

Navigating Seamless Access to a Fertility Preservation Program Near You



Olivia Jaworek Frias, MSN, RN III, CNL
Patient Navigator of Fertility Preservation
Comprehensive Fertility Care and Preservation Program
Cincinnati Children's Hospital Medical Center
3333 Burnet Ave Cincinnati, Ohio, 45229



Outline

- Programs near you/ Access!
 - Resources
- How can we ensure seamless coordination of care if executed for our patients/families IF we do NOT have fertility preservation options available internally
- Clinical questions to ask prior to sending a referral
- Case Study

The GOAL



Do you have a Fertility Preservation Program?

What is your program's goal?

CFCPP Goal:

Complete fertility consultation on >90% of all patients seen in within our cancer and blood diseased institute, regardless of risk/

Accepted Exclusions from Consultation

*Surgery only

* Observation only

*Palliative/Phase I treatment

*Second opinion/Consult only

*Previous fertility consult completed without change in infertility risk

*Family declines fertility consultation

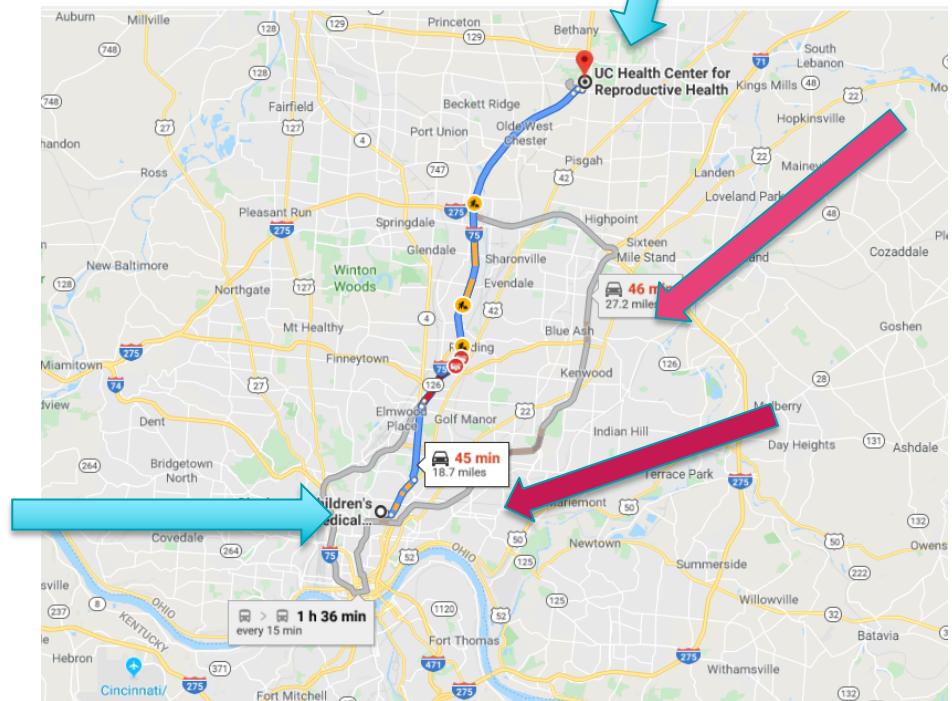


Fertility Preservation – Low hanging fruit

- Fertility preservation services
- Existing partnerships



by Frits Ahlefeldt



History of preservation options

CFCPP has been on both ends of the referral spectrum:

2009: **Sperm cryopreservation, Oocyte freezing**, ovarian transposition, Lupron

2012: OTC Protocol

2014: Offered TTC to High Risk males
-traveled to Pitt Dr. Orwig

2015: First OTC only outside referral

2017: TTC protocol offered at CCHMC

2019: No TESE (local Reproductive Urologist)

ACCESS!?!?!?

the Oncofertility[®] Consortium

About ▾ Resource Browser ▾ News ▾

CLINIC / CENTER EXPLORER

Refine By

Google

Map data ©2019 Terms of Use

Enter terms

Filter by country:

- United States (122)
- Argentina (6)
- China (5)
- Canada (4)
- United Kingdom (3)
- Australia (3)
- Thailand (2)
- Nigeria (2)
- Kenya (2)
- Uruguay (1)
- Turkey (1)
- Portugal (1)
- Philippines (1)
- Panama (1)
- Mexico (1)
- Lithuania (1)
- Iran (1)
- Greece (1)
- Spain (1)
- Germany (1)
- Chile (1)
- Austria (1)
- Brazil (42)
- South Africa (5)
- India (4)
- Russia (3)
- Colombia (3)
- Tunisia (2)
- Saudi Arabia (2)
- South Korea (2)
- Italy (2)
- Ukraine (1)
- Serbia (1)
- Poland (1)
- Peru (1)
- Netherlands (1)
- Morocco (1)
- Japan (1)
- Indonesia (1)
- France (1)
- Egypt (1)
- Czech Republic (1)
- Belgium (1)

Filter by target age group:

- Pediatric (12)
- Adult (90)
- Not age-specific (143)

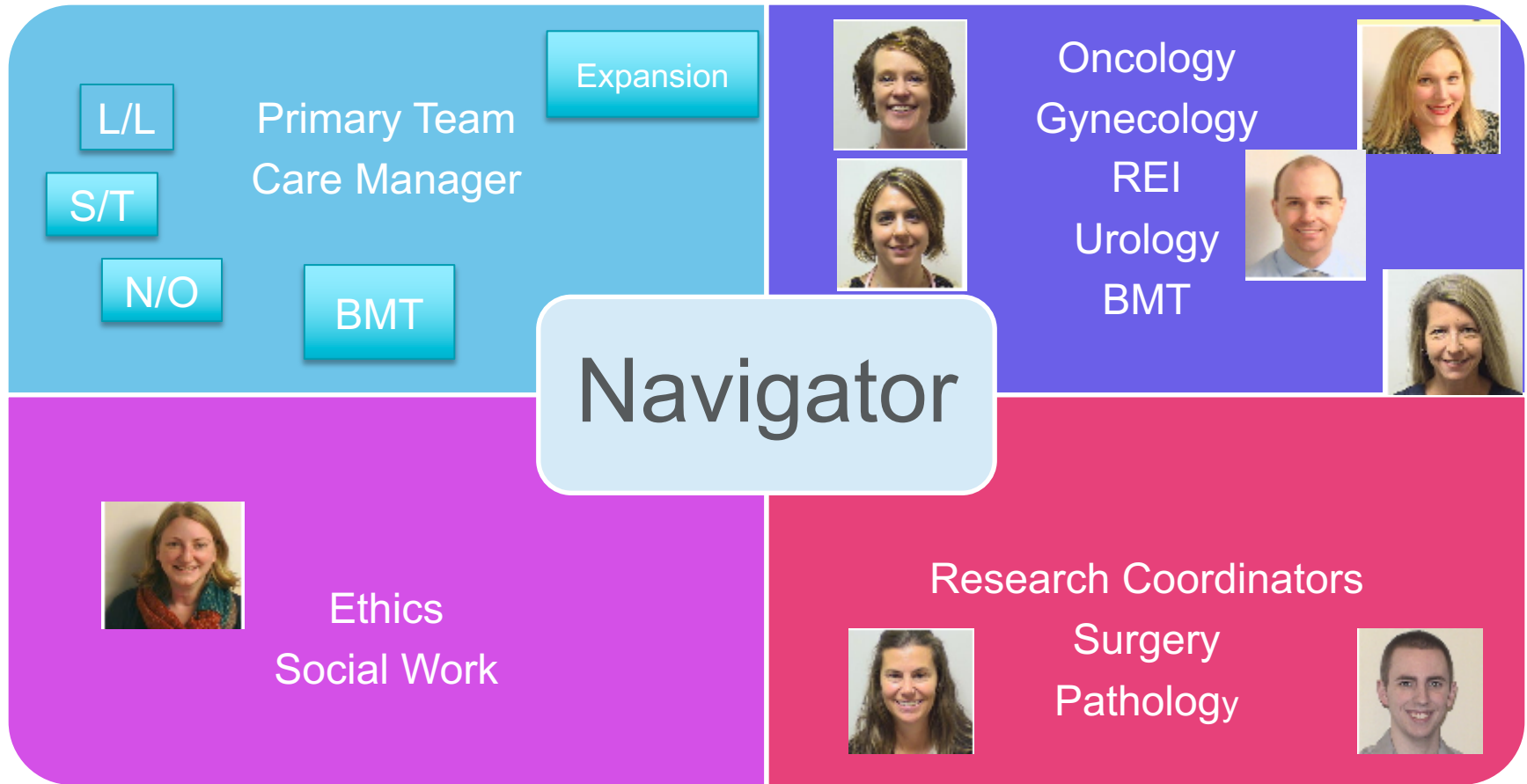
Filter by services offered:

- Egg (Oocyte) Banking (116)
- Embryo Banking (116)
- Sperm banking (116)
- Emergency IVF (66)
- Pre-Implantation Genetic Diagnosis (PGD) (58)
- Testicular Sperm Extraction (57)
- Ovarian tissue cryopreservation (53)
- Egg Donation (52)
- Testicular tissue cryopreservation (48)
- Ovarian Transposition (27)
- Ovarian Shielding (21)
- Donor Sperm (20)
- Trachelectomy (18)
- In vitro maturation (3)
- Ovarian Suppression (3)
- Ovary transplantation (3)
- Ovarian Tissue Transplant (2)
- Testis transplantation (2)

<http://www.oncofertility.northwestern.edu/find-a-clinic-or-center>

Please update!!!

