

## **2018 ANNUAL REPORT**

Ovarian Cancer Research Alliance (OCRA) is the largest global organization dedicated to fighting ovarian cancer. OCRA's mission is to promote, advocate for and support scientific research as it relates to the causes, prevention, diagnosis, treatment, and cure for ovarian cancer; to provide education about ovarian cancer; to promote, advocate for and provide supportive services to persons affected by ovarian cancer; and to foster alliances to further those purposes.

At OCRA, we believe the best solution for fighting ovarian cancer is to come at it from all angles: that's why we're laser-focused on making progress in the research lab and driving policies to protect ovarian cancer patients on Capitol Hill, while providing steadfast support to those in our community.

Every day, we're doing all we can for women diagnosed with ovarian cancer, while taking action to find a cure - and we couldn't do it without you.

We are so pleased to share with you some highlights of our work this year - progress made possible with your generous support. This is just a glimpse into our progress in 2018. We invite you to visit ocrahope.org, sign up for our emails, and follow us on social media for updates.

On behalf of everyone at OCRA, we thank you for your support.

## **2018 RESEARCH ACCOMPLISHMENTS**

- OCRA funded study focuses on the dissemination of ovarian cancer. An OCRA supported study, published in *Oncogene*, delved into the mechanics of how ovarian cancer spreads throughout the body. Researchers at Johns Hopkins, including OCRA grantee and lead author le-Ming Shih, MD, PhD, investigated spleen tyrosine kinase (SYK), which is heavily involved in ovarian cancer tumor progression, in an effort to understand the role it plays in the invasion and dissemination of cancer cells. Dr. Shih and his team have been evaluating a drug used in treating autoimmune diseases in its effectiveness in inhibiting ovarian cancer. The drug targets the network inside the cancer cell, which attributes to the invasiveness of the ovarian cancer cells into normal tissue. A clinical trial using this drug in ovarian cancer patients will determine if this drug can benefit ovarian cancer patients in the near future.
- OCRA funded study explores implant that detects ovarian cancer biomarker. <u>Science Advances</u> published a study by OCRA grantee, Ryan Williams, PhD, that succeeded in detecting HE4, a biomarker for high-grade serous ovarian cancer (HGSC), by implanting an optical sensor near a disease site in mice. HE4, like CA-125, is approved by the U.S. Food and Drug Administration as a biomarker for HGSC. However, these biomarkers are more likely to become detectible only after the disease has reached an advanced stage. This implant seeks to change that by placing a semipermeable membrane, which can pick up trace levels of HE4, near disease sites such as the fallopian tubes or ovaries.

• OCRA funded research identifies biomarker linked to HGSOC treatment and survival outcomes. In an international collaboration funded in part by OCRA, published in *Cell*, researchers used proteomics, the large-scale study of proteins, to identify an important indicator for treatment and disease-free survival in patients with high grade serous ovarian cancer. The biomarker, known as CT45, is associated with better response to chemotherapy and longer disease-free survival. After testing tissue samples from the University of Chicago's ovarian cancer tissue bank, they found that patients with high levels of biomarker CT45 survived up to seven times longer than those with little to none of the biomarker.

After identifying that CT45 was important for HGSOC patients, they set out to find out why. Knowing that patients with high levels of CT45 responded to platinum based chemotherapy led them to look at how CT45 reacted to the chemotherapy. In patients with high levels of CT45, a standard-of-care chemotherapy called carboplatin caused damage to the DNA, which in turn led to cell death, reducing the size of the tumor. Additionally, two peptides were found in ovarian cancer cells containing CT45, which activated an immune response to fight cancer cells.

• OCRA funded study increased genetic counseling referrals for epithelial ovarian cancer patients. A study by the Mayo Clinic aimed to increase the amount of genetic counseling referrals to epithelial ovarian cancer patients by supplying patients with a Genetics Referral Toolkit. The research was funded by OCRA through the Stand Up 2 Cancer Ovarian Cancer Dream Team. The toolkit included a checklist, a way to track the patient's family history, and awareness materials. In order to track referral rates, researchers compared 81 newly diagnosed ovarian cancer patients from 2013 to 62 newly diagnosed patients during the time of the study, in 2015.

