Support and Resources for People with Ovarian Cancer

October 20, 2018
FORCE Resources and Programs for People with Ovarian Cancer

October 20, 2018
Raising awareness that every woman diagnosed with ovarian cancer meets standard of care guidelines for genetic counseling and testing.

KNOW MORE: Ovarian Cancer
www.facingourrisk.org/KNOWMORE
Addressing barriers to hereditary metastatic breast cancer research

“Poor physician and nurse engagement driving low patient recruitment
Less than 0.2% of patients seen annually are referred into clinical trials

“I just learned about a clinical trial but my doctor says we have treatment options and research is a last resort.”

“My friend’s doctor told her clinical trials were only for patients with no other options and put her on ineffectual chemotherapies. When her breast cancer recurred to her brain, she was ready for a clinical trial, but too sick to qualify.”

“I wanted to start a clinical trial but my doctor just started me back on chemo last week.”
FORCE recruited for ovarian cancer treatment registration trials leading to PARP inhibitor approvals
- SOLO
- NOVA
- ARIEL

Current recruitment for ovarian cancer treatment studies
- PARP inhibitors
- Immuno-oncology agents
- Frontline studies
- Recurrence studies
- Maintenance studies

Hereditary Cancer Research Matching Tool
www.facingourrisk.org/research
Peer Navigation Program
www.facingourrisk.org/PNP

- Matching people with volunteers and information based on their personal situation: age, mutation, diagnosis, and geographic location
Media coverage of cancer news can be misleading. XRAYS was developed to help young women understand breast cancer research in the news.
XRAYS

1. Summarizes science in plain language
2. Rates clinical relevance
3. Rates accuracy of media coverage
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1. Summarizes science in plain language
2. Rates clinical relevance
3. Rates accuracy of media coverage
4. Provides information on research and availability of clinical trials
5. Expand to include ovarian, pancreatic and prostate cancer
XRAY: eXamining the Relevance of Articles for You

Research Article: Metastasis in mice is affected by wound healing and inflammation

Most Relevant For: People diagnosed with cancer who need surgery

Relevance: Medium High

Strength of Science: High

Research Timeline: Human Trials

Clinical Trials Available: More Info

This study in mice looked at how wound healing after surgery affects metastasis. Researchers found that wound healing caused changes in the mouse immune system that allowed some cancer cells to grow, but that treatment with a non-steroidal anti-inflammatory drug (NSAID) reduced inflammation and frequency of metastases. This research is being studied in clinical trials in humans. If results are positive, it could change clinical care.

More Info
Connect With Us

Website:
FacingOurRisk.org

XRAYS:
FacingOurRisk.org/XRAYS

Helpline:
866-288-RISK (7475)

Email:
info@FacingOurRisk.Org

Get Social:
FacingOurRisk
Marina Baroff
Senior Director, Service Innovation
Focus
STEPS THROUGH OC
SUPPORT FOR LIFE WITH OVARIAN CANCER
Feel, function, live well with OC
How it works

OC Coordinates
How it works

OC Coordinates

Partnership with a professional OC Counselor
How it works

OC Coordinates

Partnership with a professional OC Counselor

Proactive system: counseling, education, referrals, practical support
How it works

- OC Coordinates
- Partnership with a professional OC Counselor
- Proactive system: counseling, education, referrals, practical support
- Ongoing relationship
Exclusive focus on ovarian cancer
Counselors hold 360° view
STEPS THROUGH OC
SUPPORT FOR LIFE WITH OVARIAN CANCER
www.stepsthrough.org
Ready
Calm
Comfort
Action
Expertise
Community
NOCC Resources and Programs for People with Ovarian Cancer

October 20, 2018
OUR MISSION STATEMENT

The mission of the National Ovarian Cancer Coalition is to save lives by fighting tirelessly to prevent and cure ovarian cancer and to improve the quality of life for Survivors.
Millions of pieces of our TEAL® (Take Early Action & Live) literature have been distributed.
CancerConnect
HIPAA Compliant,
Secure, Moderated
patient forum
Chapter Survivor Gatherings and Education Events
Support and Resources
Ovarian Cancer Research Alliance (OCRA)

We are the largest global charitable organization dedicated to advancing ovarian cancer research while supporting women and their families

Committed to national collaboration through Community Partnerships
Our Mission

three cornerstones of our mission

FUNDING RESEARCH
OCRA's ongoing investment in the most promising scientific research is funding discoveries, creating new treatments, and hastening desperately needed breakthroughs.

ADVOCATING FOR PATIENTS
We are THE voice for the ovarian cancer community, working with legislators to ensure federal ovarian cancer research and education funding, patient safety, and access to high-quality care are protected on Capitol Hill.

