Navigating fertility & family-building after a cancer diagnosis

Pamela Simon, MSN, CPNP, CPON
Catherine Benedict, PhD

Bay Area Cancer Connections
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Presentation Objectives

- Discuss adolescent and young adult (AYA) oncofertility facts
- Discuss risks of treatment on fertility
- Discuss preservation options
- Explore issues related to fertility and survivorship
- Family-building decisions
- Find resources to offer support

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Oncofertility Facts

- Due to advances in cancer treatment, survival rates for AYAs with cancer has significantly improved (NIH 2024, Moke, et al, 2019,).
- Meistrich (2009) notes that in most circumstances it is not the cancer that is the cause of infertility or subfertility (difficulty getting pregnant) but rather the treatment itself; chemotherapy, radiation, and surgical removal of reproductive organs that leads to fertility issues (Kondapalli, and Crisci 2014).
- According to a recent Clinical Practice Group (CPG) review virtually 80% of AYAs with cancer are expected to survive 5 years after receiving a cancer diagnosis and most will live well into adulthood achieving long-term survivorship (Font-Gonzalez, Mulder, and Loeffen 2016).
- There is a real possibility that many of these long term survivors may experience fertility issues based on the effects of treatment and lack of preservation prior to treatment, which can lead to the phenomenon of reproductive regret

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ASCO Clinical Practice Guidelines

- In 2006, ASCO published a clinical practice guideline on fertility preservation for adults and children with cancer and updated in 2012 and 2018
  - Discuss fertility preservation with all patients of reproductive age if infertility is a potential risk and address prior to starting treatment
  - Refer patients who express an interest in fertility preservation
  - Document fertility preservation in medical record

- APHON in 2012 released Fertility Preservation Position Statement in 2012

But studies continue to show that patients are not receiving this information and that fertility is a subject very important to cancer patients.

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Impact of Treatment on Fertility: General Principles

- Determinants of fertility post-therapy
  - Dose and type of chemotherapy
  - Type of surgical intervention
  - Field and dose of radiation
  - Age at treatment initiation

- Most harmful regimens
  - Alkylating agents (Cyclophosphamide)
  - SCT chemotherapy dosing (Melphalan, Busulfan, Thiotepa)
  - TBI (total Body Irradiation)
  - Cranial radiotherapy that impairs hypothalamic-pituitary function

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Impact of Chemotherapy on Fertility: In the Ovary

- Importance of Age
  - Women have a fixed number of follicles at birth = ovarian reserve
  - Follicular depletion peaks around 38 years of age (10% of reservoir remains)
  - Antitumor therapy accelerates this process

- Chemotherapy Mechanism of Action
  - Cell cycle nonspecific agents (ex: cyclophosphamide) – destroy primordial cells
  - Cell cycle specific agents (eg methotrexate) – spare primordial cells

Pittsburgh Fertility Risk Calculator: https://fertilitypreservationpittsburgh.org/fertility-resources/fertility-risk-calculator/

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Risk Stratification

Female Risk Stratification			Minimally Increased Risk	Significantly Increased risk	High level of Increased risk
Alkylators CED gm/m^2		Prepubertal	CED <8 gm	CED 8-12 gm	CED >12 gm
		Pubertal	CED <4 gm	CED 4-8 gm	CED >8 gm
Heavy Metal mg/m^2			Cisplatin Carboplatin		
Hematopoietic Stem Cell Transplant					Alkylator +/- Total body irradiation Myeloablative and Reduced intensity regimens
Radiation exposure	Ovary	Prepubertal		<15 Gy	≥15 Gy
		Pubertal		<10 Gy	≥10 Gy
	Hypothalamus		22-29.9 Gy	30-39.9 Gy	≥40 Gy

CED = Cyclophosphamide Equivalent Dose

Meacham L et al. Adolescent Young Adult Oncol 2020 May 26
Pediatric Initiative Network of the Oncofertility Consortium

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Female Preservation Options

- Embryo freezing
- Egg (oocyte) freezing
- Ovarian shielding
- Ovarian transposition (Orchiopexy)
- Ovarian Tissue Cryopreservation (OTC)
- Ovarian suppression

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Ovarian Tissue Cryopreservation

Table 1. Edinburgh selection criteria for cryopreservation of ovarian tissue.

