

# APPROACHING DIVERSITY, EQUITY, & INCLUSION FROM A CANCER SURVIVORSHIP PLANNING PERSPECTIVE

PRESENTED BY HELEN PALOMINO, LCSW, CEO  
CANCER RESOURCE CENTER OF THE DESERT



# Approaching DEI from a Cancer Survivorship planning perspective

## The Cancer Resource Center of the Desert (CRCD)

- CRCD is a small non-profit organization dedicated to providing Cancer Patient Navigation to persons diagnosed with cancer who live in Imperial County, CA since 2006
- CRCD serves men, women, and children diagnosed with cancer, anywhere on the cancer continuum: any cancer, any stage, at no cost to the patient
- Remove/mitigate barriers to cancer care
- Strategically integrated with oncologists in multidisciplinary effort to support POC
- We are a team of 7 Bilingual/Bicultural medical social workers specializing in cancer care
- Funding: Private Donations, contracts, Fundraising, Grants, Medicare/Medicaid, Research

# CRCO's Geographical Area & Population

- Location: Imperial County, California, is a rural, border community that borders Arizona, Mexico, and the regions of Palm Springs and San Diego, California.
- Population: 182,000
- Imperial County is known as an underserved region 100 miles away from the nearest tertiary care center with a predominantly 85% Latinx population
- Imperial County is a U.S. community that commonly engages in binational access to healthcare both in the U.S. and in Mexico
- Imperial County ranks last out of all counties in California for socioeconomic factors, is designated as a Health Professional Shortage Area and a Medically Underserved Area.



# PATIENT NAVIGATOR (PN) APPROACH TO DEI

- Impoverished community; monolingual Spanish speakers, low literacy and even lower health literacy.
- Remove/mitigate barriers and “push the system” on patient behalf to provide fair access
- Person with cancer is in emotional distress; financial distress; uninsured or underinsured
- PNs approach the patient with cancer and their family with dignity and respect, communicating in patient’s primary language.
- Identifying what the person understands about their cancer diagnosis AND What they are wanting (their goal) as well as establish stabilizing goals for cancer POC
- While experiencing COVID-19 Pandemic

CRCD Patient Navigators approach our cancer patients right where they are in their cancer experience and partner with them and their families

- ◆ **Initial emotional crisis upon receiving the cancer diagnosis:** CRCD provides emotional support. Increases knowledge about the specific diagnosis.
- ◆ **Fear of the implications of the cancer diagnosis:** CRCD utilizes tools from the National Cancer Institute (NCI) & other national organizations, educates the patient and family.
- ◆ **Difficulty understanding the cancer diagnosis:** CRCD uses specialized tools to review specific information about diagnostic work-ups, staging, treatment options, etc. At patient's request, assist with information on obtaining a 2<sup>nd</sup> opinion.
- ◆ **Difficulty understanding the treatment process:** CRCD educates the patient & family about the specific treatment plan associated with their diagnosis & provides them with educational materials.
- ◆ **Difficulty communicating with physicians:** CRCD assists the patient/ families to communicate their questions, concerns, and other important information to their physicians through counseling. At patient's request, CRCD also will speak to the physician on the patient's behalf or communicate via memos or letters to the physician.
- ◆ **Language/Cultural differences:** CRCD staff is bilingual (English/Spanish) and bi-cultural. CRCD educates patients in their language, addressing cultural issues.
- ◆ **Lack of insurance or underinsured:** If uninsured, CRCD assists the patient to apply for medical coverage including specialized State programs for certain cancer types. If underinsured, CRCD determines if there are co-pay relief programs the patient is eligible for and assist in the application process.
- ◆ **Lack of adequate transportation:** CRCD determines if the patient is eligible for transportation assistance through local programs & applies on their behalf when eligible; will register & apply to national organizations that provide specific transportation assistance; augments those services with complimentary gas cards.
- ◆ **Reduced Income due to diagnosis& treatment:** Consideration of State & Federal programs the patient may be eligible for including State Disability Insurance, Social Security Disability, & Supplemental Security Income & assistance in applying for such programs when needed.



