# ANNUAL REPORT

## 2017

**OCRFA**

Ovarian Cancer
Research Fund Alliance

OCRFA.ORG

# WHERE IT MATTERS MOST

With gratitude to our strong community of ovarian cancer survivors, patients, caregivers, researchers and supporters. **Thank you.**

# THANK YOU FROM OUR PRESIDENT

**Audra Moran**

OCRFA President & CEO

Dear Friends,

Thank you for joining us for a look back on the year. Many of you joined us in the fight against ovarian cancer for the first time. Many continued your longtime support, inspired by a loved one or by your own survivorship. And while we know this is not a battle anyone chooses to embark upon, we're so grateful for your support.

With your help, were able to make more of an impact with that support than ever before. It was our first complete year as a fully multi-faceted organization, combining "the heart" of the former Ovarian Cancer National Alliance with "the science" of the former Ovarian Cancer Research Fund.

The official mission of OCRFA 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 OCRFA, 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 2017. We invite you to visit ocrfa.org, sign up for our emails, and follow us on social media for updates.

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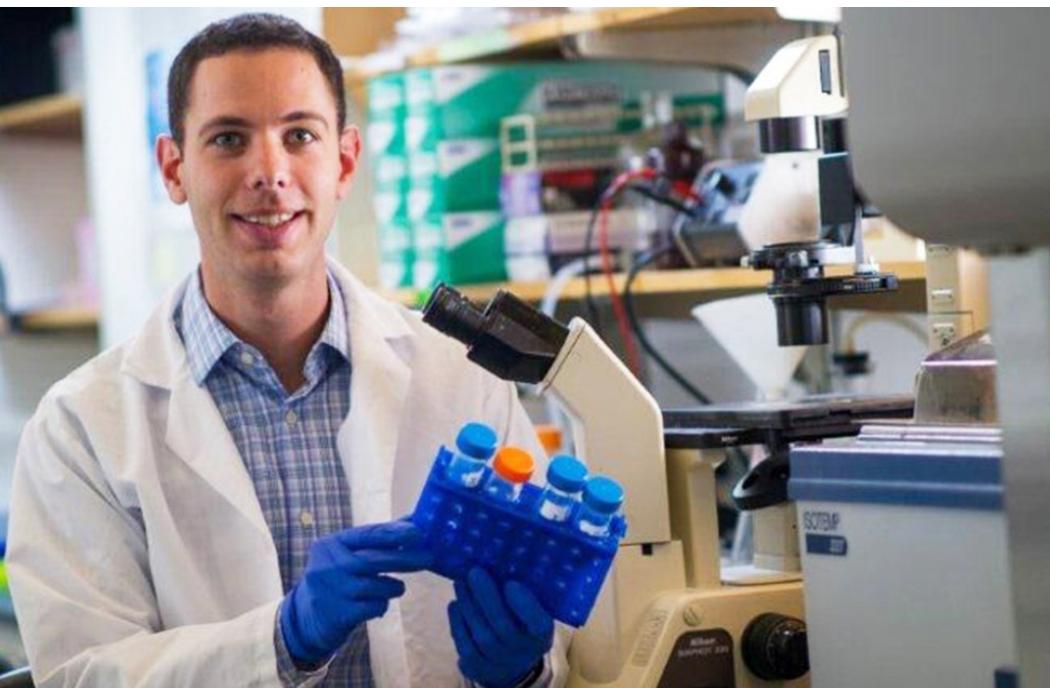
Sincerely,

Audra L. Moran, President & CEO

# IN THE RESEARCH LAB

We saw a significant increase in research grant applications and responded by committing to the largest amount of research funding in our history - $6.7 million. This brings our total investmen in life-saving research to over $75 million. These grants were awarded to twenty top scientists at thirteen leading medical centers.

"These research projects tackle the most pressing issues in ovarian cancer today, focusing largely on the biology of ovarian cancer, and especially on novel therapeutic approaches to advanced ovarian cancer, including immunotherapy," says Dr. Jeff Boyd, Director, Translational Research and Genomic Medicine at Miami Cancer Institute and Chair of OCRFA's Scientific Advisory Committee.

