

The Childhood Ovarian Cancer Association

Business Plan (2022)

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MISSION STATEMENT

The Childhood Ovarian Cancer Association is a non-profit organization whose mission is to provide high quality education for patients, families of children and adolescents with ovarian malignancies as well as research and education for health care providers who treat this patient population.



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Executive Summary

The Childhood Ovarian Cancer Association is a non profit organization committed to bringing families and health care providers together for support, information, and research on childhood ovarian cancers. These cancers are rare, and until recently, minimal resources were available for families and health care providers. The needs of these children and adolescent's families are important.

Founded in 2010 by Dr. Hope Haefner, MD, a practicing gynecologist and 50 year survivor of ovarian cancer, the mission of this organization is to provide a forum on childhood ovarian cancers for providers, patients and their families; to obtain current information for education and clinical trials; to develop a comprehensive referral resource center and registry; and to advance research in childhood ovarian cancers. Through fostering a community through a patient registry, providing educational and informational resources and fundraising for childhood ovarian related research initiatives, the Childhood Ovarian Cancer Association aims to better the lives of patients, their families and increase awareness of childhood ovarian cancers.

Leadership



Founder and Director: Hope K. Haefner, M.D.

Dr. Hope Haefner is the Harold A. Furlong Professor of Women's Health in the Department of Obstetrics and Gynecology at the University of Michigan Hospitals in Ann Arbor, Michigan where she received her medical degree. Dr. Haefner completed her obstetrics and gynecology residency at the University of Michigan Medical Center in 1990. She completed a fellowship in gynecologic pathology in 1993. Dr. Haefner is board certified in obstetrics and gynecology.

She opened the University of Michigan Center for Vulvar Diseases in 1993. It is one of a few clinics in the United States that specializes in treating these conditions. She has a national and international reputation in this field. She is a specialist in vulvoscopy. She has a particular interest in high grade squamous intraepithelial lesions of the vulva, lichen sclerosus, lichen planus, and hidradenitis suppurativa (including skin grafts and flaps for patients with Stage 3 hidradenitis suppurativa). She is the primary author of the Vulvodynia Guideline, published in 2005. Dr. Haefner is active in vulvovaginal disease research.

She has received numerous awards including:

- APGO, Martin L. Stone, MD Award for the Center for Education, "Educational Partners for Life"
- Career Development Award, Michigan Agenda for Women
- The Silver Speculum Award, the University of Michigan senior resident teaching awards
- ASCCP "Meritorious Award for Service"
- CREOG National Faculty Award for Excellence in Residency Education
- The American College of Obstetricians and Gynecologists Award for Outstanding Service on the Committee on Continuing Medical Education

Dr. Hope Haefner is Past President of the International Society for the Study of Vulvovaginal Disease. She is Past President of the American Society for Colposcopy and Cervical Pathology.

Most importantly, Dr. Hope Haefner is a survivor of ovarian cancer herself. She was diagnosed 50 years ago with a malignant germ cell tumor on her left ovary. She has spent her career researching gynecologic diseases and hoping to help others diagnosed with gynecologic cancers in childhood or adolescence, in particular, ovarian cancer.



Assistant Director: Barbara Getty, NP

Barbara Getty RNC, MS, is a Women's Health Nurse Practitioner currently working at the University of Michigan. She has specialized in high risk pregnancies for the last 27 years. She has worked in Labor and Delivery, and has worked as a childbirth educator and nurse educator. Barbara's interest in gynecologic cancer comes from multiple family members experiencing breast and ovarian cancers. Barbara has been a board member of the Childhood Ovarian Cancer Association since its inception, and has a passion for supporting patients and their families on the journey from cancer diagnosis through survivorship.

Gail Straith, JD is on the executive board. She provides advice when needed for nonprofit policies.

Advisory Board:

A. Lindsay Frazier, M.D.



Dr. Lindsay Frazier is an international expert on germ cell tumors (GCT). Her contributions span clinical research, biology and epidemiology. Her work has transformed the care of children and adults with germ cell tumors with practice-changing insights on predictors of risk, a new risk stratification for pediatric GCT, new treatment strategies, the development of a new method of screening patients for recurrent disease with serum miRNAs, and developing work that describes the genomic aberrations associated with outcomes. Dr. Frazier has been a member on the steering committee of the Children's Oncology Group's (COG) Germ Cell Committee since 1996 and assumed leadership of the Committee in 2007.



