



Nicole's Oncofertility Toolkit

©Faye Flemming, RN, BSN, OCN

If you download and utilize the toolkit, it would be greatly appreciated if you would email oncofertility@hotmail.com and give Faye contact information to participate in future surveys for input on use, outcomes, and improvements. If you have questions or suggestions/feedback regarding the toolkit, please email to oncofertility@hotmail.com.

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SECTION 1: GENERAL INFORMATION

INTRODUCTION

This toolkit is dedicated to my brave and inspiring niece, Nicole. It is because of the unnecessary emotional turmoil she faced due to the lack of attention, knowledge, resources, and preparation of healthcare providers and insurers to assist her with her oncofertility needs that led me to develop this toolkit. Her perseverance and determination has made her a genuine hero to those who know and love her.

At 28, Nicole returned from her honeymoon to be told she had Hodgkin's Lymphoma. From the minute the physician told her she had "some type of lymphoma," Nicole started asking questions and searching for answers as to what she needed to do to best preserve her chances of having children in the future. Time for action was short. Being a very knowledgeable woman, no one had to warn her of the risks therapy might have on fertility.

Nicole's attitude at the start was vibrant and optimistic. She could deal with all the warning signs, get through therapy, and continue life as she knew it. Just tell her what she needed to do, and she would do it!

Within just a few short weeks, Nicole went from being this vibrant, optimistic patient to becoming depressed and feeling helpless. Because of a lack of fertility-related preparedness and support from her healthcare team, Nicole began feeling a sense of hopelessness.

Timely assessment of fertility needs and desires, education about risks and options, financial and mental health counseling, quick referrals and care, and constant follow-up are every cancer patient's rights. How can such caring oncology healthcare professionals be so focused on distress management and psychosocial care yet forget or diminish such a huge, preventable source of anguish in our patients?

After years of talking and reading about fertility-related needs, it is time for *all* oncology healthcare professionals to take a stand. We must all ensure we are assessing, educating and ensuring timely interventions and follow-up for this important oncology patient need. It is every oncology patient's right and every oncology provider's responsibility to ensure fertility needs are properly addressed.

—Faye Flemming, RN, BSN, OCN

GLOSSARY

Assisted reproductive technology (ART): the utilization of any technology to assist males and females to conceive

Childbearing-age: age at which men and/or women can create a biologic offspring

Cryopreservation: a process where cells or tissue are preserved by freezing

Donor eggs: another women's egg used to become fertilized with their partner's sperm (not a genetically related offspring to wife, but genetically related to the spouse)

Donor embryo: an embryo conceived from both donor egg and donor sperm (not a genetically related offspring)

Donor sperm: sperm donated by a fertile donor

Egg freezing: mature eggs are removed, frozen, and stored without being fertilized (considered experimental)

Embryo: the product of human conception for the first eight weeks after fertilization

Embryo freezing: mature eggs are removed, fertilized with sperm from the partner or donor, frozen, and stored (most successful female fertility preservation method)

Epididymal sperm aspiration: an experimental option for men to obtain sperm by inserting a needle into a tiny opening made in the epididymis and aspirating the sperm

Family planning: the process of planning for conception or to avoid conception

Fertility: the ability to conceive

Fertility preservation: assistance to help cancer patients to preserve their fertility after treatment

Fetus: the product of human conception after the embryo stage (after the first eight weeks)

Gametes: the cells that fuse together to form the product of human conception (egg and sperm)

In vitro fertilization (IVF) treatments: collecting a woman's eggs, fertilizing them outside of the body and then implanting an embryo into her body

Infertility (general accepted definition): the inability to either start or maintain a pregnancy after at least one year of regular, unprotected sex

Infertility (oncology definition): inability to start or maintain a pregnancy

Oncofertility: a new medical field that addresses the reproductive needs and care of cancer patients

Ovarian tissue freezing: part of the ovary is removed and frozen for later use (considered experimental)

Ovarian transposition: the ovary is moved to the outside of the radiation field

Radiation shielding: if it does not affect the needed treatment results, some patients may be able to have external shields utilized to protect their reproductive organs if they are within the radiation treatment fields

S.965, The Family Act of 2011: proposed legislation that would provide tax credits for cancer patients and other individuals who undergo fertility preservation and in vitro fertilization (IVF) treatments

Sperm banking: sperm cells are frozen and stored for later use (most successful male fertility preservation method)

Surrogacy: another woman carries a child for the patient

Surrogacy Agency: an agency that assists patients to find and screen potential matches for a surrogate

Surrogate, gestational: surrogate carries patient and spouse's embryo

Surrogate, traditional: surrogate has her own mature egg fertilized by the spouse and she carries the baby (surrogate is the genetic mother)

Testicular sperm extraction (TESE): tissue is removed from the testicle and the sperm found are used immediately or frozen for later use (considered experimental)

Testicular tissue freezing: freezing testicular tissue for later use (considered experimental)

ONCOFERTILITY FACTS

U.S. Cancer Incidence Rates, Age at Diagnosis 15- 44[‡]

AGE	COUNT
15-19 years	4,325
20-24 years	6,902
25-29 years	10,766
30-34 years	16,185
35-39 years	27,669
40-44 years	51,220
Total	117,067

Source: 1999-2006 (CDC WONDER online). Rates are per 100,000 and are age-adjusted to the 2000 U.S. Std Population. [‡]These individuals are women and men of childbearing age.

Cancer survivor rates are increasing.

There are an estimated half a million U.S. cancer survivors of childbearing age.

Cancer, surgery, chemotherapy, radiation therapy, hormonal therapy, and other treatments can temporarily or permanently affect the fertility of childbearing-age cancer patients.

Fertility-related needs and planning should be a part of the diagnosis and treatment planning for all childbearing-age patients.

The actual or potential loss of fertility can be devastating and create emotional turmoil in already distressed cancer patients.

The fertility-related needs of our cancer patients are often forgotten, avoided, or not assessed and supported by healthcare providers.

Oncology professionals need to ensure that the treatment planning process includes fertility and other specialists required for fertility-related care for those at risk.

In 2006 the American Society of Clinical Oncology (ASCO) published the “American Society of Clinical Oncology Recommendations on Fertility Preservation in Cancer Patients.”

There are procedures and assistance available for patients to preserve their fertility, but often healthcare providers and/or patients are not aware of these options.

Fertility-related options are based on disease, treatment plan, sex, age, culture, values, family/relationship history, family planning desires, and sometimes finances.

Physicians and healthcare providers need to provide timely information and support to childbearing-age cancer patients about risks and options for fertility preservation and reproductive options prior to treatment.

The patient's significant others should be included in fertility education and discussions as well as in fertility-related planning and support.

Each patient presents with unique needs and desires, so each fertility-related care plan needs to be individualized to that patient.

Many men and women prefer to have genetically related children.

To ensure oncofertility needs are met, these needs and fertility choices need to be determined immediately after diagnosis and prior to the start of treatment.

Healthcare providers, insurers, and patients often have different perspectives about fertility-related issues.

Some people believe fertility preservation, especially in women, is a luxury for those who can afford it, NOT a standard option for all patients.

More often than not, insurance payers may not cover all or some of the costs of fertility preservation.

Only 14 states require insurers to provide some coverage for infertility diagnosis and treatment.

Most cancer patients with fertility-related needs will need to speak to a financial coordinator immediately before they make their fertility preservation choices and treatment begins.

Many cancer patients choosing fertility preservation options will require financial aid to meet the costs of these options and this must be obtained quickly.

There is a very small window of time for cancer patients to become informed, make fertility-related decisions, and complete required procedures.

Oncology professionals need to assist patients by guiding and supporting them during the fertility planning and implementation processes.

Some fertility preservation options must be completed prior to the start of treatment and may delay the start of treatment, especially in women.

The treating oncologist(s) and reproductive providers need to communicate frequently and coordinate care to ensure an acceptable time frame for reproductive preservation and start of cancer treatment for each patient since this will be an important factor to obtain optimum reproductive preservation.

Women are infertile when they do not produce mature eggs, mature eggs cannot be fertilized, have abnormal hormone levels, experience premature menopause, do not have at least one pathway for

sperm to travel to fertilize an egg, or when a fertilized egg cannot implant or grow inside their uterus.

Men are infertile when they have compromised sperm production (low counts, no sperm, motility issues, quality issues, and/or genetic issues), have abnormal hormone levels, or any part of the pathway for sperm is blocked or removed.