After implementing the use of the Toolkits, researchers saw an increase in referral rates, growing from 48.1% in the 2013 patient population to 74.2% in the 2015 population. Separately, researchers also broke down another population of patients who had never been referred to a genetic counselor into two subgroups, those who sought counseling and those who were tested. In the historic population, or those not specifically referred in the past, 87.9% had counseling and 79.3% were tested. In the population that was provided a Genetics Referral Toolkit, 60% were seen by a counselor and 100% were tested. The researchers concluded that the Toolkit vastly increased the amount of newly diagnosed patients who sought out genetic counseling and testing.

• OCRA funded research reveals immune suppression in ovarian cancer. Researchers from Weill Cornell, led by OCRA grantee, Juan Cubillos-Ruiz, PhD, published a study that helps to explain why the body's natural immune response struggles to fight back against ovarian cancer. Using ovarian tumors from humans and mice, they found that T cells, vital to destroying cancerous cells, are inhibited because of the tumor's effect of the endoplasmic reticulum (ER), which gives the T cells access to one of their energy sources, glutamine. The ER has another function in the tumor environment, which is to use glucose to collect proteins within the cell. When the T cells don't function properly, the ER can't function properly either, which signals a stress response by

a pathway known as IREa-XBP1. With this pathway in a constant state of stress in addition to having no accessible glucose is detrimental to the T cells.

The team at Weill Cornell were able to shut off that pathway in the lab environment. When that pathway was disabled, it allowed the T cells to access the glutamine, which meant it was able to function properly again. In the future, the team hopes that using a drug that inhibits this pathway will allow immunotherapy treatments to be more effective. Understanding how chronic stress signals suppress T cell function within tumors is going to be extremely important, particularly for developing the next generation of immune-based treatments for cancer.

# **2018 GRANTS**

In 2018, OCRA awarded \$5.3 million in research funding to 23 researchers at 15 of the leading medical centers across the country and continued its financial support of the OCRA/Stand Up 2 Cancer Ovarian Cancer Dream Team for a total annual research investment of \$6.3 million. OCRA's Scientific Advisory Committee, comprised of twenty-six of the leading gynecologic oncologists and researchers in the nation, has designed three funding programs to advance ovarian cancer research.

## **Collaborative Research Development Grant**

Launched in 2004, and renamed in 2016, this bold research program provides funds for ovarian cancer research projects that involve several investigators within one institution or collaborations between groups in multiple institutions. The grant is for investigators seeking to develop program project grant applications for submission to peer-review funding agencies (e.g. NCI, RO1, SPORE, DOD). Support of \$300,000 annually for three years is awarded to the institution(s) in which the recipients will conduct the research. Additionally, OCRA offers grantees the opportunity to apply for a competitive renewal grant of \$300,000 for one year.

## **2018 Collaborative Research Development Grant Recipients**

Gordon Mills, MD, PhD

MD Anderson Cancer Center
Rational Combination Therapy in Ovarian Cancer

David Sabatini, MD, PhD

Whitehead Institute for Biomedical Research

A Personalized Approach to Identify and Target Ovarian Cancer Liabilities

## **Liz Tilberis Early Career Award**

Launched in December 2000, the Liz Tilberis Early Career Award is directed toward junior faculty with a strong commitment to an investigative career in the field of ovarian cancer research. The intent of these awards is to support a substantial time commitment to research and academic endeavors in ovarian cancer. Each scholar receives a three-year grant of \$150,000 per year. OCRA also offers Tilberis grantees

the opportunity to renew their award for two years at \$200,000 per year. The program honors OCRA's late president, Liz Tilberis, whose tremendous efforts brought OCRA to new heights of excellence.

## **2018 Liz Tilberis Early Career Award Recipients**

## Maria Victoria Botuyan, PhD

Mayo Clinic

Probing the Antagonistic Roles of 53BP1 and RAD18 in HR DNA Repair

## Katherine Fuh, MD, PhD

Washington University in St. Louis
Inhibition of Metastasis in BRCA2-associated Ovarian Cancers

## Hilary Kenny, PhD

The University of Chicago

The Role of Mesothelial Cells in Ovarian Cancer Metastasis

## Chunsheng Li, PhD

The University of Pennsylvania
Imaging Guided Immunotherapy Targeting CD248 for Epithelial Ovarian Cancer

