

Cancer Research & Patient Advocacy – personal perspectives from a cancer researcher, caregiver and patient

Oliver Bogler, PhD

NCI
Center for Cancer Training

Disclosure

I work at the National Cancer Institute.

I am giving this presentation from a personal perspective and the opinions I give are my own.

My Cancer Journey: Breast Cancer

1% of breast cancer patients are men



Diagnosis



Irene

- Diagnosed October 2007
- Age 46
- Invasive Ductal Breast Carcinoma
- ER/PR+
- Her2-
- Stage II

Oliver

- Diagnosed September 2012
- Age 46
- Invasive Ductal Breast Carcinoma
- ER/PR+
- Her2-
- Stage III

Treatment

MEDICINE

Cancer strikes twice for oncologist couple

By Todd Ackerman

HC A Houston couple who has made cancer research their life's work now share an unusual distinction: They've both been diagnosed with breast cancer.

Oliver Bogler got the unexpected news in September, five years after his wife, Irene News-ham, began treatment for the cancer diagnosed about 200,000 times a year in U.S. women but only about 2,000 times in men.

It's a first at the University of Texas M.D. Anderson Cancer Center, where they both work. "No one's told us the odds of a husband and wife both getting breast cancer, but obviously it's pretty unusual," said Bogler, a professor of neurosurgery and senior vice president of academic affairs.

The odds are even more miniscule that a couple would be diagnosed with the same stage cancer (II) and the same type

Prognosis continues on A6



Oliver Bogler is undergoing chemotherapy for the same type of breast cancer his wife, Irene News-ham, fought five years ago. They are oncologists at the University of Texas M.D. Anderson Center, where Bogler is being treated.

Nick de la Torre / Houston Chronicle

Irene

- Neoadjuvant chemotherapy
 - 12 cycles Taxol
 - 4 cycles FAC
- Modified radical mastectomy + reconstruction
- Radiation therapy: 50 Gy in 25 fractions followed by a 10 Gy boost
- Tamoxifen (2 years), Arimidex (8 years+ planned)

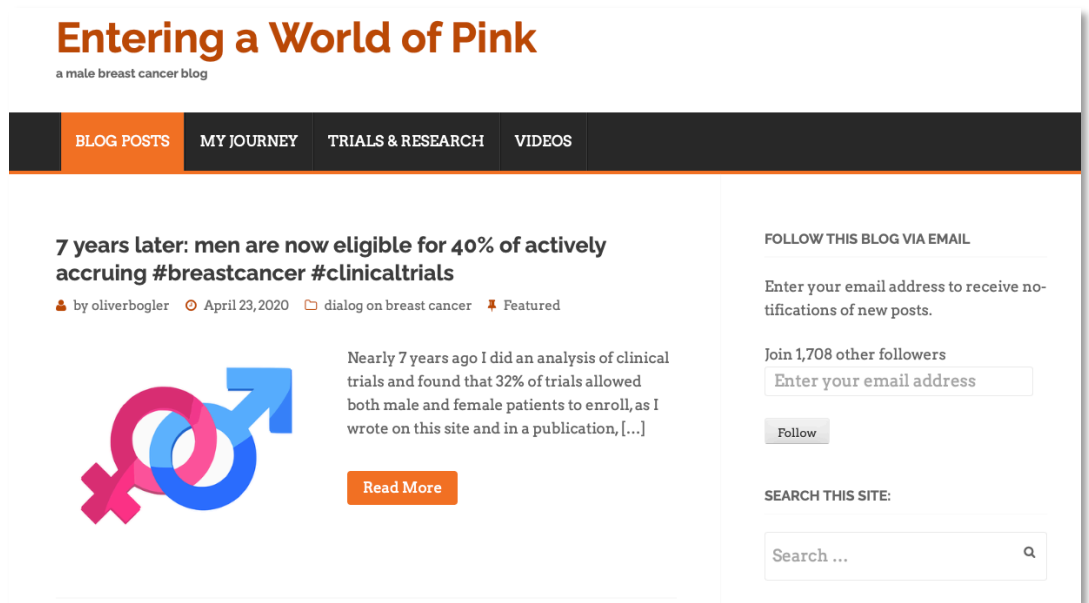
Oliver

- Neoadjuvant chemotherapy*
 - 11 cycles Taxol
 - 4 cycles FAC
- Modified radical mastectomy
- Radiation therapy: 50 Gy in 25 fractions followed by a 10 Gy boost
- Tamoxifen (10+ years planned)