Some women may develop long-term complications from [cancer] treatment such as heart and lung problems that may make becoming pregnant too high risk for the patient.

Some women may become infertile temporarily, gain back fertility, and then develop an early menopause causing permanent infertility.

Having a period does NOT mean a woman is fertile.

Women's fertility preservation is more difficult and costly and delays treatment longer.

Some types of cancers, such as certain breast and ovarian cancers, may be sensitive to hormones, and patients with these types of cancers may need to avoid routine fertility preservation procedures that utilize hormones. There are other procedures that are safer for these patients.

Embryo freezing is the standard and most successful evidence-based fertility preservation method for women.

Embryo freezing takes weeks. Though not ideal, it is possible to do a "shortened cycle" for cancer patients whose oncologist recommends not to delay the start of treatment for the length of time it takes to complete the regular process.

Sperm banking is the standard and most successful evidence-based fertility preservation method for men and can be successful even when men have issues with their sperm such as a low count.

Radiation shielding is an accepted practice to decrease the chance of fertility issues in both men and women when this does not affect the required treatment dose.

If an oncologist and/or a patient is concerned about the utilization of hormones in the fertility-preservation process, there are often other experimental options the patient can consider.

The average cost of one cycle of in vitro fertilization (IVF) is more than \$12,000, and most women require more than one cycle.

The average cost of sperm banking is more than \$1,500 for just the sperm banking (does not include costs for the use of the sperm to create a pregnancy).

Most fertility preservation procedures remain experimental.

Experimental procedures should be offered only in a research setting.

Patients should always be informed if recommended fertility preservation methods or options are the standard of care or experimental, unfortunately this does not always happen.

The only approved, non-experimental procedures for preservation of fertility are sperm and embryo cryopreservation.

The goal for reproductive preservation in cancer patients is to preserve an ideal amount of tissue and/or gametes in a window of time that does not have a potential to affect the cancer treatment outcomes or prognosis for the patient.

There will be times when a smaller amount of tissue/gametes is all that can be obtained in the limited time a particular patient has before treatment needs to begin. Though this is not the ideal, anything is better than not obtaining any tissue/gametes and could be that patient's only chance for a genetically related offspring.

Fertility should be re-addressed in the survivorship stage when the patient has completed treatment and is beginning to look at the future and getting back to "life."

Fertility should ALWAYS be assessed and addressed in the diagnosis/treatment planning stage and NEVER addressed for the first time in the survivorship stage.

It is important to remember that there is no evidence (except for genetic syndromes) that having cancer increases the odds of offspring developing cancer.

Legal and ethical issues such as what will be done with unused sperm or eggs need to be addressed when patients opt for many methods of reproductive preservation.

Cancer patients who have previously received some cancer treatments may be at higher risk for complications during pregnancy if they do conceive and often should be treated as high-risk pregnancies.

More than 2 percent of all pregnancies occur in women ages 40 – 45 with more women waiting until later in life to start families.

Fertility preservation offers no guarantees and patients need to understand this and be prepared to choose other options should their first choice fail.

SECTION 2: ONCOFERTILITY IN THE COMMUNITY CARE SETTING

ONCOFERTILITY TEAM

Every healthcare provider and facility needs to create an oncofertility team that consists of healthcare providers, facilities, and organizations who can work together to best meet the fertility needs of every cancer patient. Once this team is created, all healthcare providers need to be educated about: the team; the importance of quick, early referrals prior to treatment; the fertility related needs of childbearing oncology patients; and how to refer a patient to one or all of the team.

Your oncofertility team should be chosen based on your patient demographics and cultural mix, oncology diagnoses, oncology treatment options provided, location, available providers, available facilities and agencies, and specific patient population's needs.

The following healthcare providers and facilities should be assessed for inclusion in your oncofertility team:

- Medical oncologists/hematologists
- Surgical oncologists/surgeons
- Radiation oncologists
- Oncology gynecologists/gynecologists
- Urologists
- Primary care physicians
- Reproductive endocrinologists/infertility specialists
- Bone marrow/stem cell transplant specialist
- Physicians' nurses and staff for all of the above specialties
- Oncology nurses
- Social workers
- Mental health staff
- Nurse and patient navigators
- Case managers
- Financial counselors
- Pastoral care staff
- Genetic counselor
- Survivorship staff
- Local family planning organization and staff
- Local infertility specialists' nurses, staff, and researchers
- Sperm banking facilities' staff
- Pharmacist

ONCOFERTILITY ROLES

To assist all cancer patients in achieving optimum reproductive health to meet their reproductive needs, a multidisciplinary team of physicians, healthcare providers, and staff need to work closely together. Communication and coordination of all education, treatment planning, and referrals must occur early in the diagnosis and treatment planning phase, and be timely and support the patient and family through this sometimes difficult time. Potential multidisciplinary team members have been addressed previously in the oncofertility team section of this toolkit. Some of the roles for team members include:

Patient: Patients need to be aware of their patient rights and need to ensure they ask providers all questions they may have. Patients need to answer all providers' questions honestly, letting them know when they do not understand. Patients must ensure that they understand all information and options.

Significant others: Significant others need to be present, offer support, discuss the information learned with the patient, ask questions, and assist with decision making that will meet both of their fertility needs.

Oncologists (medical, radiation, and surgical/surgeon): Oncologists need to be knowledgeable about the actual and/or potential effects of recommended cancer treatments on their patient's fertility. They should know about basic reproductive and fertility options for both male and female cancer patients.

Oncologists need to have a process in place that is utilized for all of their childbearing-age cancer patients to ensure they all receive timely information, support, referrals, and follow-up for fertility-related needs. They should obtain informed consent, which includes education about fertility-related risks for recommended treatments as early as possible in the diagnosis and treatment planning phase.

Oncologist should have a referral system for consults with endocrinologists and reproductive health specialists that includes the sharing of information, treatment plan, timing, and monitoring of progress. They should also have information and contacts for local referral sources for fertility-related needs such as financial and psychosocial care.

Genetics counselor: These specially trained healthcare professionals in the field of genetics and counseling should counsel, inform, test, and support patients at a high risk for genetic abnormalities and/or their offspring about possible genetic cancer risks.

Oncology nurses: Oncology nurses need to assist the oncologists and oncology team in providing education, care, assessment, distress management, referrals, support, navigation, and coordination of care.

Primary care physician (PCP): PCPs usually know patients best and have a long-term relationship with patients. PCPs can help support, educate, and guide patients.

Social workers and mental health counselors: These professionals can provide needs assessments, distress management, emotional support, counseling, referrals, psychosocial, and mental health support. They can also assist with meeting cultural, ethical, and spiritual needs.

Nurse navigators and case managers: These healthcare providers can conduct needs assessments, assist with access, provide support with navigating the system and providers, as well as communication support, education, distress management, and referrals.

Pastoral care/clergy: Pastoral care/clergy offer spiritual, psychosocial, and emotional support to assist patients with decision making.

Pharmacist: A pharmacist is a specially trained healthcare professional in the safe and effective use of medications. A pharmacist can assist the patient in understanding cancer and fertility-related drugs.

Family-planning specialists: Specialists trained in all aspects of family planning, they can help better educate patients and their families about parenting options.

Gynecologists: Gynecologists may be the physicians diagnosing female cancers. They often have a long-standing relationship with their patients. Gynecologists can help to prepare and guide patients in addressing fertility needs.

Oncologic gynecologists: These specialists are physicians trained in cancer-related gynecology. They are often the surgeon providing fertility-sparing female surgery.

Urologists: Urologists may be the physicians diagnosing some cancers or the surgeons providing fertility-sparing surgery. They can help to prepare and guide their patients in addressing their fertility-related issues.

Endocrinologists and reproductive specialists: These specialists are experts in all fertility-preservation methods. A timely consult can help patients make better informed decisions about their future fertility. These specialists will explain options, procedures, costs, timing, success rates, and available support. They will also complete any fertility-preserving procedures if chosen as the option.

Adoption professionals: Adoption professionals are experts in adoption. A timely consult can help patients make a better informed decision about having non-biologically related offspring. Adoption professionals can explain the criteria, timing, cost, process, availability, and answer any questions.

Financial counselors: Financial counselors provide timely financial needs assessments and assist with financial, insurance, and related support, information, and referrals.