Age younger than 35 years
A realistic chance of surviving for 5 years
A high risk of premature ovarian insufficiency (> 50%)
No previous chemotherapy or radiotherapy if aged 15 years or older at diagnosis; Mild, non-gonadotoxic chemotherapy acceptable if younger than 15 years
Informed consent (from parents and, where possible, patient)
Negative serology results for human immunodeficiency virus, syphilis, hepatitis B
Not pregnant and no existing children

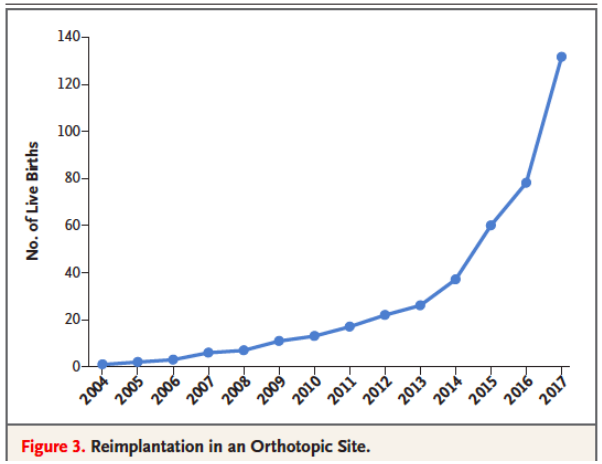

Figure 3. Reimplantation in an Orthotopic Site.

- First pregnancy reported in 2004
- As of 2022, over 250 live births
  - Pregnancy rate of 29%
  - Live birth rate of 23.3%
- There have been pregnancies and births resulting from a single ovarian-tissue reimplantation procedure

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Impact of Chemotherapy on Fertility: In the Testis

Male Risk Stratification		Minimally Increased Risk	Significantly Increased risk	High level of Increased risk
Alkylators CED gm/m^2		CED <4 gm		CED ≥4 gm
Hematopoietic Stem Cell Transplant				Alkylator +/- total body irradiation Myeloablative and Reduced intensity regimens
Heavy Metal mg/m^2		Cisplatin Carboplatin	Cisplatin >500 mg	
Radiation Exposure	Testicular	0.2-0.6 Gy	0.7-3.9 Gy	≥4.0 Gy
	Hypothalamus	26-29.99 Gy	30-39.9 Gy	≥40 Gy
Surgery			RPLND	

CED = Cyclophosphamide Equivalent Dose

Meacham L et al. Adolescent Young Adult Oncol 2020 May 26
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- Cytosensitivity
  - Spermatogenesis is affected because of higher cytosensitivity of the germinal epithelium
  - Testosterone production is less affected because of lower cytosensitivity of the Leydig cells

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Male Preservation Options

- Sperm banking
- Testicular sperm extraction (TSE)
- Radiation shielding
- Testicular tissue cryopreservation (TTC)*

*experimental

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Possible Fertility Outcomes

- Normal fertility
- Fertility followed by early menopause
- Immediate menopause (female)
- Compromised fertility
- On medications that do not allow pregnancy

Other Oncofertility Issues

- Ethical considerations
  - Religious considerations
  - Age
  - Cultural
  - Gender identity
- Psychosocial
- Cost
- Genetic testing of embryos (PGD/PGS)

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Stanford Oncofertility Team

Anna Sokalska, MD

Stephanie Cizek, MD

Robyn Service, FNP-C

Catherine Benedict, PhD

Pam Simon, NP

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CA Senate Bill SB 600
Approved by Governor October 12, 2019

- When a covered treatment may directly or indirectly cause iatrogenic infertility, standard fertility preservation services are a basic health care service, as defined in subdivision

- Does not include government insurance (MEDI-CAL, Tri-Care (military) or ERISA plans)

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Major Barriers

- Urgency to initiate treatment
  - Inadequate information
  - Clinic time constraints
  - Cost
  - Parents
  - Sociodemographic status
  - Hospital process

- Get education – ECHO & ENRICH

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Resources

- Fertility preservation
  - Team Maggie
  - Chick Mission
- IVF/Surrogacy Grants
  - SAMFund
  - Baby Quest
  - Tintina Q Cade Foundation
  - Hope for Fertility Foundation

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Post Treatment

- Need to rediscuss, rediscuss fertility
- Annual hormone testing (AMH) for females
- Resources to help get your life back

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AYA Resources

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Stanford Children's Health

Stanford HEALTH CARE

Stanford Adolescent and Young Adult Cancer (SAYAC) Program

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Fertility, Family Building, and Survivorship

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Oncofertility Post-treatment

- Most young adult female (YA-F; 18-39yo) survivors hope to have children some day
- Distress about fertility commensurate with cancer distress; infertility after cancer described as a “double trauma”
- Clinically significant levels fertility distress after treatment (20%-77%)

Geue et al, 2014; Zebrack et al, 2013; Logan et al., 2018. Systematic Review.