SUPPORTING SURVIVORS
Our programs help women navigate an overwhelming diagnosis, supporting patients and their families when and where they need it most.
Merger of Ovarian Cancer Research Fund and Ovarian Cancer National Alliance in 2016 created OCRFA, now OCRA.

**History:** Ovarian Cancer Research Fund founded by and propelled nationally by ovarian cancer survivors Ann Schreiber and Liz Tilberis.

**History:** Ovarian Cancer National Alliance was formed by five leaders of individual ovarian cancer organizations joining forces.
Research

Since 1998, we have invested nearly $90 million to jumpstart promising research at 73 leading medical institutions.

OCRA is the largest non-government founder of ovarian cancer research
Advocacy

Capitol Hill advocacy to help secure $2.5 billion in federal funding since 1998
Programs we offer

Woman to Woman
Inspire Ovarian Cancer Community
Patient Support Line
Education

- Ovarian Cancer National Conference
- Survivors Teaching Students: Saving Women’s Lives
  
  *Each year 11,000 healthcare providers are educated about risk factors and symptoms from 850 survivors*

- Website with critical information and resources
- Webinars
Updated website resource links!
Resource links: Information

- General Information
- Treatment
- Managing side effects
- Hair Loss
- Neuropathy and Lymphedema
- Menopause and Sexual Health
- Nausea and Vomiting
- Finding a Doctor
- Clinical Trials
- Genetics
- Complimentary, Alternative, and Dietary Therapies
Resource links: Support

- Support for You
  - Online and face to face support groups
    - Young Adults
  - Camps, Retreats, and Wish Programs
    - Scholarship and School
- Support for Caregiver, spouse and children
Resource links: Financial Assistance

- Insurance and Legal Resources
- Financial Help
- Lodging
- Transportation
- Pharmaceutical Patient Access Programs
Resource links: More...

- Palliative Care and End of Life
- Advocacy and Research
For more information and to access resources:

Patient Support: 212-268-1002 and support@ocra.org

www.OCRAhope.org
Our Mission

SHARE is a national nonprofit that supports educates, and empowers women affected by breast or ovarian cancer, with a special focus on medically underserved communities.

Our mission is to create and sustain a supportive community of women affected by breast or ovarian cancer.
SHARE’s Vision

- Our trained survivors will continue to educate and support people and their loved ones throughout their diagnosis, treatment, and beyond.
- We will empower women to make more informed decisions about their care.
- We will be on the cutting edge of technology to disseminate information and support to as wide an audience as possible.
Our Services Include:

- Peer support helplines, available 7 days a week
- Peer-facilitated support groups, in person and via teleconference
- Educational programs and webinars
- Online community of peer support
- Outreach in underserved communities
- Workplace seminars
SHARE’s services are . . .

- SHARE services touched nearly 160,000 people last year alone.
- Every service that we offer in English, we offer in Spanish as well.
- All of SHARE’s services are free of charge.
Ovarian Cancer Helpline

- Callers talk to survivors and caregivers and get a viewpoint that can only come from someone who’s been there.
- 1,000 calls were handled in 2017 in English and Spanish
Support Groups

- Women facing ovarian cancer share experiences and support one another with the help of a trained facilitator.

- 10 support group sessions are offered each month in locations throughout NYC, as well as Pennsylvania and via teleconference.

- 11 Spanish-language support groups serve women with ovarian cancer.
Ovarian Cancer Education

- The public gets up-to-date information about ovarian cancer research and new treatments from top oncologists and other leaders in the field, in person and online.
- Nearly 20,000 people learned from ovarian cancer educational programs in 2017.
SHARE Ambassadors

- Latina and African-American survivors educate medically underserved NYC communities about ovarian cancer risks, screening, and what to do if they encounter symptoms.
- 31,675 people were reached by SHARE Ambassadors in 2016.
Support with a Technology Twist

- SHARE hosts a peer-facilitated online support community with over 1,200 members.
- Monthly Topic-Driven Roundtables offer an online educational opportunity where attendees can share their experiences and support each other.
Patient Advocacy & Collaborations

- SHARE works with ovarian cancer researchers to amplify patient voices as they develop new treatments.
- SHARE is also a leading collaborator with a range of ovarian cancer organizations, including FORCE, OCRFA, Foundation for Women’s Cancer, and NOCC.
SHARE’s Partnerships

- Hospitals, clinics, and doctors' offices across the U.S. refer women to SHARE.
- We provide support groups at 9 hospitals.
- We subcontract with NYU to provide outreach services.
- We are currently under contract with the NYC Department of Health for 7 years to provide outreach.
- The American Cancer Society and Patient Access Network Foundation refer women to SHARE for peer support.
CONTACT US

Please contact Ivis Sampayo, Senior Director of Programs at isampayo@sharecancersupport.org (212.937.5576). Learn more at sharecancersupport.org.