ONCOFERTILITY PATIENT NEEDS

Childbearing-age cancer patients have unique needs relating to fertility. All childbearing-age cancer patients should be assessed for risk to their fertility. If at risk, they should have all of their needs assessed and an individualized fertility plan developed and implemented based on their needs and desires. These needs include:

- Multidisciplinary team and care
- Coordination of fertility and cancer care
- Identification as childbearing-age pre-treatment
- Thorough identification of fertility-related risks
- Thorough assessment of fertility-related needs and desires
- Development of a fertility-care plan
- Written patient fertility-educational material
- Emotional and psychosocial support, financial counseling and support, and distress management

- Assessment, referral, and support for cultural, ethical, and religious concerns
- Education and referral to fertility resources and fertility-preservation providers
- Explanation of all risks and benefits of fertility options and cancer treatment options
- Timely access to information, care, and resources.

ONCOFERTILITY CARE

Care of the oncofertility patient requires a multidisciplinary team approach including assessment, provision of support, and care for all fertility and psychosocial needs. This care should include:

- A multidisciplinary team knowledgeable about oncofertility
- Multidisciplinary care
- A formal fertility process and/or program
- Fertility risk and needs assessment
- Psychosocial assessment
- Treatment planning inclusive of fertility planning
- Timely fertility-related referrals, support, and monitoring
- Financial, insurance assessments and counseling
- Psychosocial support
- Patient and family educational materials and resources
- Genetic counseling as needed
- Informed consent
- Referral information about fertility-related providers
- Coordination of care between all providers and treatment planning
- Support throughout the care process and into survivorship
- Quality assurance and monitoring of all aspects of care

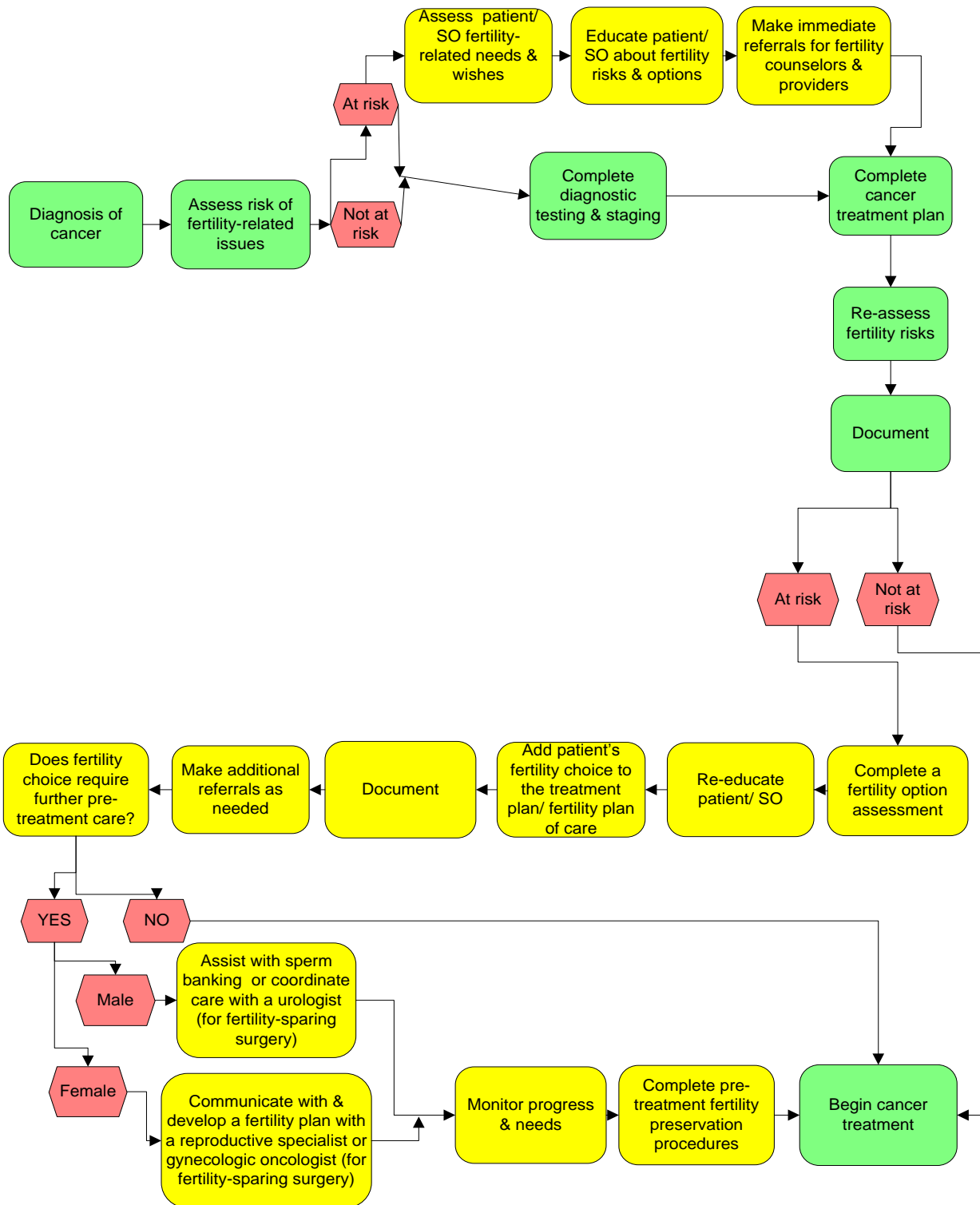
ONCOFERTILITY OPTIONS FOR MEN

- Choose to have no children.
- Do nothing and take a chance on having children naturally after treatment is completed and the physician approves.
- Do nothing until after treatment is completed, and then assess fertility. If the decision is made to have children, choose from post-treatment options.
- Use radiation shielding for reproductive areas during radiation treatment if it does not affect the required treatment field.
- Use fertility-sparing surgery if it will not affect the cancer treatment outcome.
- Adoption: Approximate cost: \$2,500-\$50,000 or more.
- Foster parenting: Approximate cost paid by agency \$500-\$900 a month depending on location and age, but this is to be used for care and supplies for the child, not compensation.
- Sperm banking: Approximate cost: \$675-\$2,000 plus \$350-\$750 a year for storage. (“Live ON”: one year total = \$675 if qualify.)
- Obtain a donor:
 - Sperm—Approximate costs: \$200-\$1,500 plus artificial insemination or IVF costs.
 - Embryo—Approximate costs: \$12,000-\$15,000/cycle plus pregnancy fees plus \$5,000-\$10,000.
- Experimental options (should be done for research only):
 - Testicular sperm extraction (TESE): cost varies.
 - Epididymal sperm aspiration: cost varies.

ONCOFERTILITY OPTIONS FOR WOMEN

- Choose to have no children (saves money!).
- Do nothing and take a chance on having children naturally after treatment is completed and the physician approves.
- Do nothing until after treatment is completed, and then assess fertility. If the decision is made to have children, choose from post-treatment options.
- Use radiation shielding for reproductive areas during radiation treatment if it does not affect the required treatment field.
- Use fertility-sparing surgery if it will not affect the cancer treatment outcome.
- Adoption: Approximate cost: \$2,500-\$50,000 or more, dependent on agency/source.
- Foster parenting: Approximate cost paid by agency: \$500-\$900 a month depending on location and age, but this is to be used for care and supplies for the child, not compensation.
- Embryo freezing: Approximate cost: \$12,000-\$40,000 or more, plus storage.
- Obtain a donor:
 - Egg—Approximate cost: \$17,000-\$35,000 or more per cycle.
 - Embryo—Approximate cost: \$17,000-\$25,000 or more per cycle.
- Surrogacy: Use of shielding for reproductive areas if this does not affect the required treatment area:
 - Traditional (utilizes surrogate's egg and cancer couple's male sperm): Approximate cost: \$12,000-\$15,000 or more per cycle if IVF used.
 - Gestational (utilizes embryo of cancer patient and spouse): Approximate cost: \$12,000-\$15,000+ per cycle plus \$10,000-\$100,000 or more.
- Experimental options (should be done for research only):
 - Egg freezing banking (freeze eggs prior to fertilization): Approximate cost: \$12,000-\$35,000 per cycle, plus storage.
 - Ovarian suppression uses Gonadotropin-releasing Hormone (GnRH) analogs or antagonists to suppress ovaries during chemotherapy, approximate cost: \$400-\$600 a month.
 - Ovarian tissue freezing (freezes tissue from the ovaries and re-implants after treatment is completed), approximate cost: \$17,000 or more plus storage.

