The Childhood Gynecologic Cancer Association

Business Plan (2016)

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MISSION STATEMENT

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

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Executive Summary

The Childhood Gynecologic Cancer Association is a non profit organization committed to bringing families and health care providers together for support, information, and research on childhood gynecologic cancers. These cancers are rare, and until recently, minimal resources were available for families and health care providers. These cancers include ovarian, uterine, cervical, vaginal and vulvar cancers. 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 gynecologic 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 gynecologic cancers. Through fostering a community through a patient registry, providing educational and informational resources and fundraising for childhood gynecologic related research initiatives, the Childhood Gynecologic Cancer Association aims to better the lives of patients, their families and increase awareness of childhood gynecologic cancers.

THIS IS THE STORY OF HOPE.

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Hope was born in Michigan, the youngest child in her family. When Hope was 9, her parents took her to the ER for severe abdominal pain. At first, the doctors thought it was an appendicitis. She had surgery, and her parents were told that she had ovarian cancer (an immature teratoma). In addition to removing the ovarian cancer, the surgeon removed both her ovaries, her uterus, as well as her appendix. When Hope had surgery in 1968, advice and treatments were much different than they are today. Her parents were told that Hope was not likely to survive. The doctors advised Hope's parents not to tell her the diagnosis. Hope was told that she had an appendectomy only.

Hope recovered from her surgery, and completed radiation treatments. At nine years old, Hope did not question that radiation was not typical treatment for appendicitis. She was never told about the cancer, or that her uterus and ovaries were removed. She was not told that she may die, and that she would never be able to have children. The doctors did not think she would survive. Despite all of the difficult news given to the family, Hope did very well and continued to live her life as a student, playing all summer in the lakes of Michigan.

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At 14 years old, Hope was admitted to the hospital for abdominal pain. Scar tissue from her surgery had formed a bowel obstruction, causing her abdominal pain. During her hospital stay, a medication error occurred and Hope nearly died. Hope's heart stopped, and the medical team provided resuscitation. Hope's older sister was a witness. This was very difficult for her sister.

During this same hospitalization, a resident asked Hope about her cancer diagnosis. He also told her that she had no uterus or ovaries. Hope insisted he had the wrong patient chart. This is how Hope found out about her diagnosis. Hope was hit with big news all at once. Hope's family was coping with almost losing Hope for a second time. There was a lot of healing that needed to occur for Hope and her family. Hope had to learn to deal with the fact that her parents and doctors hid her diagnosis from her. In 1968, no one thought Hope would survive, and now she had just survived a cardiac arrest. Twice she had beaten the odds! Hope is a survivor!

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Hope decided to become a doctor. In 1968, Hope's doctors and Hope's parents and siblings had no experience or support for the rare ovarian cancers. Hope felt that others can learn from her experience. The dream of putting together a nonprofit organization, the Childhood Gynecologic Cancer Association was coming together.

Hope was successful in her medical training. She was successful in her personal life too! She met her husband in medical school. She began her residency in Obstetrics and Gynecology, gaining medical experience and building on her personal experience.

today

As Hope's practice grew, so did her family.

Although, childhood gynecologic cancer is rare, it is very real to those families and girls. Hope's personal and professional experience makes her very dedicated to the future of Childhood Gynecologic Cancer Association. Hope's medical and personal experience are the reasons for Childhood Gynecologic Cancer non profit organization. The goal of the organization is to provide information to the medical community, assist the medical community in connecting with experienced providers, and most importantly, to provide education, support, and help to girls (and their families!) with gynecologic cancer.

Who would have thought in 1968, when Hope was 9, she would someday be a physician, wife, mother, and grandmother today!

Leadership

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

Hope K. Haefner, M.D., is a Professor 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 high grade squamous intraepithelial neoplasia 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. 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.

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 Gynecologic 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:

Dr. A. Lindsay Frazier, M.D.

Dr. A. 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.

Dr. Carolyn Marie Johnston, M.D.