**"The work these scientists do every day is critical to winning the fight against ovarian cancer."**

OCRFA Grantee Michael Goldberg, PhD

*"These research projects tackle the most pressing issues in ovarian cancer today."*

*Jeff Boyd, PhD*
*OCRFA Scientific Advisory Committee Chair*

**Thanks to you, OCRFA is the largest non-government funder of ovarian cancer research in the world.**
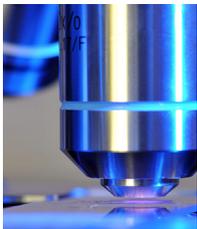
# OCRFA-FUNDED DISCOVERIES

**A Mechanism Underlying Ovarian Cancer Development**  A subset of ovarian cancers were discovered to reduce the expression of a critical gene involved in recycling the cells' proteins. Silencing the expression of a closely related gene led to cell death and prolonged survival of mice. This research "offers novel insights into a previously unknown mechanism underlying ovarian cancer development, and suggests a new therapeutic strategy may be exploitable to treat patients whose tumors arose owing to this imbalance in protein recycling."

**Michael Goldberg, PhD**
**OCRFA Grantee**

**A New Strategy for Treating Clear Cell Ovarian Cancer**  Clear cell carcinoma is a rare form of ovarian cancer that does not usually respond well to platinum-based chemotherapy, leaving patients with few options. Researchers found a drug to affect the enzyme activity in certain mutated tumors, which has resulted in reduced tumor growth and longer survival in animals. "Therapeutic approaches based on this mutation have the potential to revolutionize the way we treat these patients."

**Rugang Zhang, PhD**
**OCRFA Grantee**

**A Potential Relationship Between Hypertension and Ovarian Cancer**  Researchers from Roswell Park Cancer Institute used data from 15 studies led by the Ovarian Cancer Association Consortium to examine the relationship between epithelial ovarian cancer and hypertension, heart disease, diabetes, and their associated medications. Researchers concluded that the use of beta blockers, insulin, diuretics, and oral antidiabetics may affect the overall survival and progression free survival among epithelial ovarian cancer patients.

**Ovarian Cancer Association Consortium, OCRFA-Funded**

**A Link to Why Many Women Become Resistant to PARP Inhibitors**  Resistance to targeted therapies is a major clinical challenge in the treatment of ovarian cancer. PARPi therapy resistance can arise from specific changes in DNA repair pathways, and by combinatorial targeting of these pathways, researchers may be able to overcome PARPi resistance. This project focuses on developing new patient tumor cell-derived functional assays to evaluate these new combination treatments in individual cancers.

**Annina Farkkila, MD, PhD**
**OCRFA Grantee**

"Our OCRFA-funded research project will allow us to identify new ways to treat advanced stage ovarian cancer."

*Ie-Ming Shih, MD, PhD*
*2017 Grantee, OCRFA Scientific*
*Advisory Committee Member*

## 2017 Collaborative Research Development Grant Recipients

**Tyler Curiel, MD** University of Texas Health Science Center, San Antonio, "Rational Design of Effective Multi-modal Ovarian Cancer Immunotherapy"

**Ronen Marmorstein PhD** The Trustees of the University of Pennsylvania, " Chromatin Regulatory Mechanisms in Ovarian Cancer"

**Kenneth Nephew, PhD** Indiana University, " Epigenetic Vulnerabilities of Ovarian Cancer Stem Cells"

**Ie-Ming Shih, MD, PhD** Johns Hopkins University School of Medicine, " Development of Targeted Therapies for Recurrent Ovarian Cancer"

## 2017 Liz Tilberis Early Career Award Recipients

**Alessia Baccarini, PhD** Icahn School of Medicine at Mount Sinai, "Regulation of the Immune Checkpoint PD-L1 in Ovarian Cancer"

**Ronald Chandler, PhD** Michigan State University, "Integrated Roles of Epigenetics and Cell Signaling in Ovarian Cancer"

**Ilana Chefetz, PhD** The Regents of the University of Michigan, "Drugs Inducing Necroptotic Cell Death As A New Strategy for High Grade Serous Ovarian Cancer"

**Michael Goldberg, PhD** Dana-Farber Cancer Institute, "Rational Immunity to Improve Survival Following Standard-of-care Chemo"

**Sunila Pradeep, MD** Anderson Cancer Center, "Epigenetic Causes of Acquired Resistance to Anti-VEGF Therapy"

**Boris Winterhoff, MD** Regents of the University of Minnesota, Twin Cities, "Precision Medicine in Ovarian Cancer: Using Single Cell Analysis"