# PATIENT NAVIGATOR APPROACH TO SURVIVORSHIP CARE PLANNING

- Many people survive a cancer diagnosis. A Survivorship Care Plan (SCP) is a summary of a cancer care plan and is established towards the end of cancer treatment as the patient transitions to cancer survivorship.
- Currently CRCD and UCSD School of Medicine are conducting a SCP with a Reproductive Healthfocus(SCP-R) pilot study to improve oncofertility care in primarily Spanish speaking Latina Young Breast Cancer Survivors (YBCS).
- This study is a clinic-based oncofertility needs screen, women's health SCP-R, patient navigation and telehealth of reproductive counseling. This study addresses women's reproductive health care at breast cancer diagnosis and post-treatment.
- CRCD also participated in a previous SCP study for rural Latinas with Breast Cancer which created a comprehensive cultural and linguistically tailored SCP document and animated video (telenovela) as a SCP aid. This study did not address reproductive health.
- The cultural tailoring of the SCP intervention for rural Latinas with Breast Cancer expands the knowledge base clinicians should consider particularly those who may receive health care from different health systems, such is the case in binational, US/Mexico border context.

Survivorship Care Plan with  
Reproductive Health Focus (SCP-R)  
Reproductive health care after cancer  
treatment:

(i.e. infertility, contraception and  
preconception counseling and  
services)

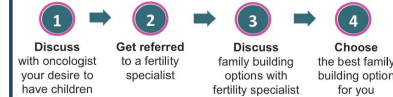
Clinically mitigates and prevents  
adverse outcomes in YBCS

Patient Guide: Fertility Concerns  
Offered in English and Spanish



## WOMEN'S HEALTH SURVIVORSHIP CARE PLAN FOR YOUNG BREAST CANCER SURVIVORS FERTILITY CONCERNS AFTER BREAST CANCER TREATMENT

### NEXT STEPS IF YOU WANT CHILDREN IN THE FUTURE



### KEY ONLINE RESOURCES

1. Society for Assisted Reproductive Technology (ART information and fertility specialists search): [www.sart.org](http://www.sart.org)
2. Livestrong fertility (fertility risks from treatment): [www.livestrong.org/we-can-help/fertility-services](http://www.livestrong.org/we-can-help/fertility-services)
3. Oncofertility Consortium (fertility preservation information): <https://www.savemyfertility.org/>

### IS IT SAFE TO BECOME PREGNANT?

- Research studies suggest that pregnancy after breast cancer does not raise the risk of cancer recurrence or affect survival, regardless of estrogen receptor status.
- There is no specific recommendation on how long breast cancer survivors should wait after cancer treatment until they try to become pregnant.
- Women should discuss the timing of pregnancy and their personal health concerns with their healthcare providers.
- Along with life situation, ideal timing depends on completion of cancer treatment, risk of relapse, age, and fertility potential.



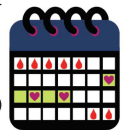
### WHAT ARE FAMILY BUILDING OPTIONS AFTER FINISHING BREAST CANCER TREATMENT?

- Fertility preservation (freezing eggs or embryos) before and after cancer treatment is possible for some women.
  - Women should discuss fertility preservation with their oncology provider and a fertility specialist.
  - The cost varies widely, but is usually between \$3,000 and \$15,000 and is often not covered by health insurance.
  - A fertility consultation may be covered. Ask your insurance company.
- Other options include getting donor eggs or embryos, using a surrogate mother to carry a pregnancy, adoption, and childfree living.




### HOW CAN A BREAST CANCER SURVIVOR TELL IF SHE IS FERTILE?

1. **Attempt pregnancy:** The best way to predict fertility after breast cancer is to try to become pregnant.
2. **Monitor menstrual bleeding:** Having monthly periods is a sign that the ovaries are working, but does not always mean fertility.
  - Menstrual bleeding can be affected by chemotherapy, gonadotropin releasing hormone (GnRH) agonists, and tamoxifen. Women may have fewer monthly periods or no periods while taking these medications. Periods usually resume within 6 months of stopping these treatments.
  - In women with no cancer treatment, menopause happens between age 40 and 60 (average age 51) after there are no periods for 12 months.
3. Fertility specialist can monitor the number of eggs in a woman's ovaries through ovarian reserve testing, which can help measure a woman's fertility potential.
  - Common ovarian reserve tests include blood tests of follicle stimulating hormone (FSH) and anti-mullerian hormone (AMH), as well as ultrasound tests of antral follicle count (AFC). FSH is best tested with estradiol between menstrual cycle days 3 and 5, while AMH and AFC can be tested at any time.
  - As women age and fertility potential declines, FSH levels increase, while AMH levels and AFC decrease to reflect decreasing ovarian reserve.
  - There is no laboratory cut off level that definitively predicts fertility.
  - Ovarian reserve test results can also change over time, so one-time results may not reflect the true ovarian reserve.



# Survivorship Care Plan with Reproductive Health Focus (SCP-R)

## Patient Guide: Contraception Offered in English and Spanish

 **WOMEN'S HEALTH SURVIVORSHIP CARE PLAN  
FOR YOUNG BREAST CANCER SURVIVORS**  
**GUIDE TO BIRTH CONTROL**

**NEXT STEPS**

- 1 DISCUSS**  
the copper IUD and other birth control options with providers such as gynecologists.
- 2 DECIDE**  
on the best birth control method for you.
- 3 START**  
using it!