The CFCPP Team



Integrating Program

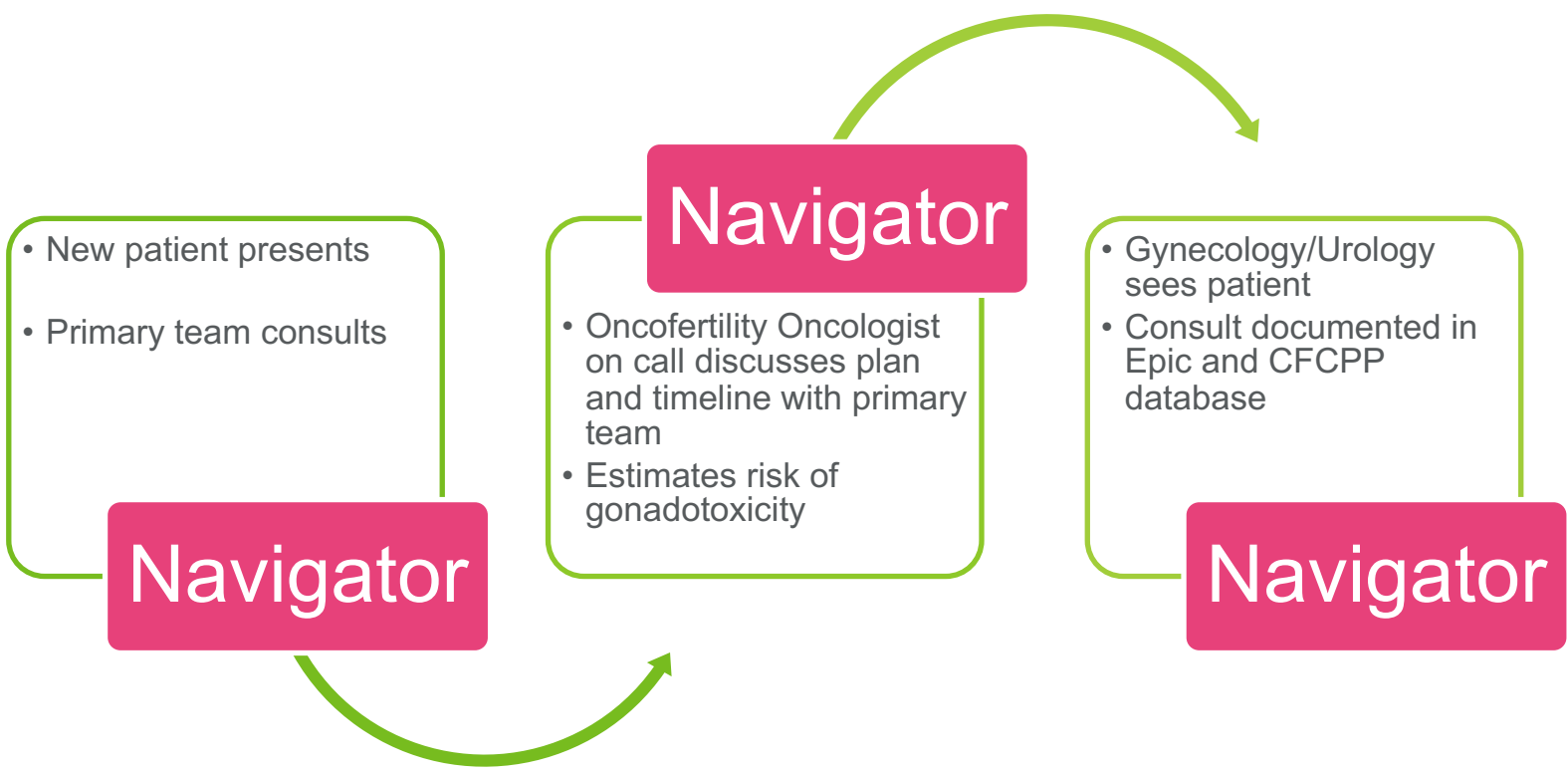
Cancer and Blood Diseases Institute (CBDI)

CBDI

- Liquids Team
 - Leukemia/Lymphoma
- Solids Team
 - Solid tumors
- Neuro Onc Team
 - CNS tumors
- Bone Marrow Transplant
 - Marrow Failures/ Immune Deficiency

Each team is unique in their own way

- Inpatient
- Outpatient
- Referral Process
- Work up



How can we maintain this process with Outside referrals?

A call for more help!



A call for more responsibilities!

- Support team within CFCPP: Key members associated with patient's underlying Dx.
- Additional Support for specific cases: Anesthesia, general surgery, scheduling

How can we maintain this process with Outside referrals?