Nicole's Oncofertility Preservation Algorithm Tool (NOPAT)



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SECTION 3: DEVELOPING A COMMUNITY ONCOFERTILITY PROGRAM OR PROCESS

ONCOLOGY TEAM PROCESS FOR FERTILITY-RELATED NEEDS

I have included a process that can be followed to help you and your practice best meet the fertility needs of your childbearing-age patients. I suggest you utilize this to create a written process and/or policies and procedures (P & P) for all team members to follow.

- I. Assess if patient will need to have a fertility-risk assessment as soon as possible after diagnosis and before treatment begins:
 - A. Are they of childbearing-age?
 1. If no, then no assessment needed. The process is complete after documentation is completed.
 - OR**
 2. If yes, then proceed.
- II. Assess fertility-related risks as soon as possible after diagnosis and before treatment begins:
 - A. Are they at risk for fertility-related issues (refer to risk assessment sheet)?
 1. If no, then no assessment needed. The process is complete after documentation is completed.
 - OR**
 2. If yes, then proceed.
- III. Educate patient and significant other about actual and/or potential fertility risks.
- IV. Obtain additional information about fertility-related history and desires as soon after diagnosis and prior to start of treatment as possible:
 - A. Assess patient desires
 - B. Assess patient and significant other's childbearing history
 - C. Is there a possibility the patient may want to conceive in the future?
 1. If no, then no further assessment needed. Ensure that they understand the risk. The process is complete after documentation of all of the steps.
 - OR**
 2. If yes, then proceed.
- V. Complete a more in-depth personal fertility-needs assessment:
 - A. How many more children would they prefer?
 - B. Is hormonal therapy contraindicated for any reason?
 - C. What are their feelings about non-genetically or partial-genetically related offspring?
 - D. What are their feelings about someone else carrying the pregnancy?
 - E. Do they have any insurance and fertility-related coverage?
 - F. What is their financial status and what resources are available for fertility needs?
 - G. What is their emotional status & present distress level (utilize Distress Management Tool)?
 - H. What is their available support system?
 - I. Are there any other co-existing challenges or support needs?
 - J. Do they have any religious, cultural or other preferences &/or needs?

ONCOLOGY TEAM PROCESS FOR FERTILITY-RELATED NEEDS (*continued*)

- VI. Provide patient and significant other basic information about fertility-related options, including:
 - A. What options are available/
 - B. Basic explanation about each option, what is involved, and if they are a standard of care or considered experimental
 - C. Risks, benefits, pros and cons of each option
 - D. Range of approximate total costs of each option
 - E. Timing for each option
 - F. Available support for each option
 - G. Expected results for each option
 - H. Location of providers
 - I. Availability of any clinical trials research
 - J. Other information as pertinent

- VII. Counsel the patient and significant other about the options and offer emotional support

- VIII. Refer immediately to all support services that will assist in meeting this patient and significant other's needs:
 - A. Clergy
 - B. Social worker
 - C. Mental health counselor
 - D. Support team/navigator
 - E. Financial counselor
 - F. Other physicians such as their gynecologist and/or primary care provider
 - G. Insurance support services
 - H. Genetic counselor

- IX. Assist patient and significant other to make fertility-related decisions
- X. Provide additional information about the chosen fertility option:
 - A. Does the patient's choice require immediate action prior to treatment?
 - 1. If no, the process is complete after documentation of all of the steps.

PLEASE NOTE: It is best for patients and significant others to have as much information as possible prior to the start of treatment, even if their choice does not require action prior to treatment. If patients choose an option such as adoption, they may find out that their chances of qualifying are not high for some reason. At that point, they may change their minds about other options. If this is done after treatment, it may be too late to assist them to meet their fertility needs.

OR

- 2. If patient's choice requires pre-treatment action, proceed.

- XI. Assist patient to obtain very timely consults as needed:
 - A. Reproductive endocrinologist/specialist
 - B. Reproductive clinic/center
 - C. Sperm bank
 - D. Fertile Hope
 - E. Financial assistance counselor and programs
 - F. Psychosocial support providers and staff

ONCOLOGY TEAM PROCESS FOR FERTILITY-RELATED NEEDS (*continued*)

- G. Legal professionals
 - H. Adoption and/or foster care professionals and agencies
 - I. Insurance (coverage, authorizations, and denials)
 - J. Surrogacy professionals and agencies
- XII. Coordinate fertility care with oncology treatment plan and care:
- A. Share patient information, treatment plan and needs (after HIPAA form completed)
 - B. Obtain information about fertility and other plans and needs from the patient and referral sources, including timing
 - C. Create a timeline for all fertility and pre-treatment care and share with patient and referrals
 - D. Schedule tentative treatment dates
 - E. Monitor status, distress, and needs
 - F. Ensure all fertility-related treatment and consults are completed and needs are met
 - G. Re-confirm treatment dates
 - H. Ensure patient and significant other are satisfied
 - I. Provide feedback to consultants and referral sources and obtain feedback for improvement
- XIII. Ensure documentation of informed consent including fertility-related risks
- XIV. Begin cancer treatment
- XV. Complete cancer treatment
- XVI. Educate patient about fertility-related post-treatment information:
- A. Sexuality
 - B. When can they try to conceive should they decide to?
 - C. When should they return to their reproductive endocrinologist/specialists?
 - D. How will they know if they are infertile?
 - E. What follow-up should they have related to fertility?
 - F. Survivorship-care plan
 - G. How soon can they have an embryo implanted?
- XVII. Assist patient with all remaining fertility-related interventions
- XVIII. Survivorship care:
- A. Provide survivorship care plan and treatment summary
 - B. Educate patient and family on follow-up care & wellness
 - C. Monitor for complications
 - D. Monitor and assist with meeting needs
 - E. Assist with returning back to a “normal life”
- XIX. Ongoing quality monitoring:
- A. Patient satisfaction

ONCOLOGY TEAM PROCESS FOR FERTILITY-RELATED NEEDS (*continued*)

- B. Outcomes
- C. Provider satisfaction
- D. Timeliness of steps
- E. All delayed cancer treatments
- F. Process
- G. Percentage of patients with fertility risks and needs assessed, referrals, etc.

NICOLE'S ONCOFERTILITY RISK ASSESSMENT TOOL

NAME: _____

MR# _____

DATE: _____

- _____ Cancer diagnosis
- _____ Age \leq 45 or $>$ 45 and desires future children
- _____ At risk diagnosis (often at risk due to treatment needs, not the disease itself) including:

- | | |
|--------------------------|-----------------------|
| NHL | Hodgkins Lymphoma |
| Uterine cancer | Cervical cancer |
| Ovarian cancer | Fallopian tube cancer |
| Testicular cancer | Germ cell tumors |
| Prostate cancer | GIST |
| Bladder cancer | Colorectal cancers |
| Thyroid cancer | Leukemia |
| Pancreatic cancer | Sarcoma |
| Myelodysplastic syndrome | Wilm's tumor |
| Myeloma | Brain cancers |
| Head and neck cancers | Lung cancer |
| Spinal cancer | Rhabdomyosarcoma |

_____ At-risk treatment planned including:

- Bone marrow or stem cell transplantation
- Hormonal therapy
- Treatments affecting the endocrine system
- Surgery affecting the reproductive organs, endocrine glands or organs, and/or reproductive nerves
- Radiation therapy with the potential to cause infertility:

Abdominal	Whole body
Spine	Pelvic
Brain (pituitary glands)	
- Chemotherapy with the potential to cause infertility:

Cytosan	Leukeran
Platinums	Procarbazine
Alkeran	Ifosfamide
Busulfan	Nitrosoureas
Avastin	Carboplatin
Ifosphamide	Taxanes
Sterptozocin	CCNU
Ironotecan	Interferon
Erbitux	Vincristine
Herceptin	Higher doses of many other chemo drugs
Tarceva	Newer agents with unknown fertility effects
Tamoxifen	TKI's (such as Gleevac & Sutent)
Nitrogen mustard	

NICOLE'S ONCOFERTILITY ASSESSMENT TOOL

SECTION I: Patient Fertility Desire (complete if patient has an "at risk" diagnosis and/or treatment)

Ages of present children: _____ Stepchildren: _____ Adopted children: _____

Desire future children? YES NO Comment: _____

SECTION 2: Fertility Assessment (complete if patient desires future children)

Estimated latest recommended treatment start date: _____

Is hormonal therapy contraindicated for any reason (females)? YES NO

Would they consider partially or non-genetically related children? YES NO

Would they consider someone else carrying their child? YES NO

Do they have insurance and fertility-related coverage? YES NO

What are their financial status & resources available for fertility needs?