**KEY ONLINE RESOURCES**

- Bedsider (non-profit organization, describes birth control methods):  
◦ <http://bedsider.org/methods>
- Centers for Disease Control U.S. Medical Eligibility Criteria (describes safety of birth control methods for women with breast cancer):  
◦ <http://www.cdc.gov/reproductivehealth/unintendedpregnancy/usmec.htm>

**WHY USE BIRTH CONTROL?**

- Survivors who are sexually active and do not want to become pregnant should consider using a reliable birth control method.
- Survivors may become pregnant, even if they do not have regular periods.
- Women who have an unintended pregnancy during cancer treatment may have harmful health outcomes.  
◦ For example, taking tamoxifen during pregnancy can cause fetal harm, such as birth defects.

**BIRTH CONTROL WITH HORMONES IS NOT RECOMMENDED FOR YOUNG BREAST CANCER SURVIVORS.**


**WHAT HORMONE-FREE BIRTH CONTROL METHODS ARE AVAILABLE FOR BREAST CANCER SURVIVORS?**


HORMONE-FREE BIRTH CONTROL	COPPER IUD	STERILIZATION	CERVICAL CAP/ DIAPHRAGM	CONDOMS	WITHDRAWAL	RHYTHM METHOD
How reliable is it? Number of women who will be pregnant during 1st year of typical use	< 1 OUT OF 100 <b>MOST RECOMMENDED</b>	<1 OUT OF 100	16 OUT OF 100	18 OUT OF 100	22 OUT OF 100	24 OUT OF 100
Where to get it?	HEALTHCARE PROVIDER	HEALTHCARE PROVIDER	HEALTHCARE PROVIDER	OVER THE COUNTER	NEITHER	NEITHER
Effort	Lasts 10 years	Lasts Lifetime	Each act of sexual intercourse with spermicide	Each act of sexual intercourse	Each act of sexual intercourse	Avoid unprotected sexual intercourse on days 8-19 of menstrual cycle
Common Side Effects	Heavier Periods, Cramps	None	Vaginal Irritation	Skin Irritation	None	None

**EMERGENCY CONTRACEPTION (EC)**


- EC is used to prevent pregnancy when another birth control method fails or no birth control is used.
- The chance of getting pregnant is less likely when EC is used right away (up to 5 days) after sex.
- The benefits of using hormone based EC to prevent a pregnancy outweigh the risks.

**HORMONE BASED**

 **PLAN B**  
Over The Counter  
One Day Use

 **ella**  
Prescription Needed  
One Day Use

**HORMONE FREE**

 **COPPER IUD**  
Healthcare Provider  
Can be used as EC AND birth control

### GLOSSARY


1. **Copper IUD:** Copper intrauterine device (Paragard); a "T" shaped non-hormonal device placed inside the uterus.
2. **Female Sterilization:** A woman's fallopian tubes are tied or closed so eggs cannot travel down the fallopian tubes after being released from the ovaries.
3. **Male Sterilization:** A man's tubes that carry sperm are closed or blocked to prevent the sperm from being released into the ejaculate.
4. **Diaphragm and Cervical Cap:** Silicone cups that are inserted into the vagina to cover the cervix; barrier methods that prevent sperm from getting into a woman's uterus.
5. **Condoms:** Male latex condoms, male polyurethane condoms, and female condoms; a barrier method that prevents sperm from getting into a woman's uterus.
6. **Withdrawal:** A man pulls his penis out of the vagina before ejaculation.
7. **Rhythm Method:** Also known as fertility awareness methods (e.g., calendar, cervical mucus, body temperature); ways a woman can use to track the release of an egg.



# Survivorship Care Plan with Reproductive Health Focus (SCP-R)

## Patient Guide: Estrogen Deprivation Concerns

Offered in English and Spanish



### WOMEN'S HEALTH SURVIVORSHIP CARE PLAN FOR YOUNG BREAST CANCER SURVIVORS

## TREATING HOT FLASHES

**NEXT STEPS**

- 1 Start: Yoga and cooling strategies
- 2 Learn more: about non-hormonal prescription treatments
- 3 Discuss: treatment options with healthcare providers
- 4 Start: the best treatment option for you

**KEY ONLINE**

- National Cancer Institute:  
◦ [http://www.cancer.gov/about-cancer/treatment/side-effects/sexuality-fertility-women/hot-flashes-pdq#section/\\_27](http://www.cancer.gov/about-cancer/treatment/side-effects/sexuality-fertility-women/hot-flashes-pdq#section/_27)

**WHAT ARE HOT FLASHES?**


- Low estrogen levels that may cause random and sudden feelings of heat that last from a few seconds to minutes.
- Women without breast cancer experience an average of 7 years of hot flashes that start 3 years before and continue 4 years after menopause.
- About two-thirds of breast cancer survivors will have hot flashes when they are treated with chemotherapy, tamoxifen or aromatase inhibitor therapy, or after having their ovaries taken out.
- Hot flashes tend to be worse during chemotherapy or start of endocrine therapy and then stabilize or decrease slightly over time.









