

Get Involved! Ways to Engage with the Ovarian Cancer Community

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OCRFA



Getting Involved - Advocacy

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Getting Involved – The Choices

Awareness and Support



Legislative Advocacy



Research Advocacy





Awareness and Support

Susan Leighton



- 1997 Ovarian Cancer (1 recurrence, currently NED)
- 2013 Stage I IDC IDC Breast Cancer
- Founding Member Lilies of the Valley Ovarian Cancer Support and Awareness Group, Huntsville, Alabama
- National Program Director, OCRFA Survivors Teaching Students®
- OCRFA Advocate Leader
- Ovarian Cancer Research Advocate
 - CDMRP OCRP Consumer Reviewer/Ad Hoc Programmatic Panel Reviewer
 - NCI Ovarian Cancer Task Force
 - FDA Patient Representative
 - AACR Scientist<->Survivor Program
 - RAN ASCO Patient Advocate
 - DIA Patient Fellow
 - AstraZeneca Patient Partnership Program
 - Patient Advocate Ovarian Cancer Survivorship Research Consortium
- Publications/Presentations:
 - AACR Poster 2012: "Survivors Teaching Students and TEAL Talks: Educating Future Healthcare Professionals and Women"
 - AACR Poster 2013: "Survivors Teaching Students: An Effective Educational Model to Raise Awareness of Ovarian Cancer"
 - Gynecology Oncology, 2017 May 17, "Quality of Life among long-term survivors of advanced stage ovarian cancer: A cross-sectional approach."

I Want to Shout about It!

- Following a diagnosis of ovarian cancer most women feel alone and frustrated that they did not know about the symptoms.
- As treatment progresses, they may want to connect with other ovarian cancer survivors and
- They will likely want to tell every woman they meet about the risk factors and symptoms.



Connecting with Others

- Support groups
- OCRFA Woman to Woman Program
- Starting your own network
 - As simple as talking to the woman in the next chemo chair
 - Get a group together for lunch
 - If you want to start a support group in your community, reach out to another OCRFA Community Partner and ask questions.



OCRFA's Woman to Woman

- Support program that pairs gynecologic cancer patients with trained survivor volunteers who provide one-on-one emotional support and mentoring to women when they need it most.
- Currently available in 29 locations; expanding this year
- For more information visit <https://womantowoman.ocrfa.org/about-woman-to-woman>
- Seek out local peer support opportunities

Awareness

- Start simple – share the information with a friend and ask her to share it with the women in her life.
- Wear teal and tell people why you wear it.
- Carry symptom cards with you and hand them out whenever you get a chance.
- Look for health fairs in your community and ask to set up a table to give out information about ovarian cancer.
- Gather the facts and offer to speak to women's groups about ovarian cancer.
- During September contact local media about covering awareness events in your community and share your story with them.

Survivors Teaching Students®

- Share your story for a purpose – educating our future healthcare professionals.
- Over 800 volunteers present at over 250 medical, nursing, Physician Assistant, and Nurse Practitioner schools in 35 states, the District of Columbia and the Virgin Islands. Also sister organizations present in the UK, Canada and Australia.
- Three survivors share their stories interspersed with a fact-based presentation describing the risk factors and symptoms of ovarian cancer.

Survivors Teaching Students®

- History of the program – Betty Reiser, stage I survivor from New York, developed the concept in 2002, and the program soon went nationwide.
- Goal - To increase the number of health care providers who recognize the risk factors and symptoms of ovarian cancer so that the disease is detected earlier.
- Empowers survivors and caregivers.
- Contact Susan Leighton at sleighton@ocrfa.org for more information.

Fund the Fight

- Awareness is very important, but **research is going to find a cure!**
- Ovarian cancer is an under-funded disease
- Donate, host a fundraiser, get your workplace involved
- OCRFA will help!
- <https://ocrfa.org/get-involved/> for ideas



- A series of fun and inspiring indoor cycling events
- Ride in honor or memory of a loved one, ride as an ovarian cancer survivors, or just enjoy the fitness challenge and support the cause
- Goal: Fund much-needed ovarian cancer research
- Ovarian Cycle rides take place in cities all across the country with new locations added regularly.
- Visit <https://ocrfa.org/get-involved/ovarian-cycle/>