Support Team at CCHMC

- Karen Burns, MD – Oncology
- Christine Phillips MD- Oncology
- Kas Myers, MD - BMT
- Julie Rios- REI GYN
- Andrew Strine, MD
- Dr. Lesley Breech- GYN

NONE MD:

- Scheduling: Cheryl and Susan
- Billing: Gretchen
- Research CRC: Brycen Ferrara and Tara Schafer-Kalkhoff
- Program coordinator: Sarah
 - Lodging, accommodations

Outside the CFCPP team

Anesthesia: Dr. Mecoli

General Surgery: Betsy Gerrein NP



The outside referral

Increased overall awareness to Oncofertility

- Media
- Institutions
- friends/peers
- Marketing



Electronic Interventions:

- Email: fertilityconsult@cchmc.org
- Desk phone/ message line
- Pager “On Call”
- EPIC in- basket
- EPIC order set
- Website



Website

Cincinnati Children's™
Patients & Family ▾ Healthcare Professionals ▾ Researchers ▾ Pro

Comprehensive Fertility Care & Preservation Program

HOME / SERVICES / F / COMPREHENSIVE FERTILITY CARE & PRESERVATION PROGRAM

- Comprehensive Fertility Care & Preservation Program
- Services and Treatment
- Services for Females
- Services for Males
- Resources for Patients and Families ✓
- Meet the Team
- Fertility Patient Navigator
- Contact Us ✓
- Give Today

The Comprehensive Fertility Preservation Program

At Cincinnati Children's, we believe that fertility is an important part of every patient, and it requires consideration even during the most difficult times.

The goal of the Comprehensive Fertility Care & Preservation Program is to help patients whose medical condition or treatment regimen may lead to complications in the future. By educating patients and their families about their diagnosis and treatments, they can determine the best available and right for them. We help the patient and family understand the limitations, successes and science behind each option.

We have teamed with the University of Cincinnati Center for Fertility and Andrology to provide all available fertility preservation options to our patients. We use up-to-date processes and techniques.

We also work closely with the patient's primary medical team to assure the best quality of care in every proposed treatment plan.

Comprehensive Fertility Care & Preservation Program

HOME / SERVICES / F / COMPREHENSIVE FERTILITY CARE & PRESERVATION PROGRAM / FERTILITY PATIENT NAVIGATOR

- Comprehensive Fertility Care & Preservation Program
- Services and Treatment
- Services for Females
- Services for Males
- Resources for Patients and Families ✓
- Meet the Team
- Fertility Patient Navigator
- Contact Us ✓
- Give Today

Talk to the Patient Navigator

Hello, I am Olivia Frias, your patient navigator for fertility preservation at Cincinnati Children's Hospital Medical Center.

Who Can See the Patient Navigator for Fertility Preservation?

The patient navigator is a resource within the Comprehensive Fertility Care & Preservation Program for patients whose medical diagnosis or treatment may place them at risk for future fertility concerns.

I meet with patients with a variety of diagnoses and treatment plans, including:

- Cancer
- Bone marrow transplant
- Chemotherapy
- Conditions in which a loss or impairment of ovarian function and/or infertility is expected

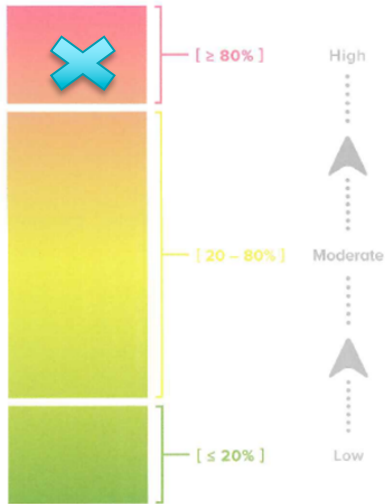


The Consult

What is my infertility risk?

It is important for you to know that every patient has a different infertility risk.

This visual shows you an estimate of your infertility risk based on your condition and treatment.



BV558564 09/16 DONOR



Provider to select assessed infertility risk

What is my infertility risk?

It is important for you to know that every patient has a different infertility risk.



Provider to select assessed infertility risk

Testicular Tissue Freezing (EXPERIMENTAL)

Process

- Small section to the scrotum under general anesthesia
- Remove testicular tissue
- These specimens are sent to Pathology
- 75% of tissue is frozen for patient's own future use
- 25% of tissue is given back to research

Time Frame

2-3 days

Fertility Success Rate

- Experimental - no known success in the future

Procedural Risk

- Bleeding
- Infection

Financial Costs (see Cost Information Sheet for current pricing)

- Up-front Costs
- Surgery
- Tissue processing and freezing
- Insurance coverage
- Annual storage fees

Long-term Costs (price will likely change over time)

- Possible testicular prophylactic later in life (epididymal)
- Possible in vitro fertilization (IVF)
- Possible intra-Cytoplasmic Sperm Injection (ICSI)
- Possible Intracavitary Insemination (ICI)

Other Considerations

- Genetics
- Ethics
- Spiritual or religious questions
- Psychology
- Social Services
- Financial

Sperm Banking (Sperm Cryopreservation)

Process

- Sperm sample collection
- 1-3 sperm samples (banked 24-48 hours apart)
- Sample analysis and freezing

Time Frame

1-7 days

Fertility Success Rate

- Sperm can be maintained indefinitely
- 4 to 8% live birth rate per cycle with Intracavitary Insemination (ICI)
- About 30% live birth rate per embryo with in vitro fertilization (IVF) or intra-Cytoplasmic Sperm Injection (ICSI)