What is their emotional status and present distress level (utilize NCCN Distress Management Tool) Score: _____ Comment: _____

What are their available support systems? _____

Are there any co-existing challenges or support needs? _____

Do they have any religious, cultural or other preferences and/or needs? YES NO

SECTION 3: Fertility Plan of Care and Monitoring

Preferred choice for reproductive risk reduction? _____

Reproductive and support referrals needed: _____

Pre-treatment fertility procedures required? YES NO

All referrals completed? YES NO

All pre-treatment fertility interventions completed? YES NO

Reproductive needs met? YES NO

Outcome: _____

Ready to begin cancer treatment? YES NO

NICOLE'S ONCOFERTILITY MINI-ASSESSMENT TOOL

DTA (Diagnosis, Treatment, and Age)

Patient has a cancer diagnosis and/or treatment planned that has the potential to cause fertility issues

Patient age ≤ 45 or > 45 and desires future children

IF BOTH ARE CHECKED, CONTINUE WITH FERTILITY PLANNING:

_____ Estimated time for staging work-up and/or until latest recommended treatment start date.

QUESTIONS

Present children's ages? _____

Desire for future children? _____

Preferred choice for reproductive risk reduction? _____

Reproductive and support referrals needed: _____

Completed? YES NO

Pre-treatment fertility procedures required? YES NO

Reproductive needs met? YES NO

Outcome: _____

SECTION 4: CHALLENGES

ONCOFERTILITY CHALLENGES

- Fast-growing cancers (time is of the essence for beginning treatments).
- Advanced cancers (too ill and concerns about parent's prognosis).
- Costs of fertility-related care.
- Lack of coverage by insurance: Only 15 states have any type of mandatory coverage for fertility treatments (AR, CA, CT, HI, IL, LA, MD, MA, MT, NJ, NY, OH, RI, TX, WV).
- No state mandates oncofertility preservation coverage.
- S.965, The Family Act Of 2011: Recently proposed legislation to assist oncology and other patients with fertility-related needs by providing tax breaks for fertility preservation procedures.
- Timing of fertility care so that cancer treatment is not delayed:
 - Timely referrals and counseling to assist the patient to make the best informed decisions relating to fertility.
 - Timely completion of all procedures required before beginning cancer treatment.
- Coordinating fertility and cancer care to meet all needs.
- Assuring all providers include fertility-related assessments, support, and care in their cancer treatment planning.
- Assisting patients and family with distress management during this time of additional stress.

SECTION 5: TOOLS

CHOOSING REPRODUCTIVE PHYSICIANS AND CENTERS

FOR HEALTHCARE PROVIDERS

If you are a healthcare provider who treats cancers in males or females of childbearing age, it is important for you to be familiar with and make referrals to local reproductive physicians and centers. Developing relationships with these physicians and centers will help your patients by improving communication and coordination of care, ensuring needs and timing are understood, and by providing better monitoring and follow-up.

Being prepared when you diagnose or have a childbearing-age cancer patient referred to you, will assist these patients to meet their fertility-related needs without affecting their cancer treatment outcome. Also, for patient's and family's it will help decrease the added emotional turmoil often caused by the idea of any possible fertility issues.

To prepare for referrals to patient reproductive specialist/endocrinologist and/or fertility center, the following steps are suggested (***please note: the author does not recommend, endorse, or assure the quality of any of the websites, providers, or agencies listed below. This information is provided only as a sample of Internet search results and information to help you get started. You may or may not find the information listed below helpful.***):

Search for the names and information about fertility facilities (centers and clinics), and reproductive endocrinologists/specialists in your locality:

❖ **Google, MSN, Yahoo, Bing and other search engines:**

<http://www.fertilehope.org/tool-bar/referral-guide.cfm>

<http://www.ucomparehealthcare.com> (find and compare providers, including fertility clinics)

<http://www.healthgrades.com>

http://www.sart.org/find_frm.html (gives information on member centers and their IVF success rates to compare to each other and the average)

<http://www.fertilitylifelines.com>

<https://www.asrm.org/euclid/detail.aspx?id=2328>

<http://www.resolve.org/>

❖ **Obtain, document, and review specific information for each provider and facility. Then compare all providers:**

- ✓ Location
- ✓ Board/facility certification
- ✓ Type of treatments performed/services provided
- ✓ Affiliations with national and local agencies and facilities
- ✓ Number of years experience/facility opens
- ✓ Provider's gender (may be important to some patients)
- ✓ Patient ratings and comments
- ✓ Number of each treatment type performed

❖ **Obtain, document, and review specific information for each provider and facility. Then compare all providers:**

- Success rate
- Diagnosis seen, specifically number/frequency of cancer patients
- Insurances accepted
- Total costs of treatments
- Availability of financial assistance including types and qualifications

- Appointment timeliness, availability and ease of scheduling
 - Friendliness of staff
 - Usual wait time for patients to see providers
 - Availability of a contact person for your office and patient
 - Willingness and methods of communication with referrers
 - Provision of emotional/psychosocial support
- ❖ **After you have obtained as much information as possible, delete any providers/facilities that you feel may not be the best choices for your patients.**
- ❖ **Take your list and call the remaining providers/facilities to:**
- Introduce yourself, your provider and facility, and your needs
 - Identify a contact person and best contact information
 - Obtain missing answers to any of the items above
 - Assess friendliness, ease of access, appointment availability, timeliness, and experience with cancer patients
 - Determine interest in working with you and your patients
 - Learn about any special support and services they provide
 - Ask how they feel they can best assist you and your patients
- ❖ **If possible, you may want to make an appointment to visit each provider at their place of business. At that time you can:**
- Assess the location and environment
 - Assess the friendliness
 - Talk with patients to get a feel for their satisfaction
 - Meet the providers and staff
 - Better understand their treatments and processes
 - Better convey your patients' needs
 - Develop a plan and process for your patients' referrals, care, and coordination
 - Obtain some of their patient- and staff-centered information for your facility
 - Review information obtained during your visits.
- ❖ **Review information obtained during your visits. Remove any referral sources that do not meet your standards, criteria or patient needs from your referral list.**
- ❖ **Develop a referral sheet including names, locations, fertility-related success rates, and information about all of the reproductive facilities and providers you prefer to refer to. Include:**
- Reproductive endocrinologists/ specialists (board certified)
 - Fertility clinics/centers
 - Adoption and foster care agencies and lawyers
 - Sperm banking facilities
 - Agencies/lawyers who work with surrogacy
 - <http://www.surrogacy.com/>
- ❖ **Some of the items to consider when choosing a physician or provider:**
- Experience with cancer patients and their care
 - Number of years at this location

- Previous locations/history
- Board certification
- Success rates
- Patient ratings and comments
- Individual attributes that are important to you (you can list these if that helps)
- Availability and timeliness of appointments
- Affiliations with local and national organizations and facilities
- Friendliness of provider and staff
- Recommendations from your physicians, staff, family, or friends
- Costs, insurance, and payment types accepted and financial support available
- Other patient support
- Willingness to work with and communicate with your multidisciplinary team

CHOOSING REPRODUCTIVE PHYSICIANS AND CENTERS

FOR PATIENTS

Some cancer treatments can cause actual or potential fertility-related issues. If you are of childbearing age, you should discuss your disease and treatment with your treating physician(s), including any possible fertility-related issues that may occur, as soon as possible after diagnosis and before any treatment is started. Many procedures to preserve fertility must be done prior to receiving any treatment.

You need to ensure that you and preferably your significant other understand all possible fertility-related issues. Do not hesitate to let your physician know what you are thinking and if you do not understand anything. Reproductive preservation is possible for most men and women. Procedures for reproductive preservation often require much time, especially in women.

Your healthcare provider may refer you to a reproductive endocrinologist/specialist, clinic/center, and/or support providers, staff, and agencies. These professionals should educate you about basic facts related to fertility options and provide you with information about local providers for each option you are interested in.

Increased financial, emotional, legal, ethical, and other issues are very common when dealing with fertility-related needs. These can cause increased emotional turmoil and depression in any patient. Please let your healthcare provider know how you are feeling and your concerns and needs at all times. There is lots of support to help you through this difficult time, but your healthcare team needs you to keep them up-to-date on these issues.