* Management of nausea improved 5 years later

Blogging about my cancer: education, awareness & advocacy

- My blogging arc:
 - Personal journey & education – writing therapy
 - Awareness
 - Advocacy



malebreastcancerblog.org

Blog: Journey & Education

- What happened?
- What was it like?
- How did it make me feel?
- What is the science behind what is happening to me?

day 114 – FAC stands for fluorouracil, adriamycin & cyclophosphamide

Posted on [January 7, 2013](#) | [Leave a comment](#) | [Edit](#)

As promised on day 110, today I am writing about the drugs in the second phase of chemo that I am doing. FAC is a combination chemotherapy, made up of three different drugs, that can be thought of as variations on a single theme: inhibiting the copying of the DNA that makes up our genetic material.

The F is for fluorouracil (<http://en.wikipedia.org/wiki/Fluorouracil>), a chemical modification (fluoro) of a basic building block of genetic material (uracil), which gums up the machinery that makes new DNA. Cancer cells, which are rapidly dividing, have a constant need to make new DNA so that when a cell divides, each of the new daughter cells gets a copy. One of the metabolites used for DNA synthesis is uracil, and when you add a fluorine group to it you change a regular metabolite into a smartbomb that inhibits the enzyme that ordinarily processes it to make it available for DNA synthesis. So not only can you not make a building block out of fluorouracil, it also stops the conversion of the body's uracil from being made into a building block. The result is that you starve the cell of a necessary raw material needed to make DNA and so to divide. This is analogous to a car assembly line stopping because you run out of transmissions.

Blog: Awareness

The SCAR Project
By David Jay

www.thescarproject.org

New York Times
February 25th, 2014

When Men Get Breast Cancer

WELL | TARA PARKER-POPE

BREAST CANCER is not always pink.

That is the message of a provocative new photography series featuring the faces, and scars, of men with breast cancer. The photos, by the New York-based fashion photographer David Jay, are part of his continuing Scar Project, a series of mostly black-and-white portraits that capture the devastation of breast cancer.

The vast majority of the photos in that project are of young women, shown topless with scars where their breasts used to be. The pictures, which are both shocking and beautiful, are featured in a traveling exhibition that will be on display next month in Toronto.

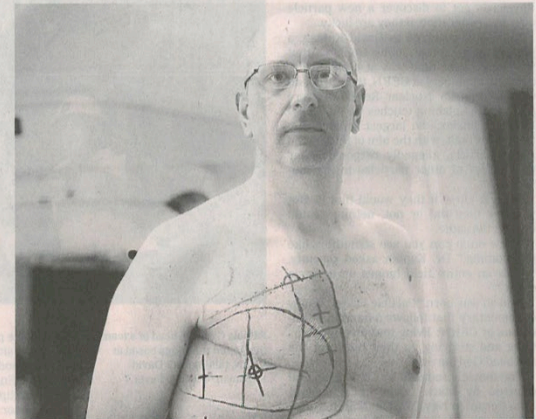
But most visitors to the Scar Project find the photos on the Internet, where they have been viewed by millions of people. One of those people is Oliver Bogler, a cancer biologist in Houston who found out that he had breast cancer 18 months ago after noticing a lump in his chest.

As in a woman's breast, the duct cells in a man's breast can undergo cancerous changes fueled by hormones that influence the growth of cells. It is not clear why some men get breast cancer while most do not, but risk factors include a family history of breast cancer, inherited gene mutations, radiation exposure, extended occupational exposure to certain chemicals or intense heat, obesity, liver disease, alcoholism, and other cancer treatments.

All of these factors can influence the level of hormones in a man's body and potentially spur breast cancer. That said, many men who develop breast cancer do not have any of these risk factors.

Fewer than 1 percent of breast cancers are diagnosed in men, but that is little comfort to the 2,400 men a year who learn they have the disease. For Dr. Bogler, 47, the diagnosis was particularly shocking because his wife had learned five years earlier that she had breast cancer.

