Disrupting the Biomedical Landscape with Patient Driven Research

Corrie Painter, PhD
Associate Director of Operations & Scientific Outreach, Cancer Program
The Internet as a Patient-Scientist

- 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!

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

Funded labs
Collaborations

Oregon Health & Science University
University of Minnesota
University of North Carolina
University of South Carolina
Washington University
Mass General
Mount Sinai
Sloan-Kettering
MD Anderson
Moffitt Cancer Center
Sanford-Burnham Institute
University of Texas health Science Center
From Bench to Bedside to Broad

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- 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
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?
Electronic consent form asks for permission to obtain tumor tissue and medical records.

Medical records are obtained and centrally reviewed.

Tumor blocks requested from local pathology departments. Patients sent a saliva kit for germline DNA.

Molecular characterization includes whole exome and RNAseq.

Clinically annotate genomic findings.

Aggregate data shared with researchers. Generalized findings communicated to patients.
A Collaboration with Patients and Advocates

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

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.
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.
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

1. Step 1. Tell us about yourself
   Click "Count Me In" and complete a simple online form to tell us about yourself and your experience. Your goal is to perform many different tasks within the metastatic breast cancer community, so allowing us to know a little bit about your experience will help us design future studies.

2. 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 you.

3. 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 future studies.
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
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

- **Official Launch With Advocacy Partners**
- **Soft launch**
- **San Antonio Breast Cancer Symposium**
- **Facebook and Twitter posts by several advocates**
- **Facebook post by a metastatic breast cancer patient/advocate**
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 MBC project in Social Media

MBC Project and 1 other liked
Lilbee @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

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

A new handle on research

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

Facebook Live.. What?

Beth Caldwell; MBCproejct Patient; METup Co-Founder
Participants, not samples
Online to real life engagement

The San Antonio Breast Cancer Symposium 2015

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

Eric Topol @EricTopol - Jun 7
The surprising power of smartphone apps to help patients w/ #cancer thrive & survive on.wsj.com/12SkHbH #ASCO16
WSJ Health News, WSJ Science, Ron Winslow and 2 others

Studies Rely on the Internet to Help Cancer Patients
People with lung cancer lived longer when using an app to report symptoms.

Eric Topol @EricTopol - Jun 7
WSJ Health News, WSJ Science, Ron Winslow and 2 others

Patient-Driven Research Project Aims to Advance Metastatic Breast Cancer Study, Why? #bcsm #ASC016 @Nikhilwagie @corrie_painter

‘Incredibly Rapid’ Enrollment in Breast Cancer Study. Why? #bcsm #ASC016 @Nikhilwagie @corrie_painter

‘Incredibly Rapid’ Enrollment in Breast Cancer Study. Why? #bcsm #ASC016 @Nikhilwagie @corrie_painter

Male Breast Cancer

He wouldn’t talk about his breast cancer dx at first. Now look @Bronxborn409! #malebreastcancer #ASC016 #MBCproject

Corrlee Painter, PhD @corrlee_painter
It’s @bromborn409 representing @BCC2014, a stellar advocacy partner of the #MBCProject #asco16 #bcsm

11:15 PM - 4 Jun 2016

6:32 AM - 6 Jun 2016

Following

Followers
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

Demographics:
• Year of birth
• Race and ethnicity

Free text about anything additional
MBCProject: Patients Enrolled, Consented, and Saliva Samples Received

- Registered
- Consented
- Saliva Received

Online consents sent to all registered patients

Saliva kits to consenting patients, in batches of 100/week
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 you have 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:

Describe treatments
Studying patients with Exceptional Responses

Any therapy >2yrs?

- Yes: 632
- No: 1107
- Don’t Know: 7
- No Response: 12

Any Extraordinary Response?

- Yes: 946
- No: 569
- Don’t Know: 195
- No Response: 48

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
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)

Based on 1688 responses (96% response rate)
Studying Young Patients with MBC

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

591 (35%) diagnosed before age 40

Based on 1707 responses (97% response rate)
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?

information
knowledge
understand
curious
informed
treatments
important
care
clinical
decisions
additional
regarding
having
something
body
benefit
oncologist
myself
new
breast
possibly
own
feel
much
find
life
family
available
samples
use
just
learn
patients
Curiosity
data
cure
make
doctor
see
need
future
interested
because
able
best
useful
other
good
believe
MBC
cancer
more
research
always
helpful
want
anything
interesting
everything
knowledge
treatment
disease
better
results
daughter
time
being
daughter
metastatic
keep
maybe
understanding
knowing
help
info
loving
one
power
me
else
medical
tumor
think
know
help
one
about
any
have
other
even
having
important
information
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?
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 MBC project participants
MBCproject in the News

- Breast cancer patients encouraged to share genetic data in new project
- Social media speeds study recruitment for cancer researchers
- Facebook, Twitter Helping Boston Institutes Enroll Across US
- Metastatic Breast Cancer Patients
- "Count Me In": How Patients Can Contribute to a Metastatic Breast Treatment Research Project
- Direct-to-patient study recruitment proves a hit in breast cancer
- Direct-to-Patient Recruitment Aims to Have Impact on Metastatic Breast Cancer Research
- 'Incredibly Rapid' Enrollment in Breast Cancer Stu...
The Broad Institute is currently exploring other projects modeled after the MBC project.

**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

By a show of likes, can you let me know if you have angiosarcoma and if you would be interested in contributing your tumor samples to research?

92 Likes 110 Comments

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! 🌟

Help transform our understanding of Angiosarcoma.

If you have or had angiosarcoma, join a nationwide movement of patients, doctors, and scientists by sharing your tumor samples, your medical information, and your voice. Together, we can develop the most comprehensive understanding of this rare cancer.
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!

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@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

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
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