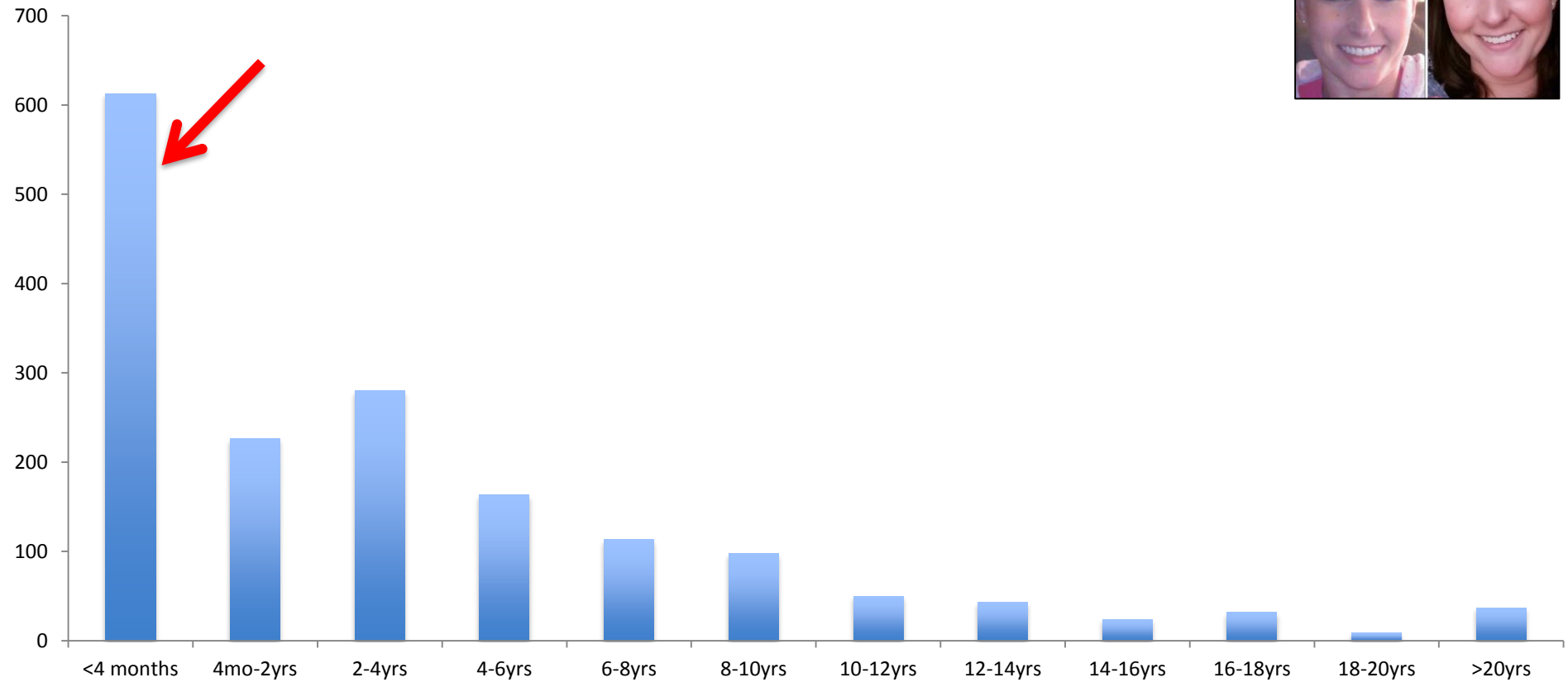


Based on 1730 responses (98.4% response rate)

Studying Patients with De Novo MBC

613 respondents (36%) report that they were diagnosed with metastatic disease less than 4 months after their initial diagnosis with breast cancer (representing Stage 4 or “de novo” metastatic disease)