Dr. Carolyn M. Johnston, MD, 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 provides gynecologic oncology care at both the University of Michigan and St. Joseph Mercy Hospitals. Dr. Johnston is recognized as an excellent surgeon and clinician and an outstanding teacher. She is a principal investigator for

Gynecologic Oncology Group (GOG) clinical research trials available at the University of Michigan. Dr. Johnston is a board member of the Michigan Cancer Consortium (2005-present) and a board member of the American Cancer Society, Great Lakes Division. Dr. Johnston is actively involved in training physicians in Ghana and recently won the SGO Humanitarianism and Volunteerism Award. She is actively involved with clinical education of fellows.

Dr. David M. Gershenson

Dr. David Gershenson is currently a Professor of Gynecologic Oncology at the University of Texas Medical School, where he conducts several clinical and translational studies of rare ovarian tumors. He is also the Co-Principal Investigator of M.D. Anderson's NCI-funded SPORE in Ovarian Cancer and Co-Project Leader of Project 3, "Personalized Therapy for Women with Low-Grade Serous Carcinoma of the Ovary." This project includes preclinical studies designed to elucidate the pathogenesis of low-grade serous carcinoma and the development of clinical trials utilizing novel targeted agents based on the preclinical findings. The clinical trials are conducted through the NCI-sponsored cooperative group—the Gynecologic Oncology Group (GOG), in which he is the Chair of the GOG's Rare Tumor Committee and member of the GOG's Protocol Development Committee.

Dr. Gershenson has previously served as a Co-Chair of the NCI's Gynecologic Cancer Steering Committee and continues to serve as the Co-Chair of the Rare Tumor Working Group of the Gynecologic Cancer Intergroup (GCIG). His other major national activities include serving as Editor Emeritus of the journal, *Gynecologic Oncology*, and as a Director of the American Board of Obstetrics and Gynecology.

Dr. Leslie R. Schover, PhD

Leslie R. Schover, PhD 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 116 peer-reviewed journal articles, 33 book chapters, 3 self-help books, and a textbook. She is currently an Associate Editor for *Fertility and Sterility*. Her research has focused on interventions to help people with cancer overcome problems with sexual and fertility issues. She was subcontract PI in partnership with Paul Martinetti, MD, Principal of Digital Science Technologies, on three, fast-track small business grants funded by the National Cancer Institute to develop and evaluate internet-based interventions for cancer survivors on sexuality and fertility. Grant funding from the American Cancer Society and the Lance Armstrong Foundation also contributed to this research. 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. In 2015, Will2Love was chosen as one of 21 companies for the initial class of a new health accelerator in the Texas Medical Center, TMCx. The plan is for Will2Love to go live in mid-2016, with a gateway web site, Will2Love.com presenting news, blog posts, webinars, and social media forums. Evidence-based interventions for men and women will be offered direct to consumers on a subscription basis. Telehealth counseling by phone or video will be piloted. Dr. Schover hopes 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 Marie Westphal is a Professor of Obstetrics and Gynecology at Stanford University School of Medicine and the founder and director of the Stanford University Fertility Preservation Program which focuses on providing women a multitude of options for maintaining fertility. Lynn Marie Westphal, M.D., FACOG graduated summa cum laude from Lawrence University, earned her medical degree at Stanford University, and did her residency training in obstetrics and gynecology at UCLA and Stanford University. She did a fellowship in molecular biology at Stanford University, and completed her fellowship in Reproductive Endocrinology and Infertility (REI) at UCSF.