## 2017 Ann and Sol Schreiber Mentored Investigator Award Recipients

**Marion Curtis, PhD** The University of Chicago, "Mediators of Chemosensitivity and Immunotherapy Targets"

**Anniina Farkkila, MD, PhD** Dana-Farber Cancer Institute, "Overcoming PARP Inhibitor Resistance in Ovarian Cancer"

**Jagmohan Hooda, PhD** The Trustees of the University of Pennsylvania, "Loss of H2Bub1 Rewires Glutamine Metabolism During Progression of HGSOC"

**Gilbert Huang, PhD** Anderson Cancer Center, "Targeting Dormant Ovarian Cancer Cells with Peptide Inhibitors of Autophagy"

**Dongyu Jia, PhD** Cedars-Sinai Medical Center, "COL11A Is A Highly Specific Therapeutic Target in Cancer-Activated Stroma"

**Venkatesh Krishnan, PhD** Stanford University, "Omental Macrophages: Drivers of Ovarian Cancer Metastasis"

**Xianzhi Lin, PhD** Cedars-Sinai Medical Center, "Systematic Discovery of LncRNA Interactome in Epithelial Ovarian Cancer"

**Beatrice Rondinelli, PhD** Dana-Farber Cancer Institute, "EZH2 Determines PARPi Resistance and Fork Stabilization in Ovarian Tumors"

**Priyanka Verma, PhD** The Trustees of the University of Pennsylvania, "BRCA-Independent DNA Repair Pathways in Ovarian Cancer"
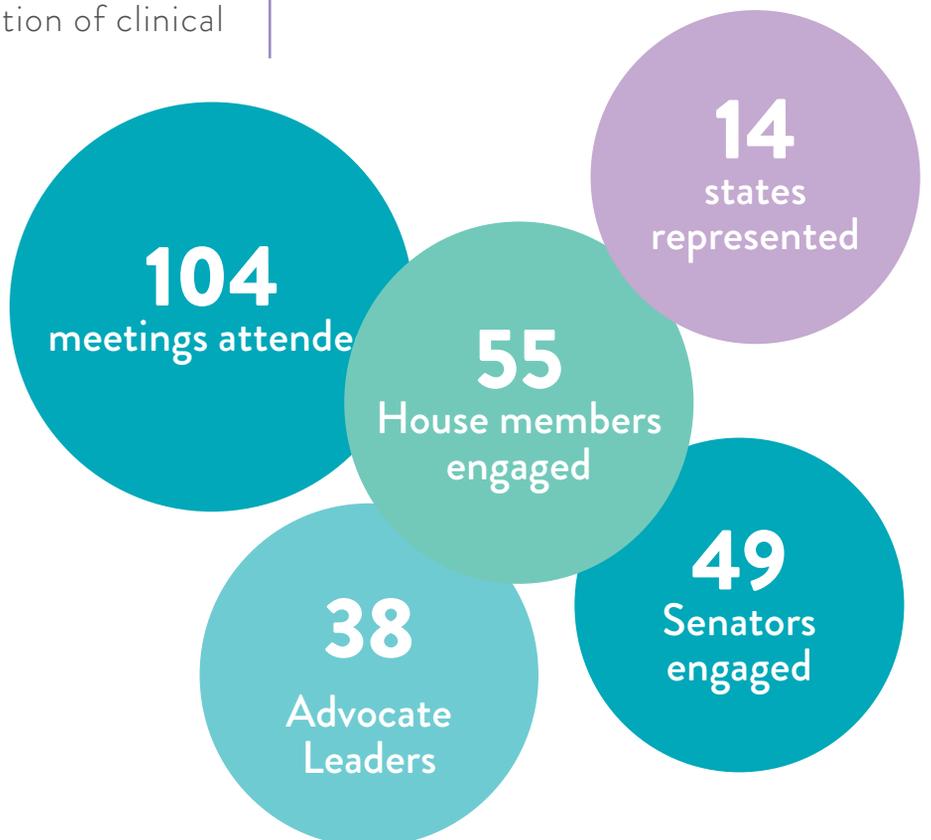
# ON CAPITOL HILL

Our annual Spring Advocacy Day 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.