It is important for you to ensure that all referral appointments are made immediately. Your fertility-related decisions need to be included in your cancer plan of care as quickly as possible. Some of the items to consider when choosing a physician or provider are:

- ❖ Board or facility certification and affiliations
- ❖ Location, environment, and ease of access
- ❖ Procedures/options provided
- ❖ Experience and success rates:
 - Number of years doing these procedures
 - Number of cancer and non-cancer patients and procedures
 - Experience with cancer patients and their care
 - Number years at this location
 - Previous locations/history
- ❖ Patient ratings and comments
- ❖ Individual attributes that are important to you (you can list these if that helps)
- ❖ Availability and timeliness of appointments
- ❖ Affiliations with local and national organizations and facilities
- ❖ Friendliness of provider and staff

- ❖ Recommendations from your physicians, staff, family or friends
- ❖ Costs, insurance and payment types accepted, and financial support available
- ❖ Other patient support
- ❖ Willingness to work with and communicate with your multidisciplinary team

QUESTIONS PATIENTS MAY WANT TO ASK

- ❖ What are my fertility risks (short term and long term)?
- ❖ Have other patients received this treatment and had children after treatment without doing anything to preserve their fertility?
- ❖ Do I have alternate treatment choices with different fertility risks?
- ❖ Is there anything that can be done to protect my fertility during treatment?
- ❖ What are my choices to preserve my fertility?
- ❖ How will I know if I am or become infertile?
- ❖ If I have a period, does that mean I am fertile?
- ❖ If I remain or become fertile after my treatment, could I still have an early menopause or become infertile sooner than is usual?
- ❖ After my treatments are complete, how long should I wait until I try to create a pregnancy?
- ❖ What effects could my cancer treatment or genetics have on any future offspring?
- ❖ What are the risks my offspring will get cancer?
- ❖ Is there anything I can do to decrease the chances of this happening?
- ❖ Will any of these options interfere with my cancer treatment?
- ❖ How will my fertility preservation choices affect the timing of my cancer treatments?
- ❖ Will my fertility choice affect my treatment results or be harmful to me?
- ❖ Can you refer me to a fertility expert?
- ❖ Do you have any survivors or healthcare professionals that I can speak with to help support me with this aspect of my care?
- ❖ Are there any support groups for fertility issues you can recommend?
- ❖ Can you help me to get the information I need to make the best choice for myself?
- ❖ What are the costs of the different fertility options and does my insurance cover it?
- ❖ That happens if I change my mind after cancer treatment has begun?
- ❖ What financial assistance is available to me for fertility-related needs?

- ❖ Can patients with a history of cancer adopt or do they run into difficulty or have special requirements?
- ❖ What are the age limits for reproductive preservation?
- ❖ How long can sperm, eggs, embryo stay frozen?
- ❖ What are the chances of birth defects compared to non-cancer patients?
- ❖ What happens to my frozen eggs, sperm, embryo if I conceive naturally, can't pay the storage fee, or cannot use them for any reason?
- ❖ How long does the fertility procedure take?
- ❖ How safe are the different fertility procedures?
- ❖ What are the risks?
- ❖ Will I be at increased risk for multiple births with any of the preservations methods?

CANCER AND SURVIVORSHIP TREATMENT PLAN AND SUMMARY

Patient Name: _____ DOB: _____ Age: _____
Patient ID: _____
Radiation Oncologist: _____ Surgeon: _____
Medical Oncologist: _____ Other physician: _____
Other physician: _____ PCP: _____
Other physician: _____

GENERAL INFORMATION

Primary support: _____ Significant Other: _____
Best contact #: _____ Other contact #: _____
Allergies: _____

Medication and Food sensitivities: _____
Pre-treatment weight: _____ Normal weight: _____ Post-treatment weight: _____
Height: _____ Pre-treatment BSA: _____ Post-treatment BSA: _____

PERSONAL MEDICAL INFORMATION

Presenting symptoms: _____
Major co-morbidities: _____
Personal risk factors: _____
Tobacco use: _____ Never _____ Quit _____ Yes Amount: _____ #yrs: _____
_____ Cigarettes _____ Pipe _____ Cigars _____ Chewing
Smoking cessation provided? _____ Yes _____ No

CANCER INFORMATION

Cancer diagnosis: _____
Cancer location: _____ Metastasis: _____
First diagnosis date: _____ TNM: _____ Stage: _____
Recurrence Location: _____ Date: _____ TNM: _____ Stage: _____
Recurrence Location: _____ Date: _____ TNM: _____ Stage: _____
Tumor histology/grade: _____
Tumor markers/prognostic factors: _____
Family cancer history: _____

FERTILITY AND PSYCHOSOCIAL ASSESSMENTS AND NEEDS

Childbearing age? _____ Yes _____ No Discussed fertility? _____ Yes _____ No
Ages of children? _____ Treatment may cause fertility-related issues? _____ Yes _____ No
Fertility wishes: _____

Referral to:
___ Reproductive Specialist _____ Gynecologic Oncologist
___ Urologist _____ Genetics Counselor
___ Navigator _____ Case manager
___ Mental health counselor _____ Clergy
___ Rehab _____ Dietitian
_____ Palliative

Legal counselors
 Foster children professionals
 Legal professionals
 Fertile Care
 Hospice
 Other agency: _____ Other: _____
 Support /self-help group(s): _____

DIAGNOSTIC STUDIES

STUDY	DATE	RESULTS
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____

TREATMENT PLAN

Surgery: None Diagnostic Only Palliative Curative
 Date: _____ Surgical procedure: _____
 Date: _____ Surgical procedure: _____
 Date: _____ Surgical procedure: _____
 Radiation therapy: None Neo-adjuvant Adjuvant Palliative Curative
 Region: _____ Dose: _____ Date: _____
 Region: _____ Dose: _____ Date: _____
 Hormonal therapy: None Adjuvant Palliative Curative
 Hormone: _____ Date started: _____ Date completed: _____
 Chemotherapy: None Neo-adjuvant Adjuvant Palliative Curative
 Chemotherapy/drug therapy/biotherapy regimen: _____
 Clinical Trial: None Sponsor: _____ Trial # _____ Name: _____
 # Cycles: _____ Start date: _____ Completion date: _____

DRUG	ROUTE	DOSE	SCHEDULE	DOSE REDUCTION	# CYCLES
_____	_____	_____	_____	<input type="checkbox"/> Yes <input type="checkbox"/> % <input type="checkbox"/> No	_____
_____	_____	_____	_____	<input type="checkbox"/> Yes <input type="checkbox"/> % <input type="checkbox"/> No	_____
_____	_____	_____	_____	<input type="checkbox"/> Yes <input type="checkbox"/> % <input type="checkbox"/> No	_____
_____	_____	_____	_____	<input type="checkbox"/> Yes <input type="checkbox"/> % <input type="checkbox"/> No	_____
_____	_____	_____	_____	<input type="checkbox"/> Yes <input type="checkbox"/> % <input type="checkbox"/> No	_____
_____	_____	_____	_____	<input type="checkbox"/> Yes <input type="checkbox"/> % <input type="checkbox"/> No	_____
_____	_____	_____	_____	<input type="checkbox"/> Yes <input type="checkbox"/> % <input type="checkbox"/> No	_____

Reason for stopping treatment: Completion Toxicity Progression
 Response to treatment: Partial No response Complete Progression
 Not measurable Other response: _____
 Treatment-related hospitalizations: Yes No Toxicity: _____ Grade: _____
 Serious toxicities during treatment: Yes No Toxicity: _____ Grade: _____
 Toxicity at treatment completion: Yes No

Toxicity: _____ Grade: _____ Treatment/ follow-up: _____

Toxicity: _____ Grade: _____ Treatment/ follow-up: _____

Toxicity: _____ Grade: _____ Treatment/ follow-up: _____

FOLLOW-UP CARE	WHEN/FREQUENCY	COORDINATING PROVIDER
-----------------------	-----------------------	------------------------------

Oncology visits:

_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____

Lab tests:

_____	_____	_____
_____	_____	_____
_____	_____	_____

Imaging:

_____	_____	_____
_____	_____	_____
_____	_____	_____

POTENTIAL LATE EFFECTS: _____

Signs and symptoms to report: _____

NEEDS

- ___ Fertility specialist
- ___ Adoption professional
- ___ Smoking cessation
- ___ Rehab
- ___ Mental health counselor
- ___ Dietitian
- ___ Social worker
- ___ Financial counselor
- ___ Legal professional
- ___ Genetic counselor
- ___ Support/self-help group
- ___ Social services
- ___ Exercise program/group
- ___ ACS
- ___ Wellness/prevention program
- ___ other: _____

REFERRALS

- ___ Nutritional counseling
- ___ Genetic risk counseling
- ___ Financial counseling/support
- ___ Emotional support
- ___ Mental health support
- ___ Exercise & physical strength support
- ___ Smoking Cessation
- ___ Fertility preservation
- ___ Speech therapy
- ___ Occupational therapy
- ___ Prevention/wellness support
- ___ Relationship support
- ___ Legal advice
- ___ Employment/unemployment support
- ___ Insurance/disability support
- ___ other: _____

NICOLE'S ONCOFERTILITY PROGRAM ASSESSMENT TOOL

Does your oncology program have a:

- Complete and timely fertility risk assessment done on all patients?
- Complete and timely fertility-related needs assessment done on all patients of childbearing age who will receive a treatment that has the potential to cause fertility-related issues?
- Timely referral process for all patients with needs to:
 - Board-certified reproductive specialists
 - Certified reproduction center/clinic
 - Distress management
 - Genetic counseling
 - Support groups
 - Adoption professionals
 - Fertile Hope
 - Nurse navigator
 - Financial counseling
 - Spiritual counseling
 - Financial assistance
 - Other support services
- Process that includes cultural and ethical needs in your fertility assessment and planning?
- Verbal and written education about fertility-related items available to all patients at risk?
- Counseling to assist with decision making for all patients at risk?
- Process for coordination of fertility care, communication with other providers and referral sources, and monitoring?
- Written informed consent including fertility risks obtained prior to the start of any treatment?
- Process to ensure documentation of all of the above?
- Process and programs to ensure patients with oncofertility needs are assisted with post-treatment care, assessment of all outcomes, completion of follow-up care and all fertility-related needs are met?
- Survivorship program that includes fertility needs?
- Quality monitoring program that includes fertility-related items?
- Written process and/or policy to address oncofertility needs?

** "Timely" is completion as close to diagnosis and before start of treatment as possible.

SECTION 6: RESOURCES

RESOURCES

Access Project

www.accessproject.org
617-654-9911

A national resource center to assist with improving healthcare access and provides information on such items as medical debt.

Adopt US Kids

www.adoptuskids.org
888-200-4005

A national organization to assist with adoption and foster care of American children.

Adoption Tax Credit

www.irs.gov/
Government tax credit to assist with adoption expenses.

Advanced Reproductive Care, Inc. (ARC)

www.arcfertility.com
888-990-2727

A national network of reproductive specialists and centers offering various financing options and guarantees.

American Academy of Adoption Attorneys

www.adoptionattorneys.org
202-832-2222

Offers a list of adoption attorneys.

American Association of Tissue Banking (AATB)

www.aatb.org
703-827-9582

Accredits sperm banks and provides lists of those accredited.

American Cancer Society (ACS)

www.cancer.org
800-227-2345

A national organization providing funding, programs, and support for cancer patients and professionals.

American College of Surgeons Commission on Cancer (CoC)

www.facs.org
312-202-5085

A national consortium of professional organizations providing cancer guidelines, accreditation, research, data, quality monitoring, resources, and information.

American Fertility Association

www.theafa.org
888-917-3777

A national association providing information about infertility treatments, reproductive health, and family planning.

American Society for Reproductive Medicine (ASRM)

www.asrm.org
205-978-5000

A national association providing information about infertility treatments, reproductive health, and family planning.

American Society of Clinical Oncology (ASCO)

www.cancer.net

877-282-2552

Oncologist-approved cancer information from the American Society of Clinical Oncology (ASCO).

American Society of Hematology (ASH)

www.bloodthevitalconnection.org

202 -776-0544

Patient information developed by the American Society of Hematology to educate the public about the importance of healthy blood and raise awareness about the most common blood diseases, such as anemia, bleeding and clotting disorders, and blood cancers. The American Society of Hematology (ASH) is the world's largest professional society concerned with the causes and treatments of blood disorders. ASH provides information for patients and professionals about blood cancers.

American Surrogacy Center, Inc. (TASC)

www.surrogacy.com

A national organization providing information, news, support and resources about surrogacy.

Association of Community Cancer Centers (ACCC)

www.accc-cancer.org

301-984-1242

A national association of cancer professionals, facilities and cancer industry representatives providing cancer support, advocacy, education and resources to oncology professionals and patients.

Avon Foundation

www.avonfoundation.org

866-505-2866

A national organization raising funds and awareness for breast cancer.

Bethany Christian Services

www.bethany.org

800-238-4269

The largest U.S. adoption agency adopting U.S. and international children.

Bethany Richmond, VA Adoption Support Group

www.bethany.org

804-360-0466

One of many support groups for adoption sponsored by Bethany Christian Services

Bleed Purple

208-699-7249

A national organization for college students providing funding for scholarships and medical costs.

Blood and Marrow Transplant Center

www.bmtinfonet.org

888-597-7674

A national organization providing information to transplant patients, families and professionals.

Bone Marrow Foundation

www.bonemarrow.org

800-365-1336

A national organization for transplant patients providing funding, services, support and assistance.

BreastCancer.org

www.breastcancer.org

A national organization offering information, support, “Ask the expert” online support and chat rooms for patients with breast cancer.

Brenda Mehling Cancer Fund

www.bmcf.net

800-878-9184

A national organization providing funding, support, and information for 18- to 40-year-old cancer patients.

Cameron Siemers Foundation for Hope

www.cameronsiemers.org

877-509-9516

A national foundation providing funding to patients aged 18 - 28 with life-threatening illnesses.

Cancer Care Copayment Assistance Foundation

www.cancercarecopay.org

866-552-6729

A national organization that provides education, support and services along with funding for cancer patients who can not afford their co-payments.

Cancer Guide

www.cancerguide.org

A national organization that publishes a cancer guide with information and resources for patients and families facing cancer.

Cancer Hope Network

www.cancerhopenetwork.org

800-552-4366

A national organization that matches cancer patients to similar survivors for support, education and resources.

Cancer Information and Counseling Line

www.ucdenver.edu/academics/colleges/medicalschool/centers/cancercenter/CancerCare/LearnAboutCancer/Pages/CICL.aspx

800-525-3777

A free telephone counseling service for patients with cancer.

Cancer Legal Resource Center

<http://www.disabilityrightslegalcenter.org/about/cancerlegalresource.cfm>

866-843-2572

A national organization providing free legal advice to cancer patients, families, employers and healthcare providers.

Cancer Support Community

www.cancersupportcommunity.org/

1-888-793-9355 (Cancer Support Helpline)

In July 2009, The Wellness Community and Gilda’s Club Worldwide joined forces to become the Cancer Support Community. By helping to complete the cancer care plan, CSC optimizes patient care by providing essential, but often overlooked, services including support groups, counseling, education and healthy lifestyle programs. Today, CSC provides the highest quality emotional and social support through a network of more than 50 local affiliates, 100 satellite locations and online.

CancerCare

www.cancercare.org

800-813-4673

A national organization providing free cancer-patient counseling, support services, support groups, and

funding for basic needs, medications, co-pays and homecare.

Catholic Charities USA

www.catholiccharitiesusa.org

703-549-1390

A national organization providing people of all faiths with funding for a place to live and medical supplies and medication.

Chronic Disease Fund

www.cdfund.org

877-968-7233

A national organization providing medication assistance to underinsured patients with chronic diseases.

Courageous Choice

www.courageouschoice.com

877-480-8255

A national company helping with adoption.

Directory of Sperm Banks

www.spermbankdirectory.com

A website providing sperm banking information and a list of U.S. sperm banks.

EMD Serono

www.emdserono.com

800-283-8088A

A pharmaceutical company that produces GONAL-f and provides a co-payment savings card that assists with co-payments for each month's prescription of up to \$200 for those with prescription drug coverage that pays some of the cost of the drug.

Extend Fertility

www.extendfertility.com

800-841-7197

A financing program for fertility care at a network of clinics.

Eyes on the Prize

www.eyesontheprize.org

A website providing information on gynecologic cancers.