"I struggled with the huge coincidence," Dr. Bogler said. "We were both diagnosed when we were 46. It seemed a bit unlikely. I couldn't imagine having this conversation with her, either: 'Honey, I think I have



Dr. Oliver Bogler, a cancer biologist in Houston, received radiation treatment for breast cancer.

at nytimes.com/well.)

The photos of men with breast cancer are admittedly less jarring than those of women. One reason may be that it is less surprising to see a shirtless man, and the absence of his breast and nipple is not as immediately noticeable. But the portraits of the men are still haunting and show, in a more subtle way, the spiritual ravages of cancer.

The photos are also similar in that they capture both the vulnerability and the

A photo series shows a disease's diverse scars.

strength of breast cancer patients, regardless of their sex.

One of the subjects, William Becker, of

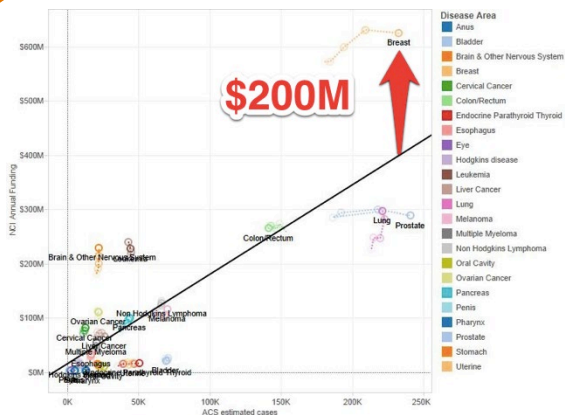
could.

"The photo is very striking," he said. "It gives you a sense of fear, in that there is this man with a scar on his chest and burn marks surrounding it from the radiation treatment — a kind of 'don't let this happen to you' image."

Dr. Bogler worked with Mr. Jay to include men in the Scar Project because he felt that more awareness was needed about the male experience with the disease. He also believes that more research into male breast cancer could help unlock new knowledge about the disease for both men and women.

Dr. Bogler added that while ovarian, uterine, prostate and testicular cancers are inherently gender-specific, breast cancer is no more gender-specific than lung or colon cancer.

Blog: Advocacy for Research



Sum of estimated cases (Incidence-Tableau (NCI spending on cancer types03.xls)) vs. sum of funding. Color shows details about Disease Area (Incidence-Tableau (NCI spending on cancer types03.xls)). The marks are labeled by Disease Area (Incidence-Tableau (NCI spending on cancer types03.xls)). The view is filtered on Disease Area (Incidence-Tableau (NCI spending on cancer types03.xls)), which keeps 24 of 24 members.

Male Breast Cancer: Opportunities for Research and Clinical Trials

Oliver Bogler, PhD

Breast cancer has been at the very forefront of the cancer awareness movement for more than 20 years, but the fact that men can have breast cancer continues to surprise many people. Sexual dimorphism and the differential cultural significance of breasts in women and men are obvious and major reasons. It is also possible that the success of the women's breast cancer awareness movement, which has made the identity of breast cancer so strongly feminine, is a factor. Raising awareness about breast cancer in men, alongside women, is therefore important, but I am going to guess that the readers of this journal have been aware of this and have been thinking about it much longer than I have.

Breast cancer has only been a major factor in my life since October 2007, when my wife was diagnosed with stage II disease, and more recently with my diagnosis with stage III disease in September 2012. One of the first things I learned at close quarters is that men and women are treated nearly identically in the clinic and that most of the data used to manage my disease were based on what had been learned from women with the disease. While I am willing to accept that this is sound medicine and science, the cancer researcher in me can't help but think that there may well be differences, too. More research needs to be done to learn about male breast

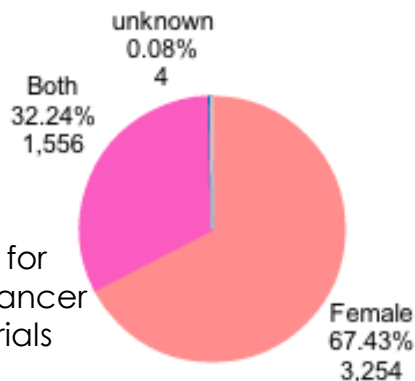
cancer, particularly now, at the dawn of the era of personalized cancer care.

