

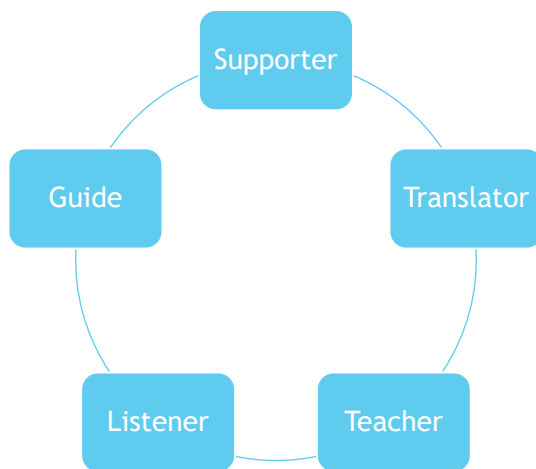
# Cancer Advocacy



Roberta Gelb  
New York, NY  
AACR Annual Meeting  
New Orleans  
April 8-13, 2022

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## Role of the Advocate



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# My Journey

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## My Journey - Part 1

1993

Close friend diagnosed with breast cancer

1994-1996

Active in Share Cancer Support

1997

Diagnosed with breast cancer

1999-2014

Facilitated Friends and Family Group -  
volunteered at Share Cancer Support

2000

National Breast Cancer Coalition - Project  
Lead training

2000-2022

National Breast Cancer Coalition Annual  
Meeting and Lobby Day

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## My Journey - Part 2

2001-2007

Participated on the California Breast Cancer Research Program - Pathogenesis

2009

Attended AACR Scientist Survivor Program

2011

Testified on behalf of Share Leaders at FDA Oncologic Drugs Advisory Committee on Avastin for the treatment of metastatic breast cancer

2012-2019

New York State Breast Cancer Network - Board member

2002-2022

San Antonio Breast Cancer Symposium

2001-2022

National Breast Cancer Coalition Annual Meeting and Lobby Day

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## Working With Patients



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## Deal With the Emotions

Being diagnosed is terrifying

Deal with the reality

Make sure patients take the time to deal with the diagnosis

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## Help Select The Medical Team

- ❑ Check backgrounds
  - ✓ In New York:  
[www.nydoctorprofile.com](http://www.nydoctorprofile.com)
  - ✓ In New Jersey:  
[www.njdoctorlist.com](http://www.njdoctorlist.com)
- ❑ How to access doctors and medical staff
- ❑ Get feedback from other patients

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## Second Opinion - Find the Nearest National Cancer Institute Cancer Center

NCI Designated Cancer Centers delivery cutting-edge cancer treatments.



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## Second Opinion (Continued)



Every step matters



Get a second opinion on the pathology



Some centers run different tests on the tissue

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## Do Not Go Alone



Have someone take notes or ask if you can record



The more knowledgeable the person is, the better

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## How To Keep Medical Records Wilma Flintstone

<b>Address:</b>	111 West 14 <sup>th</sup> Street, #1B Bedrock, New York, NY 10011
<b>Phone:</b>	212-644-4444 (work); 917-944-3333 (cell)
<b>Email:</b>	<a href="mailto:Wilma.Flintstone@gmail.com">Wilma.Flintstone@gmail.com</a>
<b>Medical Insurance:</b>	Pterodactyl <del>HealthChoice</del> AAA 808080808                      Group 3333 Copay:                                      Ofc \$30      ER \$35 Member services:                      800-377-5156 Provider services                      800-992-BLUE
<b>In case of emergency:</b>	Fred Flintstone 917-444-4444 <a href="mailto:Wilma.Flintstone@gmail.com">Wilma.Flintstone@gmail.com</a> Barney Rubble 212-444-4444 <a href="mailto:Barney.Rubble@gmail.com">Barney.Rubble@gmail.com</a>

**NO BLOOD PRESSURE, NO STICKS, NO BLOOD TAKEN IN LEFT ARM**

**MEDICAL ALLERGIES: PENICILLIN; TETRACYCLINE; ADHESIVE**



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## How To Keep Medical Records - 2

- ▶ Walk out of every appointment with a copy of the reports and CDs
- ▶ Keep electronic AND paper records



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## Making Medical Decisions

- ▶ Assist with gathering information
- ▶ Discuss all options
- ▶ Support the patient's decision

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## What Does Having An Advocate Mean To A Patient?

From Lori M. - “Getting a cancer diagnosis was surreal. I felt isolated and confused.

Having an advocate is like a Godsend. I got someone to guide me making life and death choices and to navigate a disorganized healthcare system. It is very comforting to know someone has your back always.”

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## What Does Having An Advocate Mean To A Patient?

From Tod B.

“It was reassuring to have someone who understood the language of cancer. When I got diagnosed, she was the first one I called. Within days, I had consultations with two top oncologists. Without this support, I would have been a basket case.

Some days she was the only thing between me and a panic attack.”

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