Procedural Risk

- Unable to collect sperm sample
- Not enough healthy sperm for freezing

Financial Costs (see Cost Information Sheet for current pricing)

- Up-front Costs
- Analysis and freezing of sperm samples
- Infectious disease tests (generally covered by the patient's insurance)
- Annual storage fees
- Long-term Costs (price will likely change over time)
- Possible in vitro fertilization (IVF)
- Possible Intra-Cytoplasmic Sperm Injection (ICSI)
- Possible Intracavitary Insemination (ICI)

Other Considerations

- Genetics
- Ethics
- Spiritual or religious questions
- Psychology
- Social Services
- Financial

Egg Freezing (Oocyte Cryopreservation)

Process

- Hormone injections to stimulate the ovaries
- Final oocyte retrieval

Time Frame

1-7 days

Fertility Success Rate

- Up to 80% live birth rate per embryo with in vitro fertilization (IVF)
- 20% of tissue is given back to research

Procedural Risk

- Bleeding
- Infection
- Hyperstimulation syndrome
- Damage to ovaries

Financial Costs (see Cost Information Sheet for current pricing)

- Up-front Costs
- Analysis and freezing of oocytes
- Insurance coverage
- Annual storage fees
- Long-term Costs (price will likely change over time)
- Possible in vitro fertilization (IVF)
- Possible Intra-Cytoplasmic Sperm Injection (ICSI)
- Possible Intracavitary Insemination (ICI)

Other Considerations

- Genetics
- Ethics
- Spiritual or religious questions
- Psychology
- Social Services
- Financial

Depo-Lupron Injection* (Lupron Cryopreservation)

Process

- Hormone injections to stimulate the ovaries
- Final oocyte retrieval

Time Frame

2-4 weeks

Fertility Success Rate

- 35-50% live birth rate per embryo transfer

Procedural Risk

- Ovarian hyperandrogenism
- Painful infection
- Medicine could overstimulate the ovary
- Side effects of the medicine, such as nausea

Financial Costs (see Cost Information Sheet for current pricing)

- Up-front Costs
- Fertility consult fee (generally covered by insurance)
- Medicine (often free for patients with copay)
- Procedures to get eggs and create embryos
- Lab (generally covered by insurance)
- Freezing and shipping
- Annual storage fees
- Long-term Costs (price will likely change over time)
- Possible in vitro fertilization (IVF)
- Possible Intra-Cytoplasmic Sperm Injection (ICSI)

Other Considerations

- Genetics
- Ethics
- Spiritual or religious questions
- Psychology
- Social Services
- Financial

Embryo Freezing (Embryo Cryopreservation)

Process

- Hormone injections to stimulate the ovaries
- Series of ultrasounds
- Ultrasound-guided egg retrieval under sedation
- Sperm collection by partner
- Procedure done at specialized facility

Time Frame

2-4 weeks

Fertility Success Rate

- 35-50% live birth rate per embryo transfer

Procedural Risk

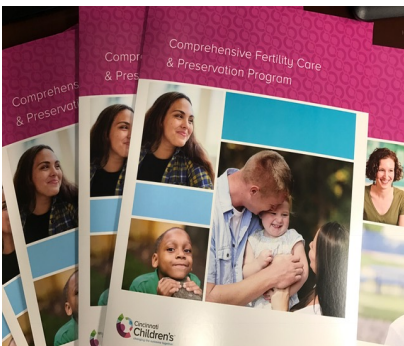
- Ovarian hyperandrogenism
- Painful infection
- Medicine could overstimulate the ovary
- Side effects of the medicine, such as nausea

Financial Costs (see Cost Information Sheet for current pricing)

- Up-front Costs
- Fertility consult fee (generally covered by insurance)
- Medicine (often free for patients with copay)
- Procedures to get eggs and create embryos
- Lab (generally covered by insurance)
- Freezing and shipping
- Annual storage fees
- Long-term Costs (price will likely change over time)
- Possible in vitro fertilization (IVF)
- Possible Intra-Cytoplasmic Sperm Injection (ICSI)

Other Considerations

- Genetics
- Ethics
- Spiritual or religious questions
- Psychology
- Social Services
- Financial



Consult Introduction

- Hello, My name is Olivia Frias and I am the Patient Navigator of the fertility team.
- I have the honor of meeting each and every patient/family regardless of one's age or sex to discuss how past or future therapies can effect either the ovaries or testicles.

Consult Continue

- Introduce the fertility team and explain the multidisciplinary approach
 - The fertility team is made up of many key members which include
 - Oncologist
 - Bone Marrow Transplant Doctor
 - Urologist(just to name a few!)