**TREATMENTS FOR HOT FLASHES**

Hormone-free is recommended & safe  
Hormone-based is NOT recommended


**STRATEGIES TO KEEP COOL!**


1. Dress in layers and light-colored clothes
2. Keep your thermostat at a lower temperature
3. Use cooling products: hand held fans, cold packs under pillow, iced water bottles, water misters





HORMONE-FREE HOT FLASH TREATMENTS THAT IMPROVE HOT FLASHES		
	BASED ON CURRENT RESEARCH	SIDE EFFECTS AND OTHER INFORMATION
 Anti-Depressants	<ul style="list-style-type: none"><li>• Venlafaxine, citalopram, or paroxetine reduced hot flash frequency and severity by 50% after 4 to 6 weeks.</li></ul>	<ul style="list-style-type: none"><li>• Paroxetine and celexa may interfere with tamoxifen action</li><li>• Prescription medication</li><li>• Nausea, dry mouth, constipation or diarrhea, dizziness</li><li>• SSRI anti-depressants can have sexual side effects</li></ul>
 Gabapentin & Pregabalin	<ul style="list-style-type: none"><li>• Gabapentin or pregabalin reduced hot flash frequency and severity by 50% after 4 to 6 weeks.</li></ul>	<ul style="list-style-type: none"><li>• Prescription neurology medication</li><li>• Dizziness, increased appetite, and less pain</li></ul>
 Clonidine	<ul style="list-style-type: none"><li>• Clonidine reduced hot flash frequency and severity by 40% after 4 weeks.</li></ul>	<ul style="list-style-type: none"><li>• Prescription blood pressure medication</li><li>• Mouth dryness and constipation</li></ul>
 Acupuncture	<ul style="list-style-type: none"><li>• Weekly or twice weekly acupuncture treatments reduced hot flash nuisance by 35%, daytime hot flash frequency by 50%, or hot flash frequency and severity by 65% after 4 to 12 weeks.</li></ul>	<ul style="list-style-type: none"><li>• Needle pain and mild bruising</li></ul>
 Hypnosis	<ul style="list-style-type: none"><li>• Weekly, 50-minute hypnosis sessions reduced hot flash frequency and severity by 68% after 5 weeks.</li></ul>	<ul style="list-style-type: none"><li>• Unknown</li></ul>
 Yoga	<ul style="list-style-type: none"><li>• Weekly, 120-minute yoga sessions reduced hot flash frequency and severity by 31% after 8 weeks.</li></ul>	<ul style="list-style-type: none"><li>• Unknown</li></ul>
 ICBT	<ul style="list-style-type: none"><li>• Weekly, 1-hour self-managed or guided internet-based cognitive behavioral therapy (ICBT) sessions reduced on average the perceived impact of hot flashes by 33% and hot flash frequency by 25% after 6 weeks.</li></ul>	<ul style="list-style-type: none"><li>• Unknown</li></ul>
 Meditation	<ul style="list-style-type: none"><li>• Weekly, 2-hour mindfulness meditation sessions reduced hot flash bothersome symptoms by 24% after 6 weeks.</li></ul>	<ul style="list-style-type: none"><li>• Unknown</li></ul>


**HORMONE-FREE TREATMENTS THAT DID NOT IMPROVE HOT FLASHES**


 Black Cohosh


 Exercise: Aerobic & Strength Training


 Soy & Phytoestrogens

 Vitamin E

 Fluoxetine

 Sertraline

 Bupropion

 Acetane®

Hot flash information comes from review of published studies and clinical guidelines on treating hot flashes in breast cancer survivors, current through December 2019

UC San Diego  
SCHOOL OF MEDICINE

CANCER RESOURCE CENTER  
DESERT

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# Thank You!

Helen Palomino, LCSW, CEO  
Cancer Resource Center of the Desert  
Email: [hpalomino@crcdinc.org](mailto:hpalomino@crcdinc.org)  
Tel: 760-353-6571  
Website: [www.crcdinc.org](http://www.crcdinc.org)