## Sumegha Mitra, PhD

Indiana University

UCHL1 Regulates Oncogenic Signaling in Ovarian Cancer

#### Jian Yuan, PhD

Mayo Clinic

The Role of BRD9-Rad51 Axis in Chemoresistance in Ovarian Cancer

## **Ann and Sol Schreiber Mentored Investigator Award**

The Ann Schreiber Mentored Investigator Award provides funding for trainees who are working under the supervision of a mentor who is a recognized leader in the field of ovarian cancer research. Applicants must be clinical fellows (Gynecologic Oncology, Medical Oncology), or post-doctoral fellows. Candidates for this program must have an MD or a PhD degree. The award provides a total of \$75,000 to be used over one or two years. OCRA believes that these awards will advance the overall scientific objectives of the cancer center, and encourage the recipient's research career in the field of ovarian cancer. This grant is named in honor of Ann and Sol Schreiber, OCRA's founders.

## **2018 Ann and Sol Schreiber Mentored Investigator Award Recipients**

## Damayanti Chakraborty, PhD

Massachusetts General Hospital

Understanding Epigenetic Regulation of Copy Number Gains in Ovarian Cancer

## Daniele Chaves-Moreira, PhD

The University of Pennsylvania

Isolation and Characterization of the PAX8 Transcriptional Complex

## Chin-Chi Chen, PhD

Johns Hopkins University

Determining the Role of ARID1A in 53BP1-mediated DNA Damage Repair

## Shih-Hsun Chen, PhD

Beckman Research Institute of the City of Hope
Targeting de-poly (ADP-ribosyl)ation for Ovarian Cancer Therapy

## Matthew Dean, PhD

The University of Illinois at Chicago

The Ovarian Microenvironment in Metastasis of Fallopian Tube Derived Cancer

## Marcela Haro, PhD

Cedars-Sinai Medical Center

Cancer Associated Fibroblasts Hinder the B Cell Anti-Tumor Response

#### Ye Hu, MD, PhD

Cedars-Sinai Medical Center Reciprocal Roles of CAFs and CD4+ T Cells in Cancer Progression

## Justyna Kanska, PhD

Cedars-Sinai Medical Center

Identifying Synthetic Lethal Targets to Mutant p53 in Development of HGSOC

## Goldie Lui, PhD

Fred Hutchinson Cancer Research Center Identifying Novel Targeted Therapies for MYC-driven Ovarian Cancer

## Sarah Stuckelberger, MD

The University of Pennsylvania

Development of A Novel Syngeneic Model System for Ovarian Cancer Research

## Yinu Wang, PhD

Northwestern University
Characterization of Chromatin Nanoarchitecture of Ovarian Cancer Stem Cells

## Shuang Zhang, PhD

New York University School of Medicine Modeling Human HGSOC Using Fallopian Tube Organoid Cultures

## ON CAPITOL HILL

Our 2018 Advocacy program brought advocates from all across the country to Washington, DC to push back against potential changes to healthcare laws that could be harmful to cancer patients and urge expanded funding for critical ovarian cancer research at the federal level. This incredible group of survivors, caregivers, and family members receives extensive training and frequent policy updates from our staff and, in turn, serves as grassroots leadership in their home communities. OCRA continues to push for legislation that raises awareness and ensures that high-quality affordable healthcare is available to all ovarian cancer patients. And, given recent medical breakthroughs and newly-available therapies, we will continue to work with regulatory agencies to make sure that patients are heard throughout the drug approval process and the creation of clinical trials.

With your help, our amazing advocates brought a unified message to representatives in statehouses around the country and with federal agencies, continuing the fight to secure funding for ovarian cancer research and education.

2018 ADVOCACY: BY THE NUMBERS	
36	197
STATES REPRESENTED plus Washington, DC	MEETINGS ATTENDED
92	105
HOUSE MEMBERS ENGAGED	SENATORS ENGAGED
36	
ADVOCATE LEADERS	

# IN YOUR COMMUNITY

**Survivors Teaching Students® Saving Women's Lives** educated future healthcare providers about ovarian cancer by bringing survivors and caregivers into medical education programs to share stories of diagnosis, treatment and survivorship, along with facts about the disease. By engaging medical and healthcare students with people personally affected by ovarian cancer in a classroom setting, we initiated crucial conversations, putting faces to the disease and ensuring the next generation of medical professionals are receptive to women reporting symptoms of ovarian cancer, and proactive in recognizing and treating women with ovarian cancer.