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Oncofertility Post-treatment

- Follow-up fertility counseling is limited / lacking
  - Only 15%, even after “high-risk” treatment

- Lack of information & misperceptions
  - 77% report unknown fertility status post-treatment
  - 62% feel uninformed about assisted reproductive technology (ART)
  - 80% would consider adoption; of those, 88% are concerned about the process

Kim et al, 2016; Keegan et al, 2012; Shay et al, 2017; Gorman et al, 2017

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Oncofertility Post-treatment

Do you have as much information as you would like about...? (N=111)

- Risk of infertility, 58% No
- Risk of early menopause, 59% No
- Options to evaluate current fertility status, 63% No
- Option to consider fertility preservation after treatment (if possible), 60% No
- Alternative family-building options (IVF, surrogacy, adoption), 71% No

Kim et al, 2016; Keegan et al, 2012; Shay et al, 2017; Gorman et al, 2017

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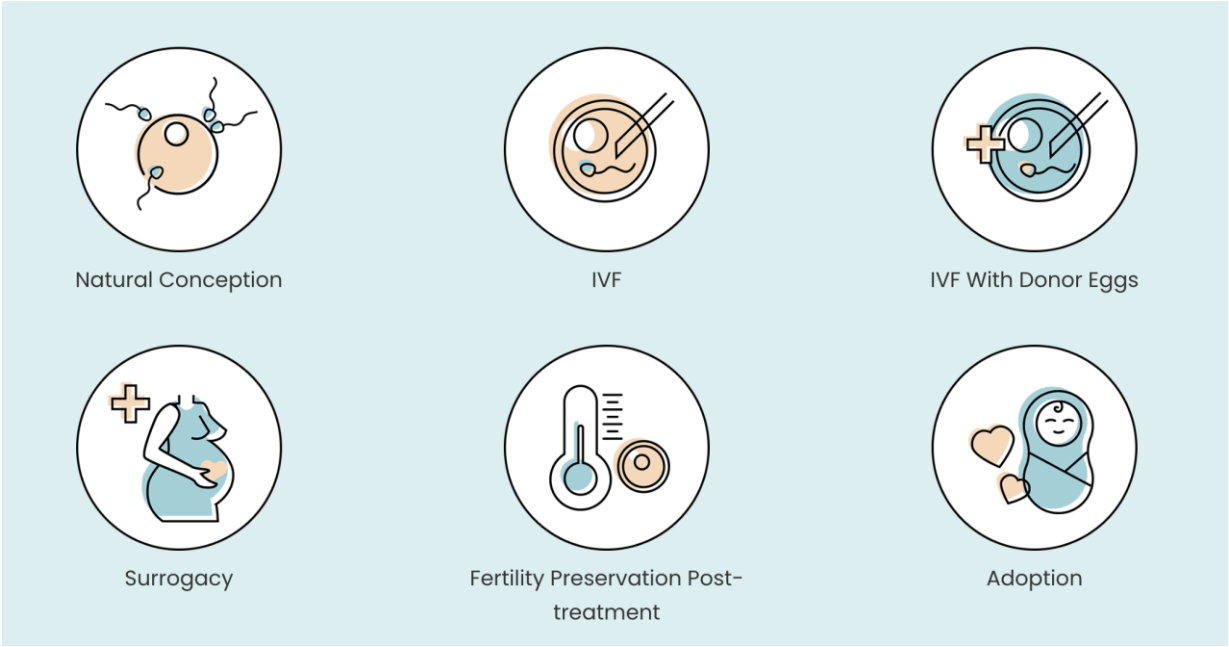
Family-building Options



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What's so hard about family-building decisions?