Consult Continue

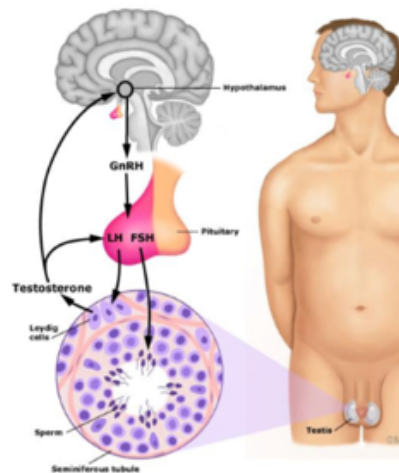
- The team has reviewed your chemo therapy plan as well as radiation. Our Oncofertility lead oncologist provided us with a risk assessment.
- The assessment helps us to understand the risk of premature ovarian insufficiency/primary testicular insufficiency.
- We always like to review the basic two roles of the ovary/testicles to remind us all why they are important to our future/present reproductive health.

Consult Continued

- The ovary has two jobs:
 - One hormone
 - Two fertility

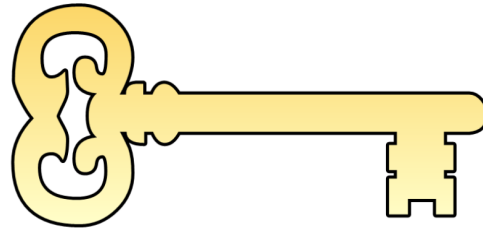


- The testicles have two jobs:
 - One Hormone
 - Two fertility



Main contact(s)

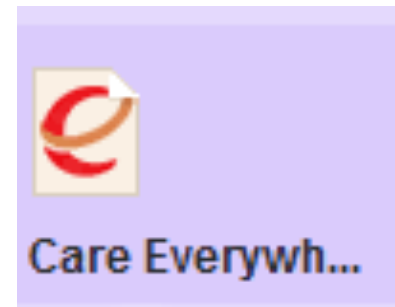
- Communication is key!
- Who are you looking for?
 - Attending
 - Care Mangers
 - APN
 - Medical Assistant
 - Care Coordinator
 - Referral coordinator



Prep

- Records and Release Forms
- Outside referral check list
 - Name
 - Date of Birth
 - Diagnosis
 - Treatment
 - History
 - BMT date
 - BMT Donor
 - Line Access
 - Most recent H&P and CBC
 - Previous fertility notes if seen by OSH team

**Create a chart in your EMR



Case Example:

Outside referral check list

DD

DOB: 04/24/1990

MRN: 11816907

Surgery Date:

Time: Unknown TBD

Dx: AML

Treatment:

- Cytarabine and idarubicin (low risk)
- Future: BMT Cy/ TBI : (High risk) – Donor is unrelated from another country

Hx: (she was a super healthy young woman who unfortunately was dx w. cancer)

- AML- acute myeloid leukemia dx: NOV 2018 with extramedullary disease
 - She was MRD neg by flow n B<A on 12/12/18
- Mass of left eye – when she first presented with AML
- Anxiety
- Secondary amenorrhea
- Transaminitis – with dx
- Pancytopenia (resolved currently)

GYN hx: G0

- fertility labs in chart, attempted egg harvest two weeks after chemo, unsuccessful
- Copper IUD however was placed on Lupron, received 1 dose in November
- no abnl paps, no STDs
- LMP: 10/28/2018
- First period: 13

Access: SL Port, however we are not going to use this when she comes here unless necessary. IV in the OR should be fine for access.

Anesthesia Consult: Today 2/15/2019 via telephone

- EKG- sent to anesthesia
- Echo - sent to anesthesia

CBC and Renal: will be drawn Monday , however last two CBC look great, placed in chart

Count recommended

Hard STOP:



ANC > 750

BMT patients: 5-7 days of healing post
OTC

**products: transfuse at OSH prior or we can transfuse pre operatively

Line – Ped Surg

Types of lines:

Percutaneous

Tunneled

Mediport

Apheresis/Dialysis

Questions to ask:

Why do you need the line?

What is the patient's access currently?

What type of central line is needed and how many lumens?

What is the mediport, leave access or de-accessed once placed?

Will the line be temporary or long term?

Is the line emergent, urgent, or elective?

Is a PICC, midline, or PIV an option?

Any previous lines? And how many and where?

Previous problems with placing lines? Clots? Stenosis?

History of bleeding disorders? (If so, will likely need coags along with stand lab work

If consult is for removal, will another line be needed?