By way of context, let me note that about 1% of breast cancers occur in men. The incidence rate varies regionally, with lower rates in some countries (eg, ~0.7% and rising in the United States¹), higher rates in others (eg, 6% in Tanzania²), and little data in many other areas (eg, Globocan³ does not allow a search for breast cancer in men.). Let's call it 1% for now. While 1% is a small proportion, it is not negligible. The American Cancer Society estimates 2240 breast cancer cases in the United States for men (234 580 for women) in 2013, which is not that different from the number of men likely to get more recognized cancers such as acute lymphoblastic leukemia (3350), chronic myelogenous leukemia (3420), or gallbladder cancer (4470).⁴

So does 1% of breast cancer research focus on the disease in men? While nothing forces strict proportionality between incidence and funding, an analysis of National Cancer Institute (NCI) research dollars versus estimated cases, courtesy of the American Cancer Society, shows that there is a positive trend (see Fig 1). Breast cancer, which receives about \$620 million per year in NCI support, rises well above the trend, no doubt in part due to strong community advocacy. As a starting point, it therefore seems reasonable to suggest that research on male breast cancer should receive \$6.2 million a year from the NCI, or about 15 R01 grants. Even if male breast cancer were funded more in line with other cancers, a case can be made for \$4 million a year, or 10 R01 grants. Notably, a broader analysis using the SciVal Funding database⁵ for all

Breast Diseases: A Year Book! Quarterly Vol 24 No 3 page 216 (2013)

eligibility for breast cancer clinical trials



Clinical Trials

- I have joined 6 trials, and declined one:
 - Molecular marker clearinghouse trial, which allowed my tumor sample to be included in a sequencing project: *Molecular Testing for the MD Anderson Cancer Center Personalized Cancer Therapy Program* (<http://clinicaltrials.gov/ct2/show/NCT01772771>).
 - A prospective trial following breast cancer patients, including men, measuring a variety of outcomes at MD Anderson
 - An immunotherapy trial to prevent recurrence: *Prospective Randomized, Single-Blinded, Multi-Center Phase II Trial of the HER2/neu Peptide GP2 + GM-CSF Vaccine versus GM-CSF Alone in HLA-A2+ OR the Modified HER2/neu Peptide AE37 + GM-CSF Vaccine versus GM-CSF Alone in HLA-A2-Negative and High Risk Node-Negative Breast Cancer Patients to Prevent Recurrence* at MD Anderson
 - Two successive neurofeedback trials to address Chemotherapy Induced Peripheral Neuropathy at MD Anderson
 - One phototherapy trial to address Chemotherapy Induced Peripheral Neuropathy at UCSF

Advocacy: Patient Representative

- Patient Representative on the EORTC prospective trial for men with breast cancer (ongoing)

> [Ann Oncol](#). 2018 Feb 1;29(2):405-417. doi: 10.1093/annonc/mdx651.

Characterization of male breast cancer: results of the EORTC 10085/TBCRC/BIG/NABCG International Male Breast Cancer Program