Legislative Advocacy

Marcie Paul



- 2009 Stage 3C Ovarian Cancer, no recurrences, currently NED
- Ovarian Cancer Legislative and Policy Advocacy
 - OCRFA Advocate Leader
 - Michigan Cancer Consortium Policy Committee
 - Michigan Cancer Consortium Clinical Trials Working Group
 - NCCS Advocacy and Policy Training
 - MDC Precinct Captain
 - Fems For Change Women's Issues Chair
- Ovarian Cancer Research Advocacy
 - CDMRP OCRP Consumer Reviewer
 - PCORI Research Advocate
 - RPCI-UPCI Ovarian Cancer SPORE
 - Karmanos Cancer Institute Patient Advisory Council
- Ovarian Cancer Education, Awareness and Support
 - OCRFA Survivors Teaching Students®
 - Michigan Ovarian Cancer Alliance, Vice President 2011-2014
 - MD Anderson Network Patient Mentor
- Media and Events Professional
 - Running With Scissors Worldwide, Executive Producer

Legislative Advocacy



Our Voices Matter



Congress legislates by anecdote

- Compelling stories prompt legislative action

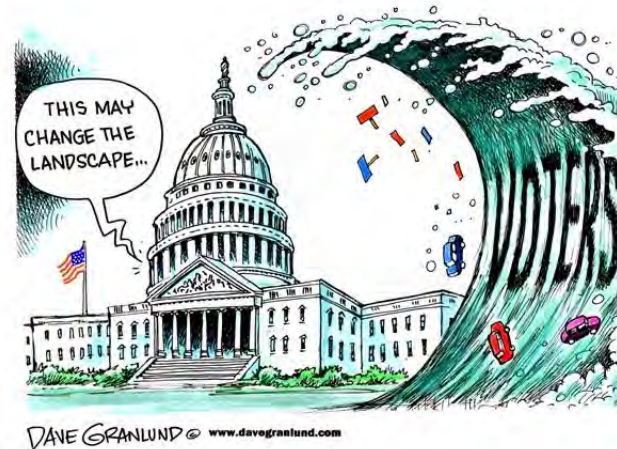


Need to understand legislation and policy from the “human” side

- Benefit from hearing personal stories and connecting programs and spending to individuals and families
- Harder to ignore “real” people – statistics do not have faces

Speaking up in DC

- Advocates not lobbyists
- As constituents, our legislators are there to represent us
- Speaking for those that cannot
- Cancer is nonpartisan and bi-partisan
- Not just a women's issue



What ...

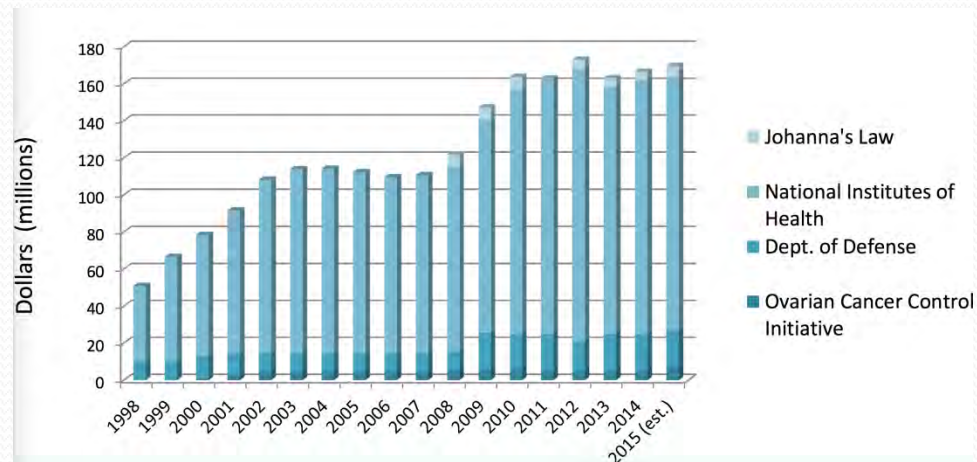
- Advocate for federal funding for ovarian cancer research and education
- Advocate for or against legislation and policies that impacts our community

Why...

- Advocates help to secure roughly \$170 M annually for ovarian cancer research and education



"Should the U. S. motto be, 'In for a buck, in for a trillion?'"



Federal Funding for Ovarian Cancer Research and Education Programs



In FY 2017



National Institutes of Health and National Cancer Institute

- NIH is largest funder of biomedical research in the US
- NCI, operating within the NIH, is the largest funder of ovarian cancer research
- **Asked: \$32 Billion**

In FY 2017



Department of Defense Ovarian Cancer Research Program

- Innovative cutting edge, nontraditional research – research the NIH cannot fund
- Survivors are instrumental in establishing OCRP research priorities alongside scientists and clinicians
- **Asked: \$20 Million**

In FY 2017



Centers for Disease Control and Prevention

Ovarian Cancer Control Initiative

- Funds public health research and interventions
- **Asked: \$8 Million**

Johanna's Law

- Funds the public awareness campaign called *Inside Knowledge*
- **Asked: \$5.5 Million**