- Uncertain reproductive viability and timeline
- Uncertain chances for success (IVF, surrogacy, and adoption) – no guarantee
- Uncertain health risks (e.g., pregnancy, cancer recurrence; genetic risk)
- Uncertain costs (and cost limitations)
- Uncertain legal and logistical parameters
- Unclear values, priorities, and goals (and partners'; dating & disclosure)

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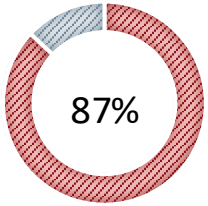
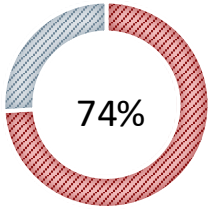
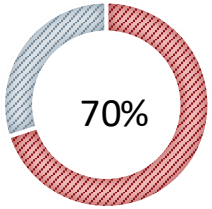
Decision support needs



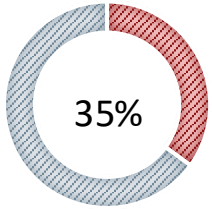
Felt uninformed



Unsure of personal values



Wanted advice and guidance



Wanted emotional support

Benedict, et al. (2016). *Cancer, 122*(13):2102-9. PMID: 29387996

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Family-building Costs

• IVF cycle	$15,000 – $24,000 per cycle
• Donor Eggs	$35,000 – $65,000
• Donor Embryos	$4,000 – $18,000
• Surrogacy	$80,000 – $150,000
• Adoption	$35,000 – $50,000

(Financial resources & charities)

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Emotional Experiences

- Feeling overwhelmed, lost
- Sadness, grief
- Anger
- Anxiety, fear
- Comparing to friends, to prior expectations
- Stress around dating & disclosure, communicating with partners

Amidst cancer survivorship difficulties

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What can you do?

- Give yourself time to adjust and grieve
- Cancer is a trauma and can alter your life in many ways including how you feel about yourself and your body, and what you want in the future
- Think about what's important to you, what you hope for…
  - What are you ready for? What do you need?
  - Goals, values, priorities (and partner's)
  - One step at a time

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What can you do?

- Talk to your doctor (build your team)
  - Oncology, gynecology, and/or primary care
  - Find someone(s) that support you, will advocate for you, be in your corner
- Get informed
  - Learn about your options
  - Fertility evaluation
- Plan ahead (e.g., post-tx fertility preservation, financial planning)
  - Can be empowering
- Pay attention to your emotions, find support

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What can you do?

- “Control the control-ables”
  - So much of the cancer and fertility experience is outside of your control… but what *can* you control?
  - What can you do now to address your questions, concerns, fears?
  - What can you do to optimize your chances of success and prepare for the future?
  - If you aren’t ready yet, making the decision to set it aside and come back to it later is smart. Do what is best for you.

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Finding Support

- What kind of help do I need?
- Who in my life is best at giving that type of support?
- What would I feel comfortable asking of them?

- Therapist that specializes in AYA cancer and/or fertility
  - Ask cancer care team for a referral

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Finding Support

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Adolescent And Young Adult (AYA) Cancer Program | Oncology

Stanford Children's Health

Stanford HEALTH CARE

Stanford Adolescent and Young Adult Cancer (SAYAC) Program

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Finding Support

- Find others who “get it”

  - Cancer-related:
    - Bay Area Cancer Connections (BACC)
    - Bay Area Young Survivors (BAYS)
    - Elephants and Tea
    - Stupid Cancer
    - Cactus Cancer Society
    - b-present
    - Young Survival Coalition
    - National LGBT Cancer Network

  - Fertility-related:
    - RESOLVE, the national infertility association
    - EarlyMenopause.com
    - Adoptive Parents Committee
    - Single Mothers by Choice
    - FertilityIQ