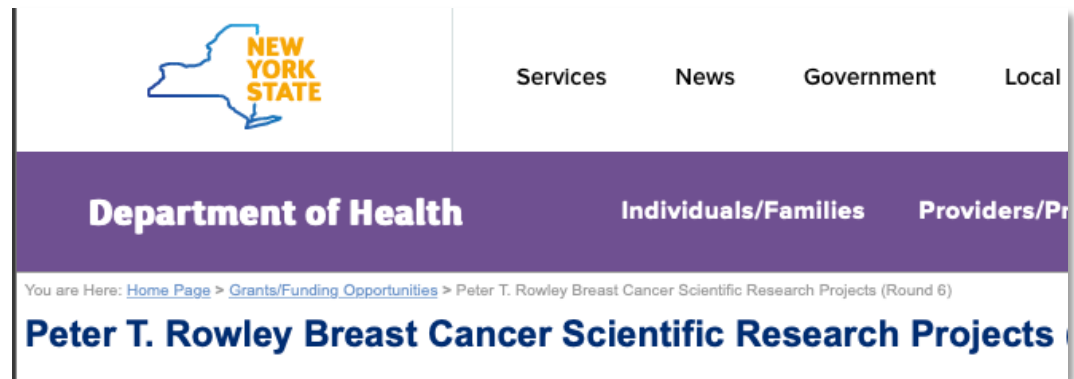
F Cardoso¹, J M S Bartlett², L Slaets³, C H M van Deurzen⁴, E van Leeuwen-Stok⁵, P Porter⁶, B Linderholm⁷, I Hedenfalk⁸, C Schröder⁹, J Martens¹⁰, J Bayani¹¹, C van Asperen¹², M Murray¹³, C Hudis¹⁴, L Middleton¹⁵, J Vermeij¹⁶, K Punie¹⁷, J Fraser¹⁸, M Nowaczyk¹⁹, I T Rubio²⁰, S Aebi²¹, C Kelly²², K J Ruddy²³, E Winer²⁴, C Nilsson²⁵, L Dal Lago²⁶, L Korde²⁷, K Benstead²⁸, O Bogler²⁹, T Goulioti³⁰, A Peric³, S Litière³, K C Aalders³, C Poncet³, K Tryfonidis³, S H Giordano³¹

Affiliations + expand

PMID: 29092024 PMCID: [PMC5834077](#) DOI: [10.1093/annonc/mdx651](#)

Advocacy: Patient Representative

- Patient Representative on grant review panels (before joining NCI)



Advocacy – increasing enrollment

NATIONAL CANCER INSTITUTE
CTS API

NCI Clinical Trials Search API

For information on NCI's efforts to improve how patients and oncologists find information and learn about clinical trials, visit <https://www.cancer.gov/syndication/api>

Fetching Daily Updates

Updates to the API are made daily (the refresh occurs each morning at 7:30 AM ET). Unfortunately, the database (which the API taps into) which captures when a trial has been modified. Future modification of the database will include `date_created` and `date_updated` fields to each table.

Until these updates are made, the best field to use to see which trials have possibly been changed in the database is `record_verification_date`. It is important to note that verification does not mean the auditor took another look at it - but this is inclusive of any instances where the auditor made modifications to the database. As an example, to see which clinical trials have been verified by an auditor since 2016-08-25...

Example: `clinical-trials?record_verification_date_gte=2016-08-25`

```
Editor - /Users/bogier/Documents/NCI/Python/NCI-Trial-API.py
1 #!/usr/bin/env python3
2 # coding: utf-8
3
4 Created on Wed Mar 10 10:19:23 2020
5
6 @author: bogier2
7
8
9 # For NCI clinical trials api see: https://clinicaltrialsapi.cancer.gov/
10
11 import requests
12 import json
13 from datetime import date, timedelta
14 import csv
15
16 def jprint(obj, targetfile):
17     """Prints a formatted string of the Python JSON object
18     text = json.dumps(obj, sort_keys=True, indent=4)
19     # Write to file
20     fileforprinting = open(targetfile, "w")
21     print(text, file=fileforprinting)
22     print("\n", file=fileforprinting)
23     fileforprinting.close()
24
25 #get today work out what date was 6 months ago
26 today = date.today()
27 timedelta = (date.today() - timedelta(days=180)).isoformat()
28 print("Trials whose status changed since:", timedelta)
29
30 # searching the trials listing by GET
31 trialheaders = {'Content-Type': 'application/json'}
32 trialdata = {'fulltext': 'C4872',
33              "anatomic_sites": "breast - Male",
34              "current_trial_status": "active",
35              "study_protocol_type": "Interventional",
36              "primary_purpose_ordinary_purpose_code": "TREATMENT",
37              "current_trial_status_date_gte": "timeago",
38              "isblinded": "false",
39              "include": "1",
40              "nct_id": "current_trial_status_date"}
41
42 trialSearch = requests.get("https://clinicaltrialsapi.cancer.gov/v1/clinical-trials",
43                             headers=trialheaders, data=trialdata)
44 print(trialSearch.json(), "TrialResultsFile.txt")
45
46 # create list of dictionaries, each of which has key 'nct_id' and value of that id
47 trialList = trialSearch.json()["trials"]
48 trialListIds = sorted(trialListIds, key = lambda i: i["current_trial_status_date"])
49
50 # create the list of trials and their data by calling clinical-trial api get Trial
51 trialList = []
52 for item in trialListIds:
53     nctid = item.get("nct_id")
54     trial = requests.get("https://clinicaltrialsapi.cancer.gov/v1/clinical-trials/%s" % nctid)
```

Clinical Trials

Below is a listing of Clinical Trials from the US National Cancer Institute (NCI) for breast cancer that accept men, which I update weekly.