Years Between Initial Diagnosis and Metastatic Disease

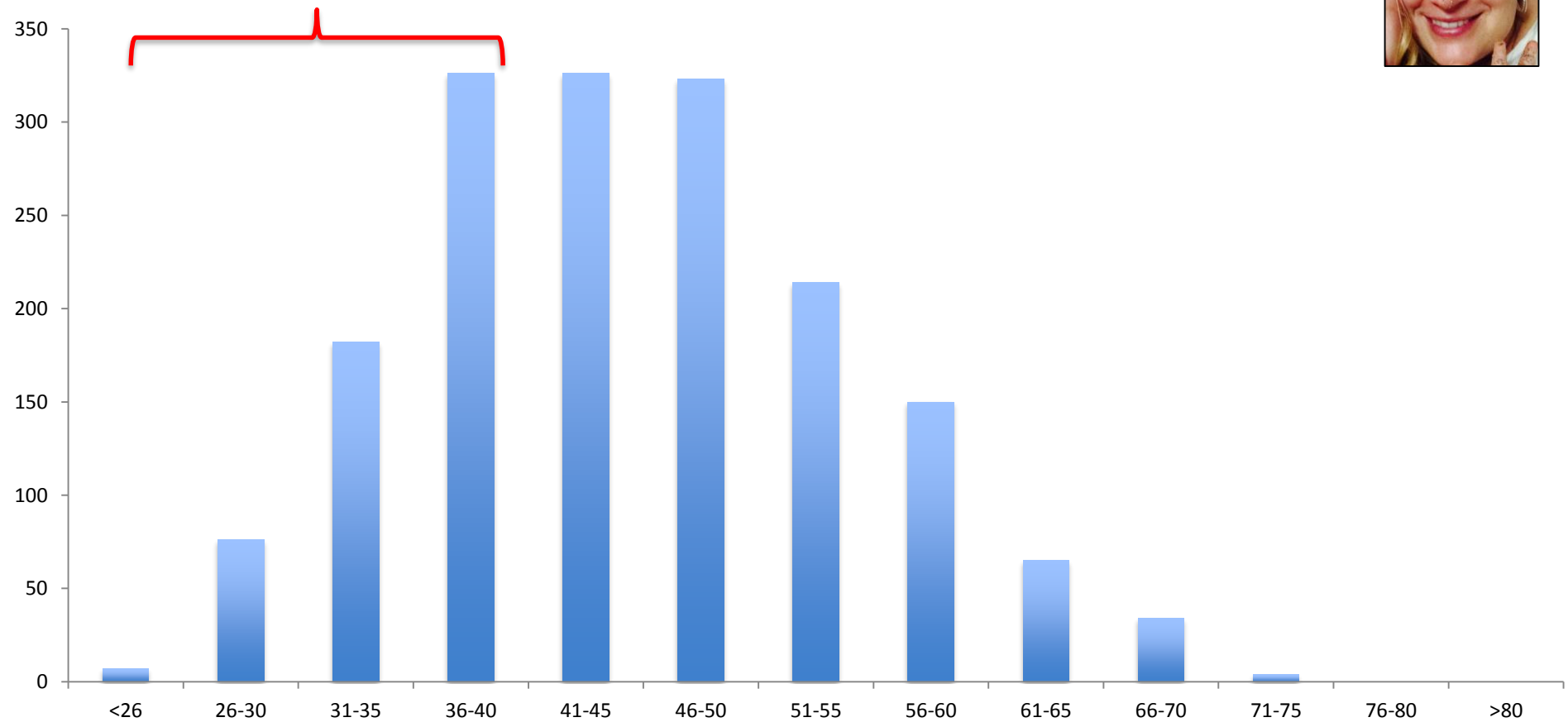


Based on 1688 responses (96% response rate)

Studying Young Patients with MBC

The average age of respondents when they were initially diagnosed with b reast cancer is 45 yrs (range 23-74 yrs)

591 (35%) diagnosed before age 40



Based on 1707 responses (97% response rate)

Optional Survey

Optional anonymous survey: We want to hear your voice

We are always eager to hear your voice and learn with you — your feedback is critical to our work. The following survey is anonymous and will not be linked to your name, email address, or answers to the questions on the previous page.
We'd love to know:

At present, we are not able to return results that we generate from analyzing your tumor sample directly to you. If we are able to return this information at some point in the future, **would you want to receive the research data that we generate from your samples, even if there was no way for you and your doctor to use it to make clinical decisions?**

Yes ---------- 1574 (91.1%)

No---------- 39 (2.3%)

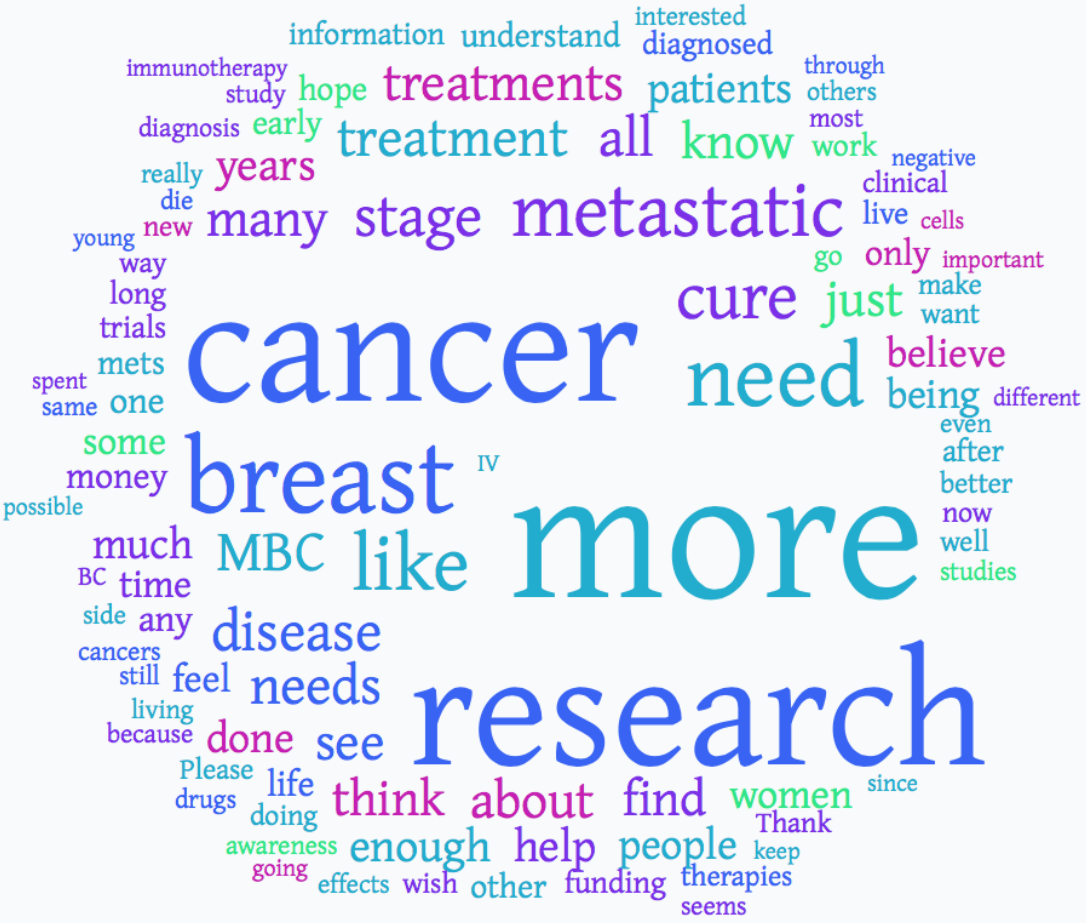
Don't know-------- 114 (6.6%)

Optional Survey Q2

Why or Why not?

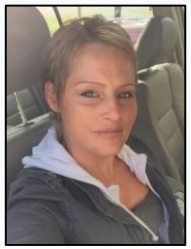
Optional Survey Q3:

Do you have any thoughts on metastatic breast cancer research that you'd like to share with us?