Carolyn Marie Johnston, M.D.

Dr. Carolyn Johnston is a graduate of the Yale University School of Medicine. She completed an obstetrics and gynecology residency at the University of Chicago and a fellowship at the Mount Sinai Hospital in New York City. Dr. Johnston joined the faculty of the University of Michigan in 1990 and provided gynecologic oncology care at both the University of Michigan and St. Joseph Mercy Hospitals. She recently retired as an active faculty in our institution but continues to provide care to women across the nation with gynecologic cancer. Dr.

Johnston is recognized as an excellent surgeon and clinician and an outstanding teacher. She was a principal Investigator for the Gynecologic Oncology Group (GOG) clinical research trials. Dr. Johnston was a board member of the Michigan Cancer Consortium and a board member of the American Cancer Society, Great Lakes Division. Dr. Johnston was actively involved in training physicians in Ghana and recently won the SGO Humanitarianism and Volunteerism Award. She is actively involved with the clinical education of fellows.

Dr. David M. Gershenson



Dr. David Gershenson is a professor of gynecologic oncology in the Department of Gynecologic Oncology and Reproductive Medicine, Division of Surgery, at the University of Texas MD Anderson Cancer Center. Dr. Gershenson has previously served as a Co-Chair of the NCI's Gynecologic Cancer Steering Committee and has been involved with the Rare Tumor Working Group of the Gynecologic Cancer Intergroup (GCIG).

Dr. Leslie R. Schover, PhD



Dr. Leslie Schover graduated from Brown University in 1974, phi beta kappa, magna cum laude, with honors in psychology. She received a PhD in clinical psychology from UCLA in 1979. Her dissertation was supported by a Woodrow Wilson Research Grant in Women's Studies. She completed a postdoctoral fellowship in sex therapy and sex research at SUNY at Stony Brook in 1981. She was Assistant Professor of Psychology in Urology at the University of Texas MD Anderson Cancer Center from 1982-1986 and served as Staff Psychologist at the Cleveland Clinic Foundation until 1999. She then returned to MD Anderson Cancer Center, becoming a tenured full professor in 2003. She retired in 2016 to devote full time to her

new startup company that focuses on cancer survivorship. She has published numerous peer-reviewed journal articles, book chapters, self-help books, and a textbook. Her research has focused on interventions to help people with cancer overcome problems with sexual and fertility issues.

She received the Holland Distinguished Leadership Award from the American Psychosocial Oncology Society in 2016. Her digital health startup, Will2Love provides online help for cancer-related problems with sexuality or fertility. Dr. Schover continues to fulfill her dream of providing timely and accurate information to cancer survivors on sex and fertility; as well as self-help options to prevent or treat problems; and guidance on finding expert medical care.



Dr. Lynn Marie Westphal, M.D., FACOG

Dr. Lynn Westphal joined the full-time faculty at Stanford University in 1998 and retired from Stanford in 2019, and is Professor Emeritus in the Department of Gynecology and Obstetrics. She is the former Director of the Fertility Preservation Program, former Director of the Third Party Reproduction Program, and former Director of the REI Fellowship. Her interest in fertility preservation for cancer survivors led her to set up one of the first oocyte cryopreservation programs in the country. She has held numerous national leadership positions and was the President of the Fertility Preservation Special Interest Group of the American Society of Reproductive Medicine from 2008-2009. She was the Director of Women's Health at Stanford from 2005-2012. In 2012, she co-founded the Stanford Center for Health Research on Women and Sex Differences in Medicine (WSDM) and served as co-director of the program for two years.

Overview of Programs and Services

The Childhood Ovarian Cancer Association has committed its time and resources to the implementation and development of programs that focus in 3 main areas:

1. Support: Assisting in the planning and coordination of care for patients.
2. Education: Providing education to patients, families and their providers through various avenues such as a website, brochures and increasing awareness through medical/nursing meetings.
3. Research: Create an International Childhood Ovarian cancer patient registry sponsored by COVCA.

Currently, the COVCA has planned out general action items for proper implementation of each of their three programs (listed below). The **check marks indicate** that our organization has moved forward in the execution of these action items, initially focusing our attention on education initiatives.