Working together

Advocate Leaders

- Contact, visit and build relationships with elected officials
- Serve as a “whip” with legislators
- Calls to action in our community
- Expand the network of local advocates
- Work with OCRFA to organize local meetings
- Attend spring and summer Lobby Days



Advocates

- Contact, visit and build relationships with elected officials
- Call and email DC offices, visit local offices
- Respond to calls to action
- Attend a Lobby Day





Research Advocacy

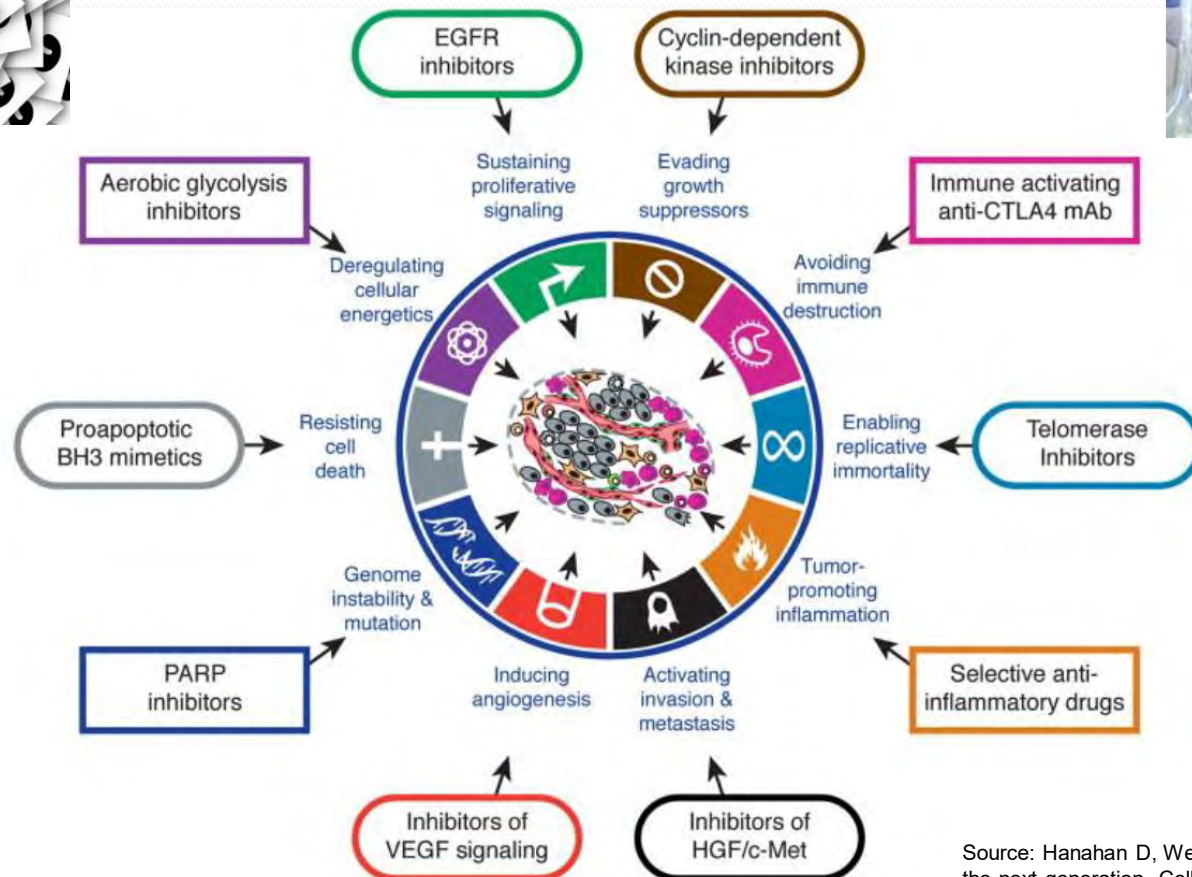
Annie Ellis



- 2004 Stage 2C Ovarian Cancer (2 recurrences, currently NED)
- 2010 Stage 1 IDC Breast Cancer
- Ovarian Cancer Research Advocate
 - OCRFA Scientific Advisory Committee Patient Advocate
 - CDMRP OCRP Programmatic Panel Consumer Member,
 - NCI Gynecologic Cancer Steering Committee
 - RPCI-UPCI Ovarian Cancer SPORE Patient Advocate
 - FDA Patient Representative
 - AACR Scientist↔Survivor Program
 - Biennial Cancer Survivorship Research Conference Survivor-Researcher Mentor Program
- Publications/Presentations:
 - Society of Gynecologic Oncology (SGO) Annual Meeting: Speaker, SHARE's presentation on The Patient's Perspective (2008)
 - OCRFA Research Symposium: A Patient's Perspective on Clinical Trials (2010)
 - Journal of Gynecologic Oncology (JGO): A qualitative study of ovarian cancer survivors' perceptions of endpoints and goals of care (2014)
 - AACR Scientist↔Survivor Program (SSP) poster: Navigating Uncharted Waters: Exploring the Resources Patients Use to Manage Long-Term Recurrent Ovarian Cancer (2014)
 - SGO: Survivors' acceptance of treatment side effects evolves as goals of care change over the cancer continuum (2016) (2017—Manuscript accepted for JGO)
 - SGO: Bridging the gap: A priorities assessment tool to support shared decision-making, maximize limited appointment time and increase patient satisfaction (2017)
- Peer Support
 - SHARE Cancer Support Helpline Volunteer, former Peer Support Group Facilitator
 - OCRFA Woman to Woman Program at NYP Columbia