Optional Survey Q4:

We are interested in the type of information that you'd like to receive from this study. Can you help us understand what's important for you to receive from us?



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results study
Anything

Ideas for Outreach / Expansion

1) Social Media
2) Advocacy Groups
3) Traditional print media
4) Patient Conferences / Meetings
5) Patient “Amplifiers” / Community Leaders
6) Community Oncologists
7) Television
8) Advertising

Major goal for 2016 to increase racial/ethnic diversity in MBCproject participants

MBCproject in the News

Breast cancer patients encouraged to share genetic data in new project

Social media speeds study recruitment for cancer researchers

THE WALL STREET JOURNAL.

New Studies Rely on the Internet for Help Treating Cancer Patients

Researchers Take Aim at Metastatic Breast Cancer

POWER TO THE PATIENTS

Facebook, Twitter Helping Boston Institutes Enroll Metastatic Breast Cancer Patients Across US

FiercePharma

cancerNetwork home of the journal ONCOLOGY

Direct-to-Patient Recruitment Aims to Hasten Metastatic Breast Cancer Research

cure

"Count Me In": How Patients Can Contribute to a Metastatic Breast Cancer Treatment Research Project

HealthImaging

Direct-to-patient study recruitment proves a hit in breast cancer project

FAST COMPANY

#Cancer: Researchers Are Conducting Huge Studies Using Twitter, Facebook

Instead of relying on the small number of patients who go to research hospitals, doctors are recruiting huge numbers of participants online.

Medscape

What Will You Tell Breast Cancer Patients About MA-17R?

'Incredibly Rapid' Enrollment in Breast Cancer Studies: Why?

Broad Institute joins Medicine Precision Medicine Summit with researchers, initiatives to drive health research forward

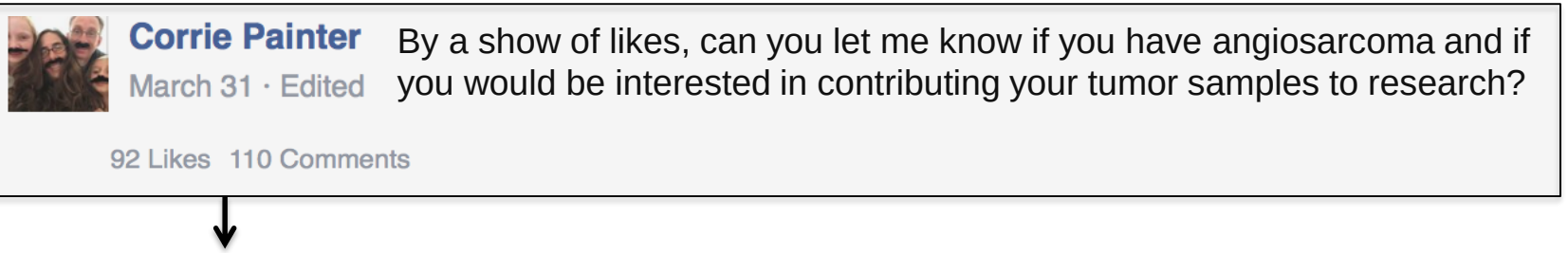
LEARNING FROM THE LAZARUS EFFECT

The Broad Institute is currently exploring other projects modeled after the MBCproject

Rare cancers

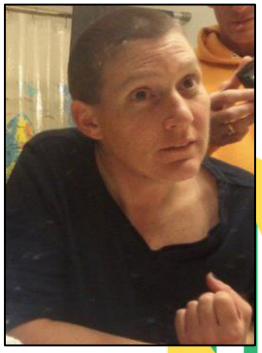
- Strong online communities
  - Patients rally behind a handful of support groups
  - Sometimes only one clinical champion in the country
- Smaller numbers of patients
  - Can sequence the entire living cohort
  - Lack of data may motivate patients with rare cancers to participate in research
- Great potential for large impact
  - Findings may provide rationale for clinical management
  - Uncharted biological territory, potential for discovery is great compared to saturated fields of study