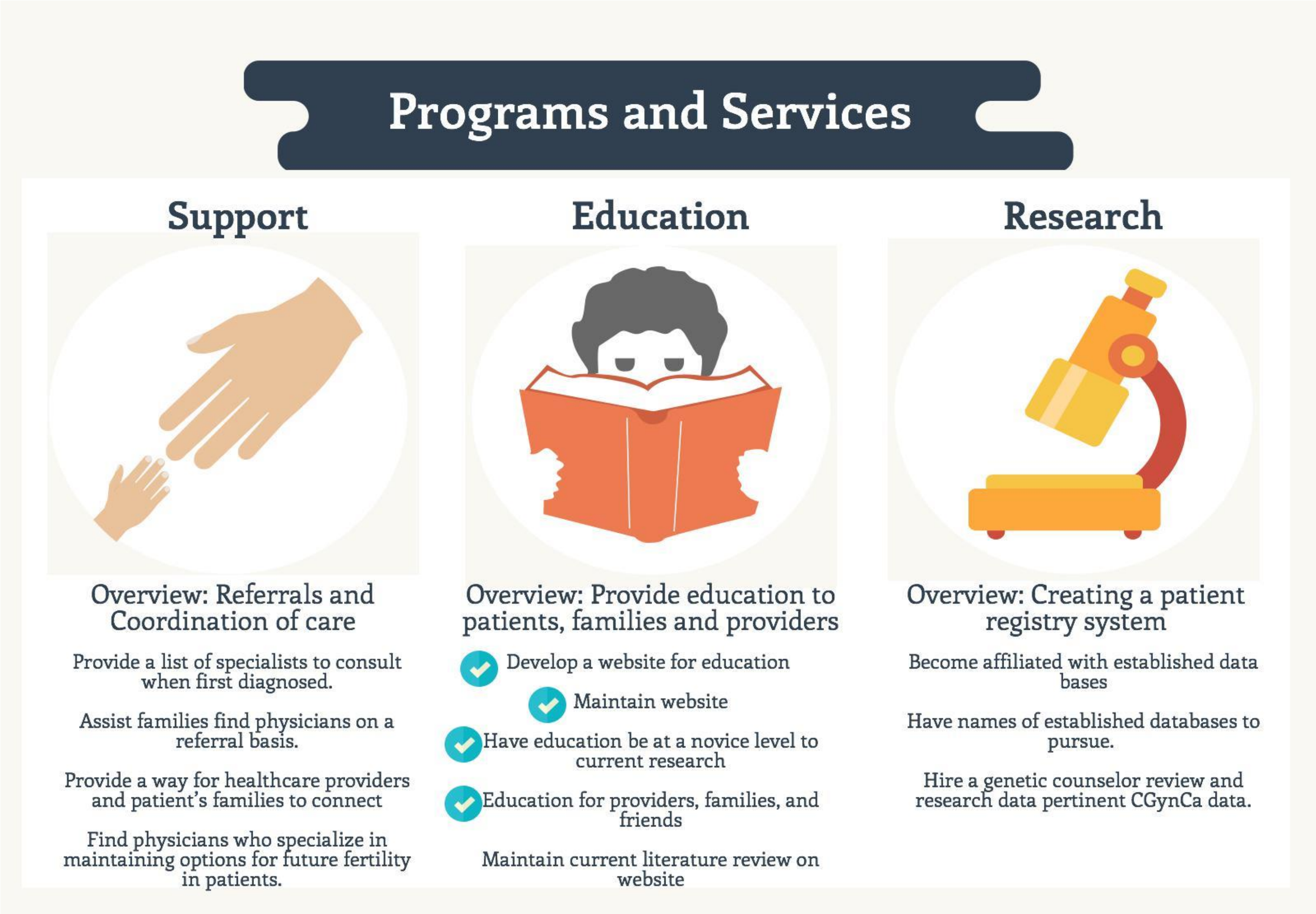
Her interest in fertility preservation for cancer survivors led her to set up one of the first oocyte and ovarian tissue cryopreservation programs in the country in 1999. She has held numerous national leadership positions, including being a past President of the Fertility Preservation Special Interest Group of the ASRM.

Overview of Programs and Services

The Childhood Gynecologic 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 gynecologic cancer patient registry sponsored by CGYNCA.

Currently, the CGYNCA 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 Gynecologic Cancer Association leaders Hope Haefner and Barbara Getty have been in 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 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 gynecologic cancers, we intend to create an international registry of patients. With over 200 new childhood gynecologic 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 Gynecologic Cancer Association is dedicated to raising money for the research on the causes, treatments, and cures for childhood gynecologic cancers.

2. **Support Services:** As the Childhood Gynecologic Cancer Association continues to increase its membership and outreach, the organization aims foster connections between healthcare professionals with families as well as connecting families to other families. Childhood gynecologic cancers are rare, often making a referral and finding support difficult. The Childhood Gynecologic Cancer Association has a list of providers with experience and interest in childhood gynecologic cancers to assist in making connections.

Identified Organizational Need

There is a need for the Childhood Gynecologic 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 gynecologic 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. In addition to ovarian cancer, we also address uterine, cervical, vaginal and vulvar cancers in children and adolescents.

As stated before, there are currently no other organizations that specifically serve patients with childhood gynecologic 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.