Labs for Line placement:

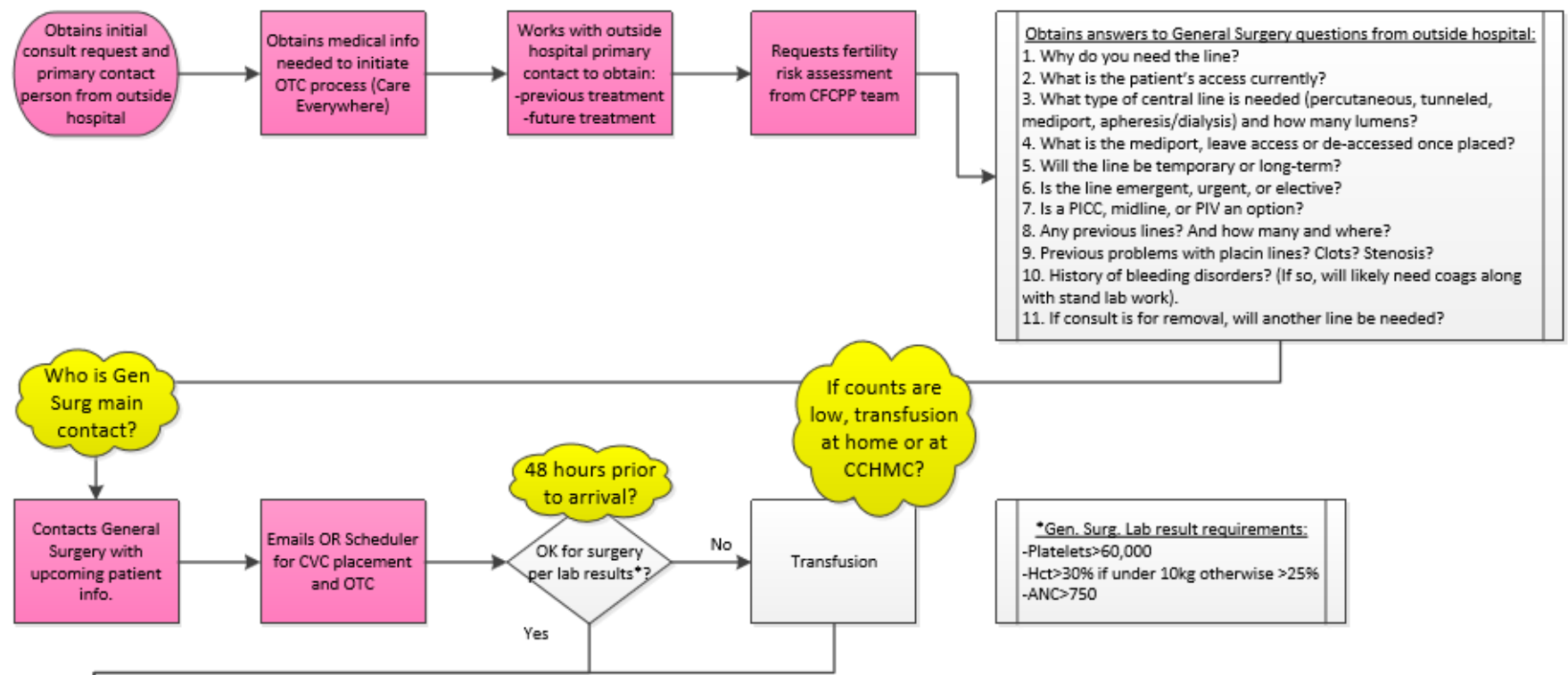
Platelets > 60,000

Hct > 30% if under 10kg otherwise >25%

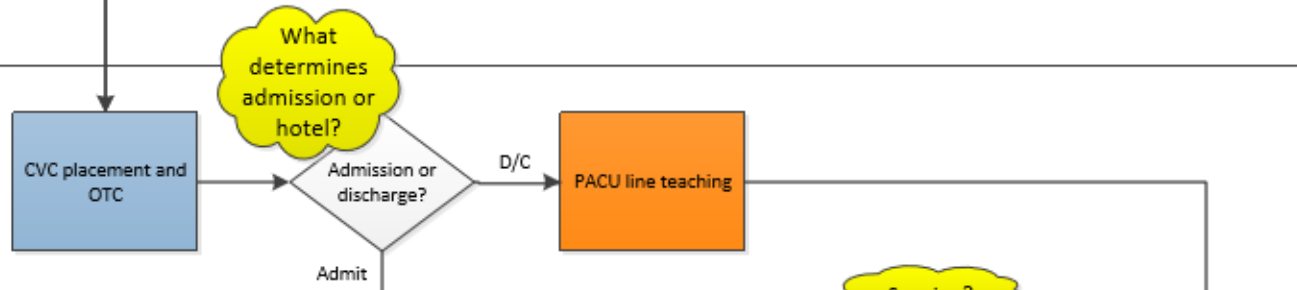
ANC 750

Process map

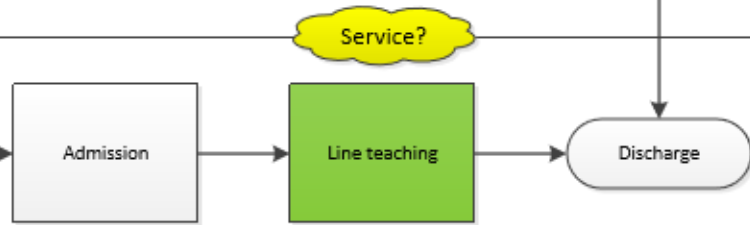
Pre-procedure



Periop



Post procedure



Prep Continue:

- E-mail sent to key players within the CFCPP team at Cincinnati Children's.
 - Patient case SAFE to accept
 - Admission plan with underlying diagnosis team (Leukemia).
 - CBC Day before at OSH
 - Hydration?