2018 SURVIVORS TEACHING STUDENTS: BY THE NUMBERS			
13,258	169		
STUDENTS	SCHOOLS		
<b>532</b> PRESENTATIONS	<b>35</b> STATES plus Washington, DC, US Virgin Islands, Canada, the UK, and Australia		

**OCRA's Community Partners** united over 70 ovarian cancer organizations into a national movement with one strong voice to promote research-based messaging and best practices. Through our Community Partners, women living with ovarian cancer anywhere in the country can find a network of affiliated organizations and locate one close to them, knowing we all share the same fundamental goal of bettering the lives of women battling this disease. All of us working together, will help bring an end to ovarian cancer.

2018 COMMUNITY PARTNERS: BY THE NUMBERS			
71	30		
COMMUNITY PARTNERS	STATES		

**OCRA's Woman to Woman program** helped women diagnosed with gynecologic cancer find emotional support and mentoring by connecting them with trained survivor volunteers who have faced the same obstacles. This summer, OCRA launched programs at eight new sites.

Along with a listening ear, women in the program actively going through treatment - and their partners, families and caregivers - received mentorship, support and encouragement. From the moment of diagnosis through the end of treatment, Woman to Woman survivor-volunteers have helped hundreds of women and their families cope with gynecologic cancer. All services are offered free of charge to all patients.

# **New Woman to Woman Program Sites**

Winship Cancer Institute, Atlanta, GA

Sue DiNapoli Ovarian Cancer Foundation, Colorado Springs, CO

Rhode Island Hospital, Providence, RI

Abington Memorial Hospital, Abington, PA

**Woman to Woman Renewal Grants** 

Northside Hospital (renewal), Atlanta, GA

University of Chicago, Chicago, IL

Baylor University, Waco, TX

**OCRA's Ovarian Cancer National Conference** gave over 300 ovarian cancer survivors and caregivers the opportunity to learn the latest information directly from top experts on topics ranging from new treatments to nutrition. Held in Washington, DC, the conference also provided ample time for attendees to connect, bond and reflect on their shared experience of navigating the world of ovarian cancer.

2018 NATIONAL CONFERENCE: BY THE NUMBERS

318 21

ATTENDEES EXPERT SPEAKERS

# **50**

# **SCHOLARSHIP RECIPIENTS**

# Attendees learned about...

New Treatments for Ovarian Cancer Caring for the Caregiver

Managing Recurrence Guide for Newly Diagnosed

Nutrition for the Ovarian Cancer Ways to Engage with the

Patient Ovarian Cancer Community

Facing Cancer Under 40 Addressing the Cost of

Treatment

Clinical Trials Palliative Care and Hospice

Sexual Health After Cancer

# **FINANCIAL INFORMATION**

From Audited Financial Reports, Fiscal Year 2018

# Revenue

Total Revenue Gains, Losses & Other Support	\$ 7,405,427
Investment income, net	\$(1,237,671)
Revenue & support	\$ 8,643,098

# **Expenses**

Pro	gram	Serv	ices:
	51 WIII	JC: 1	iccs.

Research	\$ 6,896,667
Conferences	\$ 607,043
Education, Support and Advocacy	\$ 1,694,054
<b>Total Program Services</b>	\$ 9,197,764
Fundraising	\$ 1,306,215
Administrative	<u>\$ 968,251</u>
Total Expenses	\$11,472,230

Ending Net Assets \$19,436,779

## **OUR LEADERSHIP**

## **Executive Board**

Jennifer Arminger, Treasurer Robin S. Cohen, Vice-President John Hansbury, Esq., Chair Tom Liebman, Director Dana L. Mark, Esq., Secretary Matthew Neal Miller, Director

## **Board Members**

**Natalie Auerbach Mona Baird** Susan D. Bazaar **Jeannette Chang** Carmel J. Cohen, M.D.\* Mei-Li Da Silva Vint, Esq. Andrew Feuerstein, Esq. **Ellen Fruchtman Shelley Golden Patricia Goldman Carol J. Hamilton Alison Hetherington Caroline Hirsch** Veronica Jordan Edward Labaton, Esq.\* Ylain Mayer **Chris Newcomb John Orrico** Lisa Schreiber **Elle Simone Scott Bronwen Smith Chris Tilberis Robin Zarel** 

<sup>\*</sup>Emeritus Executive Committee Member