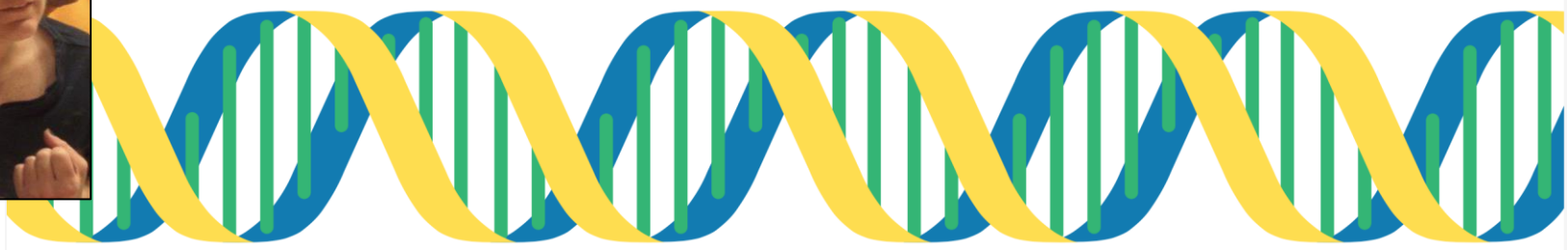
Generating the Genomic Landscape of Angiosarcoma



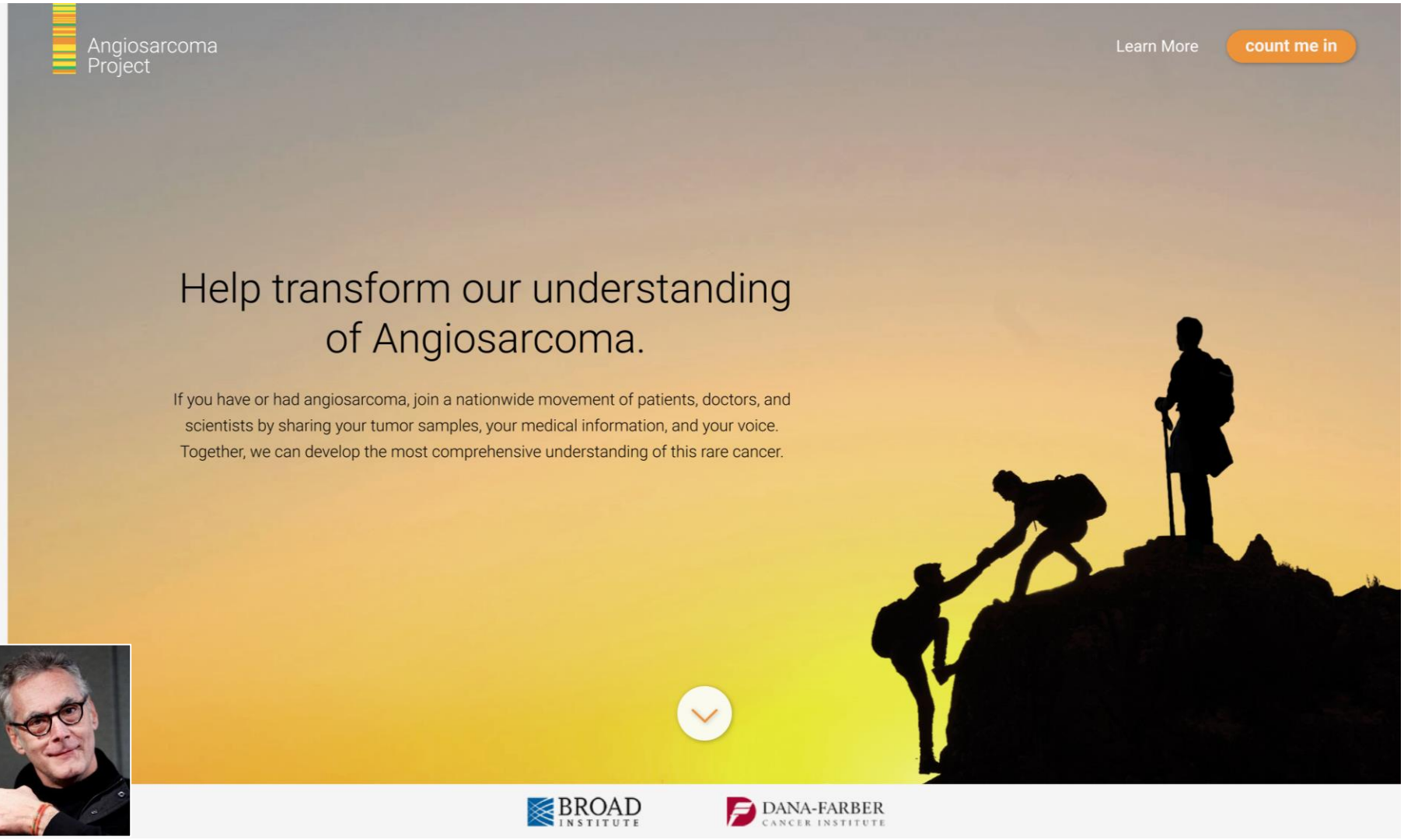
In one hour, > 90 living patients with this exceedingly rare cancer said "Count Me In"