Risk Assessment

*DD is a 29 year old female with AML. She received DAC therapy at an OSH placing her at low risk of infertility. However the patient will soon undergo a Bone Marrow Transplant, prep regime consists of Cytoxan and TBI, increasing her risk to **HIGH meaning >80 %.***

Risk Assessment Continued

ZZ is a prepubertal male with high risk neuroblastoma who will receive therapy per ANBL1531. This regimen includes 5 cycles of chemotherapy, MIBG therapy and surgery, followed by two high dose chemotherapy cycles and stem cell rescue. Following this, she will receive radiation, then antibody. His upfront chemotherapy cycles include 8 g/m² of cyclophosphamide. Her HSCT includes cycle one of thiotepa 900 mg/m² (CED 45g/m²) and cyclophosphamide 6 g/m². The second block includes melphalan 180 mg/m² (CED: 7.2g/m²). His cumulative cyclophosphamide equivalent dosing will be 66 g/m². He is at **HIGH risk** for permanent azoospermia

Risk Assessment Continued

Lucas is a 4 yo male with rhabdomyosarcoma of the soft palate. His current chemotherapy regimen is ARST 0531. This regimen includes 14 cycles of VAC which is 16.8 g/m² of cyclophosphamide. If regimen is switched to VAC/VI, there is less cyclophosphamide, however, the minimum number of doses received is projected at 7, which is 8.2 g/m², still **HIGH risk** for permanent azoospermia

Continued communication with patient/family and primary Contact(S)

Status of patient's health must be communicated weekly (at most) between primary team and referring team.

Barriers:

- Fever and Neutropenia
- Donor fell through
- Bone Marrow Aspirate – disease present

Arrival to CCHMC

CCH IRB Approval Date: 6/10/2019
IRB Number: 2011-1643

Mid afternoon arrival to clinic

- Fertility consult continued
- Assessment +/- CBC +/- Renal
- Surgical Consent Completed
- Research Consent Completed
 - Families are provided copies of all research consents and storage paper work.

CINCINNATI CHILDREN'S HOSPITAL MEDICAL CENTER (CCHMC)

INFORMED CONSENT / PARENTAL PERMISSION
FOR PARTICIPATION IN A RESEARCH STUDY

STUDY TITLE: Ovarian Tissue Cryopreservation

STUDY NUMBER: 2011-1643

INVESTIGATOR INFORMATION:

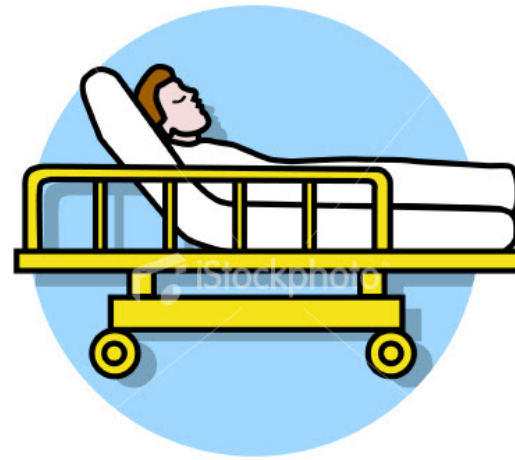
Principal Investigator: Lesley L. Breech, M.D.
Co-Principal Investigators: Karen Burns, M.D.; Julie Stoga Rios, M.D.
Telephone Number 24 hr Emergency Contact: 513-636-9400

For Staff Use	
Participant Name (first & last):	<input type="text"/>
Participant Date of Birth:	<input type="text"/> / <input type="text"/> / <input type="text"/> (mm/dd/yyyy)
Participant MRN:	<input type="text"/> Participant Study ID: <input type="text"/>

Admit v. no Admit (local hotel)

Procedure Day

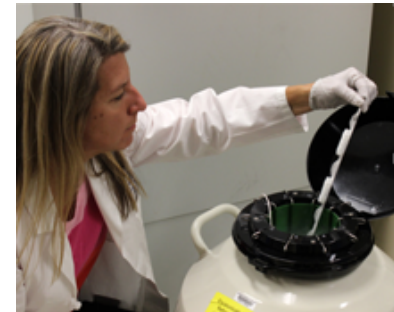
- Same day surgery or/and Inpatient
- OR
- PACU
 - Floor
 - Back to local hotel



EMAIL sent to home team that day!

Follow up post therapy

- Phone Call with patient/families
- All records sent to home team
 - operative notes
 - labs
 - Clinic note
- ReproTech paper work
- Ovary shipped to ReproTech within 2-3 weeks of removal
- Billing



Take Away:

- Lets help each other!
- Programs take time, look for a near by team to help
- Preparing and understanding what outside fertility programs need/recommend to work up a patient, expedites the process

Questions?