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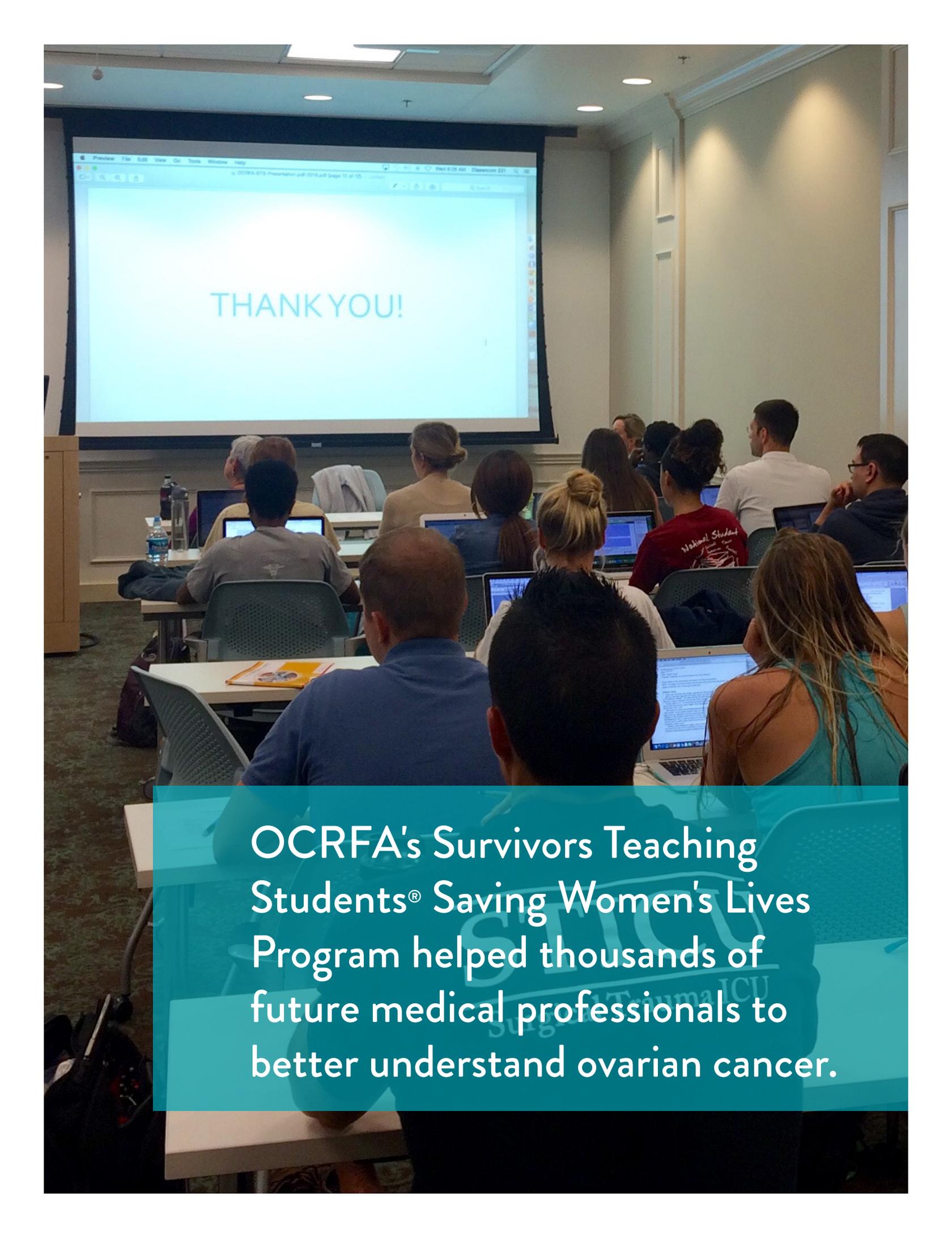
With your help, our amazing advocates brought a unified message to representatives in statehouses around the country and with federal agencies, continuing the fight to secure funding for ovarian cancer research and education.