Programs and Services

Support



Overview: Referrals and Coordination of care

- Provide a list of specialists to consult when first diagnosed.
- Assist families find physicians on a referral basis.
- Provide a way for healthcare providers and patient's families to connect
- Find physicians who specialize in maintaining options for future fertility in patients.

Education



Overview: Provide education to patients, families and providers

- ✓ Develop a website for education
- ✓ Maintain website
- ✓ Have education be at a novice level to current research
- ✓ Education for providers, families, and friends
- Maintain current literature review on website

Research



Overview: Creating a patient registry system

- Become affiliated with established data bases
- Have names of established databases to pursue.
- Hire a genetic counselor review and research data pertinent CGynCa data.

What has been accomplished?

1. **Website:** We have designed a website that we use as the hub for our organization, primarily to provide information on the history of our organization, services we provide, raise awareness and information to help patients, their families and providers. Information on this website includes how the organization was started, past/upcoming events, descriptions of the different types of cancers, and related articles. In addition to the information previously stated, the website also provides an avenue for people to donate financially and contact our organization. Moving forward, we intend on continuing to add more information that can help people in need and more information about our upcoming events. More information can be found on our website at www.cgynca.org.
2. **Presence at conferences and events:** Since its inception, Childhood Ovarian Cancer Association leaders Hope Haefner and Barbara Getty have been active in various outreach opportunities through various lectures and attendance at many conferences on both a local and national stage. National events include the Society of Gynecologic Oncology (SGO) Annual Meeting on Women's Cancer, the American Society of Clinical Oncology (ASCO), the Association of Pediatric Hematology/Oncology Nurses (APHON), and local events such as the Annual Fourth of July Parade in Ann Arbor, Michigan. From participation in these events, our organization is able to interact with hundreds of people, assisting in fundraising efforts, increase network for collaborations, and educational opportunities on how to better serve our target population.

Future Steps:

1. **Patient Registry:** In efforts to foster a community between patients of childhood ovarian cancers, we intend to create an international registry of patients. With over 200 new childhood ovarian cancer diagnoses domestically per year and even more internationally, the registry aims to further increase the line of communication between individuals, foster a needed community and support group interaction between patients and their families who are currently going through similar issues. With a registry, there is a long term goal of reviewing the information for research on these conditions in efforts to find a cure. The Childhood Ovarian Cancer Association is dedicated to raising money for the research on the causes, treatments, and cures for childhood ovarian cancers.
2. **Support Services:** As the Childhood Ovarian Cancer Association continues to increase its membership and outreach, the organization aims to foster connections between healthcare professionals with families as well as connecting families to other families. Childhood ovarian cancers are rare, often making a referral and finding support difficult. The Childhood Ovarian Cancer Association has a list of providers with experience and interest in childhood ovarian cancers to assist in making connections.

Identified Organizational Need

There is a need for the Childhood Ovarian Cancer Association to assist the healing of patients and distribute information on these rare diseases, nationally as well as internationally. There are currently 200 new cases of childhood ovarian cancer cases per year in the United States and currently no international data sources have been developed. There are several cancer support groups and other related groups that exist for women over age 18 however this is the only organization for children and adolescents that deals with this target population.

As stated before, there are currently no other organizations that specifically serve patients with childhood ovarian cancers. However there are a number of organizations that target other gynecologic cancers and clinicians that also occupy this space, some of which are potential partners. Below are examples of these organizations:

Ovarian Cancer National Alliance

Founded: 1997

Focus: Women with ovarian cancer

Mission: To advance the interests of all women with ovarian cancer.

Foster community: They connect survivors, women at risk, caregivers and health providers with the information and resources they need. Educated over **9,000** health professionals in 2014.

Impact Laws: They lobby to ensure that ovarian cancer is a priority for lawmakers and agencies in Washington, DC, and throughout the country. Raised over **\$166 million** in federal research funding in 2014.

American Pediatric Surgical Association

Founded: 1970

Focus: Pediatric surgical care

Mission: To ensure optimal pediatric surgical care of patients and their families, to promote excellence in the field, and to foster a vibrant and viable community of pediatric surgeons.

Membership: In 2015 APSA has more than **1,200 members, mostly from North America**, who represent the pediatric surgery arena from academia to government and private practice.

Sets Standards: Sets forth guidelines and statements for standards of care for children and for influencing public policy around

the surgical care of children.