Evidence-based medicine = HOPE

- How I became a Research Advocate: <https://cqrcengage.com/aacr/app/story/58736975>



Source: Hanahan D, Weinberg RA. Hallmarks of cancer: the next generation. Cell. 2011;144:646-674.

Research Advocacy: NCI Definition

- Research advocates bring a unique viewpoint to the cancer research process, making scientific and medical advances more timely and effective for people living with cancer.
- Advocates bring a human face to cancer research that reinforces the need to accelerate progress.
- Their involvement provides critical feedback and insight.

Research Advocacy Network (RAN)

- ...infusing the research process with the patient experience will dramatically improve research and collapse the time it takes for research results to become standard practice.
- Advocates channel the passion they have for making a difference for cancer patients into the research process by:
 - Driving the questions research tries to answer
 - Protecting the patients who participate in research
 - Disseminating research results

Research Advocacy

- There are four primary ways advocates engage in the research process:



- **REVIEW:** Advocates evaluate and analyze research proposals and ongoing research projects. Activities may include:
 - Participating in peer review panels
 - Editing or translating scientific language in documents to improve readability for non-scientific audiences
- **DISSEMINATE:** Advocates interpret and communicate research findings and scientific information for non-scientific audiences. Activities may include:
 - Using scientific content to develop materials explaining research findings to different cancer communities

- ADVISE: Advocates develop recommendations and provide input on strategic directions or broad policy issues. Participating on formal advisory boards. Activities may include:
 - Institutional review board (IRB)
 - Speaking on panel discussions at scientific meetings or conferences
- DESIGN: Advocates assist in developing or enhancing programs and activities. Their contributions often help in identifying barriers to implementation. Activities may include:
 - National Clinical Trials Network (NCTN)
 - Specialized Programs of Research Excellence (SPOREs)

THE BIOMEDICAL RESEARCH COMMUNITY

By working together, the stakeholders in the biomedical research community have made and continue to make lifesaving progress against cancer for the benefit of patients, survivors, and their families. Among these stakeholders are the following:

patients,
survivors, and
their families
and friends;



clinicians;



academic
researchers from
a wide range of
specialties;



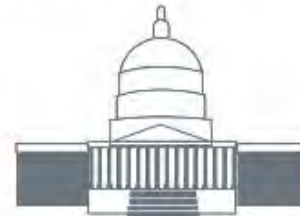
biotechnology,
pharmaceutical,
and diagnostics
companies;



citizen advocates,
advocacy groups,
and philanthropic
organizations;



policymakers;



regulatory
agencies;



funding
agencies;
and



payers.



Happy 20th Anniversary
Ovarian Cancer Research Program (OCRP)
Congressionally Directed Medical Research Programs (CDMRP)



Video—OCRP Patient Advocates: Partnering Toward a Cure
(<https://www.youtube.com/watch?v=Hm1Hf2sy9So>)

Launch of CDMRP Ovarian Cancer Research Program and Founding of Ovarian Cancer National Alliance (now OCRFA) Brought together by CONVERSATIONS! Newsletter and Ovar'coming Town Hall



- Pictured—Left: Cindy Melancon; Gayle Haward (founder NOCC FL), Cindy Melancon, Nancy Hines, Pam Faerber, Pat Goldman
Center: Cindy Melancon, Pat Goldman, Ann Kolker, Kai Bindford, Nancy Hines, Pam Faeber
Right: Pam Faerber; Pat Goldman and Betty Reiser. Not pictured: Bonnie Donihi, Susan Butler (Photo credit: Pat Goldman)
- OCNA Founding Organizations: CONVERSATIONS! The International Newsletter for Those Fighting Ovarian Cancer (Texas), The National Ovarian Cancer Coalition (Florida), Ovar'coming (Indiana), The Ovarian Cancer Coalition of Greater Washington (Washington, D.C.), SHARE: Self-Help for Women with Breast or Ovarian Cancer (New York)