**14** states represented

**104** meetings attended

**55** House members engaged

**49** Senators engaged

**38** Advocate Leaders

"We had an incredible day on Capitol Hill fighting for ovarian cancer research funding, education, awareness and healthcare for all. We carried all of you with us in our hearts. #tealaction"

*OCRFA Advocate Leader*
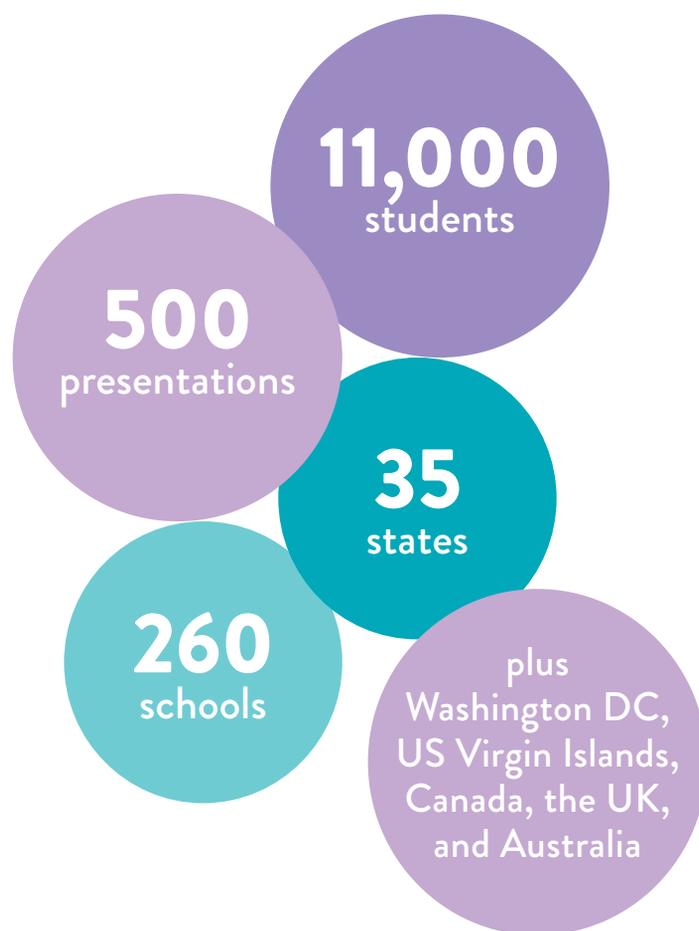
OCRFA's Survivors Teaching Students® Saving Women's Lives Program helped thousands of future medical professionals to better understand ovarian cancer.

# 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 pro-active in recognizing and treating women with ovarian cancer.

**11,000** students

**500** presentations

**35** states

**260** schools

plus Washington DC, US Virgin Islands, Canada, the UK, and Australia

**66** Community Partners

**29** states

**OCRFA's Community Partners** united over 60 ovarian cancer organizations into a national movement with one strong voice to promote research-based messaging and best practices. Through our Community Parnters, 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.

**OCRFA's Woman to Woman** program helped women diagnosed with gynaecologic cancer find emotional support and mentoring by connecting them with trained survivor volunteers who have faced the same obstacles. This summer, OCRFA 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

**Cancer Advocacy Resources Education (C.A.R.E.),** Melbourne, FL

**Cancer Support Community and Ovarian Cancer Alliance of Great Cincinnati,** Cincinnati, OH
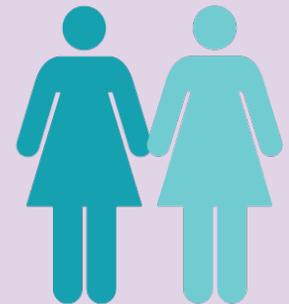
**Holy Name Medical Center**, Teaneck, NJ

**Novant Health Presbyterian Medical Center,** Charlotte, NC

**St. Dominic – Jackson Memorial Hospital,** Jackson, MS

**Tallahassee Memorial Healthcare,** Tallahassee, FL

**University Hospital,** Newark, NJ

**University of Arkansas for Medical Sciences,** Little Rock, AR

"I am so grateful to have been part of the Woman to Woman program. You helped me get through it more than you can imagine."