To the right you see a button that allows you to search the CancerTrials.org for trials focused on metastatic disease. Do a search on that site for all the trials that accept men.

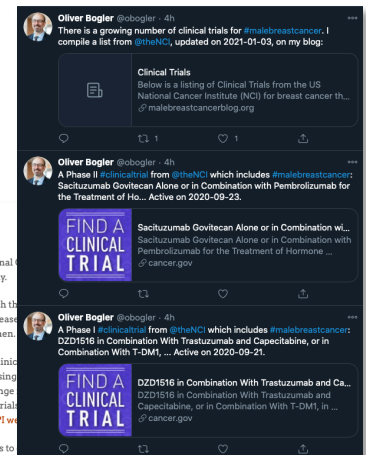
The list below was compiled by searching the NCI ClinicalTrials.org database for trials with the status change term "breast - Male" in the "anatomic_sites" field using the results to Active trials with a status change. Hopefully the best way currently to find the newest trials in the database for this, I understand from the NCI's API website.

This list therefore may contain the most recent trials to be added to the database. Please explore the trials, and posts on our Twitter page on the NCI webpage, via the links provided.

This listing contains 30 trials, and was last updated on 2021-01-03

Testing the Addition of Copanlisib to Usual Treatment (Fulvestrant and Abemaciclib) in Metastatic Breast Cancer

A Randomized Phase I / II Trial of Fulvestrant and Abemaciclib in Combination with Copanlisib (FAC) versus Fulvestrant and Abemaciclib Alone (FA) for Endocrine-Resistant Hormone Receptor Positive HER2-



NCI publishes an accessible API to its clinical trials data

I run a Weekly query of NCI's clinical trial database with a python script

Publish the trials in tweets throughout the week and on my blog's clinical trials page

Started a new Program at NCI: Formally bringing advocates and cancer research trainees together

Cancer Community Partnership



About Us

The National Cancer Institute (NCI) Cancer Community Partnership was created by the NCI Center for Cancer Training in 2020 with the goal of connecting the scientific and medical community with individuals personally affected by cancer. The Cancer Community Partnership is a collaboration between individuals affected by cancer, patient advocates, researchers, and health care providers. We hope that, together, we will be able to learn from one another through inclusive conversations and to influence the development of cancer science and cancer care by integrating the patient experience at all levels.

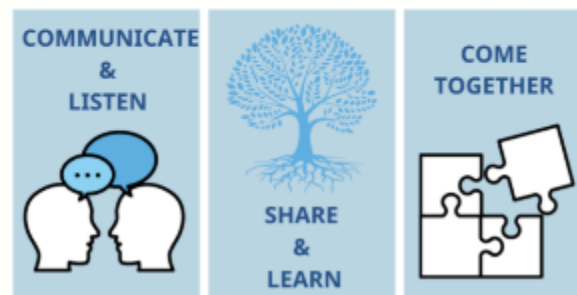
<https://www.cancer.gov/grants-training/training/about/cancer-community-partnership>

Our Mission

We are a learning community with three primary goals:

1. For early career scientists to learn about the patients' perspectives and develop skills around communicating with a lay audience
2. For individuals affected by cancer to have an opportunity to share their experiences; and for research advocates to share the collective patient perspective and help advance science
3. To bring together people from across the cancer continuum to learn from one another

Subscribe to the Cancer Community Partnership email list to receive updates and invitations to events



Bob Riter



HOME FOR COMMUNITY MEMBERS FOR STUDENTS/TRAINees SEMINAR (BIOMs 646) CREATE YOUR OWN PARTNERSHIP ABOUT

Cornell Community Cancer Partnership

Connecting Cancer Researchers with the Local Community

Thank you



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@obogler