Cancer Advocacy

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

Role of the Advocate

- Supporter
- Guide
- Translator
- Listener
- Teacher
My Journey

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
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

Working With Patients
Deal With the Emotions

- Being diagnosed is terrifying
- Deal with the reality
- Make sure patients take the time to deal with the diagnosis

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
Second Opinion - Find the Nearest National Cancer Institute Cancer Center

NCI Designated Cancer Centers deliver cutting-edge cancer treatments.

Every step matters
Get a second opinion on the pathology
Some centers run different tests on the tissue
Do Not Go Alone

Have someone take notes or ask if you can record

The more knowledgeable the person is, the better

How To Keep Medical Records
Wilma Flintstone

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<th>111 West 14th Street, #1B Bedrock, New York, NY 10011</th>
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<tbody>
<tr>
<td>Phone:</td>
<td>212-444-4444 (work); 917-944-3333 (cell)</td>
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<tr>
<td>Email:</td>
<td><a href="mailto:Wilma.Flintstone@gmail.com">Wilma.Flintstone@gmail.com</a></td>
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<td>Provider services</td>
<td>800-992-BLUE</td>
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<td>In case of emergency:</td>
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<td>Barney Rubble 212-444-4444 <a href="mailto:Barney.Ribble@gmail.com">Barney.Ribble@gmail.com</a></td>
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NO BLOOD PRESSURE, NO STICKS, NO BLOOD TAKEN IN LEFT ARM
MEDICAL ALLERGIES: PENICILLIN; TETRACYCLINE; ADHESIVE
How To Keep Medical Records - 2

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

Making Medical Decisions

- Assist with gathering information
- Discuss all options
- Support the patient’s decision
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.”

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.”