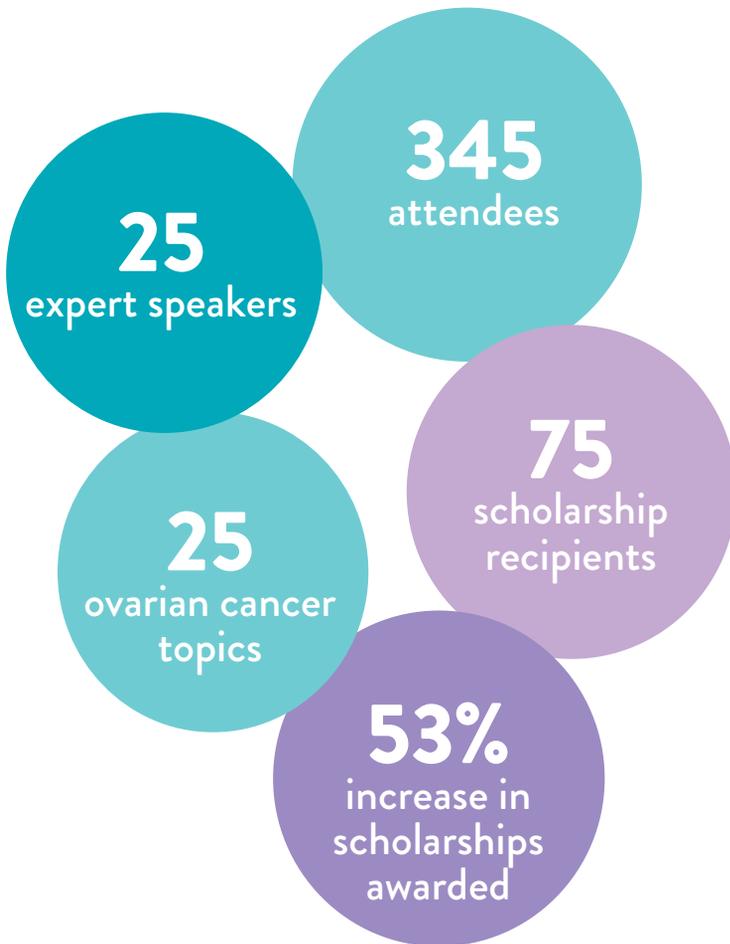*Patient, NewYork Presbyterian Hospital Program*

**8** new program sites

**37** programs across the country

OCRFA's Ovarian Cancer National Conference empowered survivors and caregivers with a front row seat to the latest news in ovarian cancer research.

**OCRFA'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 for the first time in Chicago, the conference also provided ample time for attendees to connect, bond and reflect on their shared experience of navigating the world of ovarian cancer.

**25**
expert speakers

**345**
attendees

**25**
ovarian cancer topics

**75**
scholarship recipients

**53%**
increase in scholarships awarded

**Attendees learned about...**

- New Treatments for Ovarian Cancer

- Caring for the Caregiver

- Managing Recurrence

- Guide for Newly Diagnosed

- Nutrition for the Ovarian Cancer Patient

- Clinical Trials

- Facing Cancer Under 40

- Addressing the Cost of Treatment

- Ways to Engage with the Ovarian Cancer Community

- Palliative Care and Hospice

- Sexual Health After Cancer

- and much more

"I met some people who live close to me who I never knew. I met people who have the same type, subtype, and stage of diagnosis. I was worried that I wouldn't find anyone and now I am a part of a support group."

*First-Time National Conference Attendee*

OCRFA's Ovarian Cycle® raised awareness and critical funds for research and patient support by rallying people to take action in their own communities.

**15** cities

**4,444** donors

**946** riders

**$690,000** raised

# FINANCIAL HIGHLIGHTS

**Financial Information:**
From Audited Financial Reports, Fiscal Year 2017

**Total Revenue and Support:** $13,144,746

**Expenses**

    Program Services:

| | |
|---|---|
|         Research | $6,895,447 |
|         Conferences | $ 600,520 |
|         Education, Support and Advocacy | $1,618,046 |
|     **Total Program Services:** | **$9,114,013** |
|     **Fundraising** | **$1,211,885** |
|     **Adminstrative** | **$1,018,661** |
| **Total Expenses** | **$11,344,559** |

**Ending Net Assets**                 **$23,503,582**

# ABOUT OCRFA

OCRFA

Ovarian Cancer Research Fund Alliance (OCRFA) is the largest global organization dedicated to fighting ovarian cancer. OCRFA advances research to prevent, treat and defeat ovarian cancer, supports women and their families before, during and beyond diagnosis, and works with all levels of government to ensure ovarian cancer is a priority.

As the largest non-government funder of ovarian cancer research, OCRFA invests in innovative, promising research.  And OCRFA is the voice for the ovarian cancer community: fighting for more resources and policies on Capitol Hill, helping future health professionals recognize the disease through ourSurvivors Teaching Students® program, providing hope and insight by pairing newly diagnosed patients with our Woman to Woman program and connecting survivors at our Ovarian Cancer National Conference.

We are united to defeat ovarian cancer.  Visit ocrfa.org to learn more.

Our mission is not only an investment in research and programs; it's an investment in people.

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