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Resources

FertilityIQ

fertilityiq.com

- Educational material

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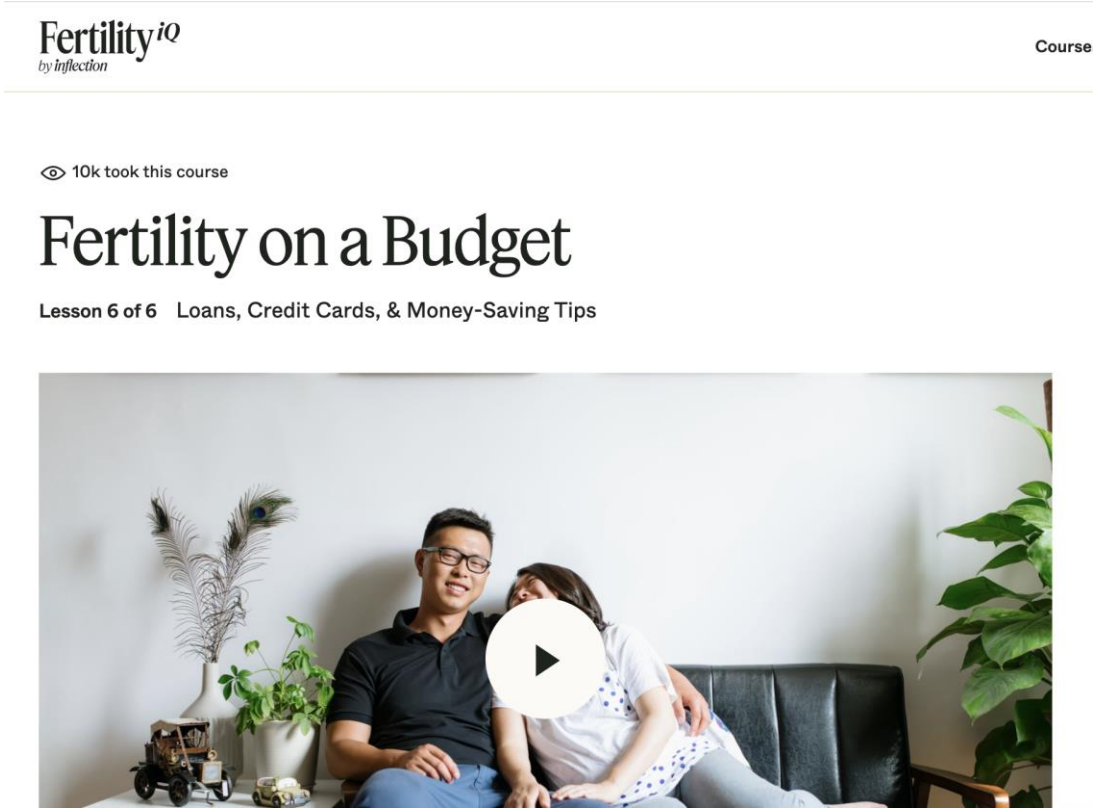
Resources

FertilityIQ

fertilityiq.com

- Financial Grants & Charities



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Resources

Financial Grants & Charities

Worth the Wait

SAMFund Surviving and Moving Forward

Gift of Adoption FUND

PATHWAYS for LITTLE FEET

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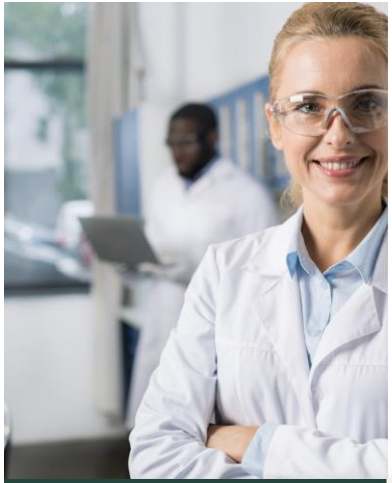
Resources

the Oncofertility® Consortium

> Resources for Patients



Patient Navigator

Providing care to reproductive-age cancer patients who wish to pursue fertility preservation prior to initiating cancer treatment—the oncofertility patient—requires the collaborative efforts of oncologists, reproductive endocrinologists, nurses, and counselors, and all within a very short time frame. Both clinician and patient education about the potential gonadotoxicity of cancer therapies and the available options for fertility preservation are essential to improve patient access to these procedures. In the hospital setting, an oncofertility patient navigator can help guide patients across institutional and disciplinary boundaries to assess their cancer treatment and infertility risk, seek consultation with reproductive endocrinologists, and discuss treatment options and costs.

READ MORE

SaveMyFertility

SaveMyFertility.org is an authoritative resource for adult cancer patients and the parents of children with cancer who want to learn more about preserving their fertility before and during cancer treatment, and protecting their hormonal health after treatment.

READ MORE

Community Resources

Learn about the organizations that partner with the Oncofertility Consortium to ensure advanced care for young cancer patients. Also, hear patients' stories about their experiences with fertility preservation and access other learning materials provided by the Oncofertility Consortium.

READ MORE

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“Roadmap to Parenthood” Study

This study will test a website designed to help you make decisions about family building and plan for the future.


wcrc
community
compassion
change
women's cancer resource center


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City of Hope
AYA PROGRAM


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Thank you!

Questions?

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