- WES of tumor normal matched samples, and RNAseq for every living person with angiosarcoma
- Generation of clinically annotated data for wide distribution





Angiosarcoma Project is being developed, data coming soon!



Where there are patients there can be projects

- Online patient groups can bring this to the table:
  - The *desire* to be involved in research
  - *Organic communities* with an extensive wealth of information
  - Crowd sourcing *tumor samples*

- Broad can bring this to the table:
  - Large-scale *genomics* studies
  - Generation of *shared resources* for the entire biomedical community
  - *High impact* through unconventional methods

Patients are the biggest stakeholders in our collective efforts to thwart disease.

Thank you!

SUSAN F. SMITH CENTER FOR WOMEN'S CANCERS

DFCI / BWH / Broad
Center for Cancer Precision Medicine

DANA-FARBER CANCER INSTITUTE

BROAD INSTITUTE

DANA-FARBER/BRIGHAM AND WOMEN'S CANCER CENTER

HARVARD MEDICAL SCHOOL

nikhil_wagle@dfci.harvard.edu
@nikhilwagle

painter@broadinstitute.org
@corrie_painter

Thank you!

Nikhil Wagle, Principal Investigator
Metastatic Breast Cancer Project

- Lauren Ryan
- Every member of the Angiosarcoma FB group
- Every registrant in the MBCproject.org
- #BCSM, #MBCproject tweeters
- MBCproject working group FaceBook members

Corrie Painter, PhD @corrie_painter · Dec 10
Poster with the best people I know!! #SABCS15 #MBCproject #BCSM

- Eli Van Allen
- Jon Bistline
- David Siedzik
- Nadya Lopez
- Kristen Zarrelli
- Jesse Boehm
- Kate Mulherin
- Bina Venkataraman
- Coyin Oh
- Gregory Kryukov
- Max Krevalin
- Max Lloyd
- Jessica Sohl
- Deb Dillon
- Lee McGuire
- Lisa Girard
- Clare Midgley
- Mary Carmichael
- Emily Lipscomb
- Andrea Saltzman
- Stacey Donneley

- Tania Simoncelli
- Jenn Chen
- Justine Levin-Allerhand
- Elizbeth Frank
- Scott Sutherland
- Samira Bahl
- Namrata Gupta
- Sara Seepo
- Katie Larkin
- Kristin Anderka
- Liz Gottardi
- Bang Wong
- Niall Lennon
- Nicole Brellenthin
- Stacy Gabriel
- Eric Winer
- Eric Lander
- Todd Golub