Ferring Pharmaceuticals

www.ferringfertility.com/heart

888-361-4542

Pharmaceutical company producing Bravelle®. Provides assistance for 1/4 of the vials free for Bravelle.

Fertile Dreams

www.fertiledreams.org

321-397-3868

A national organization that provides funding for IVF treatments.

Fertile Hope

www.fertilehope.org

888-994-4673 (HOPE)

A national volunteer organization affiliated with the Lance Armstrong Foundation providing fertility information, education, financial assistance for fertility preservation, and support to cancer patients at risk for infertility.

FERTLINE

MyOncofertility.org

888-708-3378 (FERT)

A national resource for patients and families providing resources and sponsored by the Oncofertility Consortium at Northwestern University (<http://oncofertility.northwestern.edu/>).

FORCE: Facing Our Risk of Cancer

www.facingourrisk.org

866-824-7475

A website providing woman at risk of developing hereditary ovarian and breast cancer and healthcare professionals with information about these two hereditary cancers and genetic testing.

Friends of Man

www.friendsofman.org

303-798-2342

A national organization providing low-income and disabled patients with funding for medications.

Healthgrades

www.healthgrades.com

Website offering comparative information on healthcare providers and facilities, including reproductive endocrinologists which also provides patient ratings for most.

HealthWell Foundation

www.healthwellfoundation.org

800-675-8416

A national organization providing funding for medical care and drug costs for patients unable to afford insurance.

I'm Too Young For This

www.imtooyoungforthis.org

A national organization providing information, social networks, blogs and support to young adults 15 –40 years old with cancer.

IntegraMed Fertility Network

www.integratedfertility.com

800-882—5483

A large network of fertility clinics and specialists offering low-interest financing and various programs to assist with the cost of fertility treatments.

International Council on Infertility Information Dissemination (INCIID)

www.inciid.org

703-379-9178

General oncofertility information, CHAT, support, and funding for IVF for those patients without insurance.

International Premature Ovarian Failure Association

www.pofsupport.org

703-913-4787

A national organization providing support and information to women who have premature ovarian failure.

Kristy Lasch Miracle Foundation

www.kristylasch.org

412-872-4125

A national foundation providing funding for basic needs, medical costs, and drug costs for low-income women under 30 years old.

Legal Information Network for Cancer (LINC)

www.cancerlinc.org

877-644-5642

A national organization providing assistance , navigation and support relating to such issues as insurance, legal problems, employment, and finances.

Life With Cancer

www.lifewithcancer.org

703-698-2526

A national organization providing education, support, wellness activities and services for cancer patients and healthcare professionals.

Live: On Kits (Cryogenic Laboratories)

www.liveonkit.com

800-466-2796

Provides kits for healthcare professionals to keep at the office & for patients to collect sperm & mail to the lab for storage with reduced rates.

MedlinePlus

www.nlm.nih.gov/medlineplus/cancers.html

MedlinePlus is the National Institutes of Health's website for patients and their families and friends. Produced by the National Library of Medicine, MedlinePlus offers reliable, up-to-date health information on diseases, conditions, and wellness issues.

Minnie Pearl Cancer Foundation

www.minniepearl.org

615- 467-1936

National organization providing support, information, hope, & clinical trials to patients and families with cancer.

National Adoption Foundation

www.nafadopt.org

A national organization providing information, support, and funding for Adoption.

National Cancer Institute (NCI)

www.cancer.gov

800-422-6237

A federal government agency providing information, support, funding, and research for cancer patients and professionals.

National Coalition for Cancer Survivorship

www.canceradvocacy.org

888-650-9127

A national advocacy group of cancer survivors.

National Collegiate Cancer Foundation

www.collegiatecancer.org

A national foundation providing services, blogs, funding and support to cancer patients aged 18-35.

National Comprehensive Cancer Network (NCCN)

www.nccn.org

888-229-6188

A national alliance of cancer centers providing professional practice guidelines and patient information about cancer and cancer treatments.

National Organization for Rare Disorders Co-Payment Assistance Program (NORD)

www.rarediseases.org

Hodgkins *Lymphoma*: 800-999-6673

Peripheral T-cell lymphoma 877-508-0411

Kidney and liver cancers: 866-828-8902

A national organization providing assistance with drug co-payments to patients with kidney and liver cancers, Hodgkins Lymphoma, and peripheral T-cell lymphoma.

National Transplant Assistance Fund & Catastrophic Injury Program

www.transplantfund.org

800-642-8399

A national organization providing cancer transplant patients with funding for medical costs.

NeedyMeds

www.needymeds.org

A website providing information on services to assist patients with obtaining medications including education, resources, discount medication cards, and funding.

Neuva Vida

www.nueva-vida.org

866-986-8432

A national organization providing support and services for Latino cancer patients.

Oncofertility Consortium at Northwestern University

<http://oncofertility.northwestern.edu>

312-503-3378

A national organization supported by the NCI to provide education, resources, tools, support, and fertility preservation program referral information.

OncoLink

www.oncolink.org

215-349-8895

A national support service provided by the University of Pennsylvania giving cancer patients and professionals information and support.

Oncology Nursing Society (ONS)

www.thecancerjourney.org

www.ons.org

877-369-5497

A national association of oncology nurses and professionals that provides, information, support, funding, certification and research for oncology nurses and professionals. ONS has a separate website for cancer patients (www.thecancerjourney.org).

Organon Fertility Patient Assistance Program

www.patientassistance.com

800-331-1002

A pharmaceutical company providing patient financial assistance for their fertility medications.

Partnership for Prescription Assistance

www.pparx.org

888-477-2669

A national organization providing qualified patients without prescription coverage funding for drugs.

Patient Access Network Foundation (PAN)

www.panfoundation.org

866-316-7263

A national organization providing funding assistance for insured patients who can't afford out-of-pocket costs.

Patient Advocate Foundation

www.patientadvocate.org
800-532-5274

A national organization providing advocacy and assistance to cancer patients having difficulties with finances, employment or healthcare coverage issues, and scholarships to survivors less than 25 years old.

Patient Resource Cancer Guide

www.PatientResource.net
816-333-3595

A national organization publishing cancer patient guides and providing information, advocacy, and support for cancer patients and healthcare providers.

Patient Services Incorporated

www.uneedpsi.org
800-366-7741

A national organization providing funding for medical and drug costs for patients unable to afford insurance fees for treatment.

People Living With Cancer

www.plwc.org
888-651-3038

The American Society of Clinical Oncology's (ASCO's) website and phone number to help patients and families make informed cancer-related choices.

Planet Cancer

www.planetcancer.org
512-452-9010

A national organization providing entertainment, support, information, advocacy, advice and fertility preservation information to young adult cancer patients.

R.A. Bloch Cancer Foundation

www.blochcancer.org
800-433-0464

A national organization providing a national cancer hotline, information, support, and guidance to assist patients and families fight cancer.

REACH Global

www.reachglobal.org
561-394-9100

An organization offering education and awareness about hereditary cancers.

Resolve

www.resolve.org
703-556-7172

A national infertility organization promoting reproductive health.

RxAssist

www.rxassist.org
401-729-3284

A national organization providing financial advice and assistance for patients who need help paying for drugs.

Sharing Hope Program For Men

www.fertilehope.org

866-965-7205

A program sponsored by Fertile Hope that helps male cancer patients with sperm banking by working with providers to decrease the costs to the patient and providing discount mail-in sperm collection kits to patients and providers.

Sharing Hope Program For Women

www.fertilitylifelines.com

866-538-7879

A program sponsored by Fertile Hope that helps female cancer patients to freeze egg and embryo by working with providers to decrease the costs to the patient.

Surviving and Moving Forward: the SAM Fund for Young Adults

www.thesamfund.org

866-439-9365

A national organization providing financial assistance, including fertility-related assistance for young adult cancer patients.

Survivorship A—Z

www.survivorshipatoz.org/cancer

A website providing support, resources, social, legal, and financial information and support for life-changing illnesses, including cancer.

Susan G. Komen for the Cure

www.komen.org

877-465-6636

A national organization providing cancer funding, research, advocacy, assistance with health disparities, and patient and professional information.

The Center for Cancer Support and Education

www.centerforcancer.org

781-648-0312

A national organization providing cancer and wellness support and services to patients, families and healthcare providers.

The Lance Armstrong Foundation (Livestrong)

www.livestrong.org

512-236-8820

A national organization providing cancer information, tools, advocacy, funding and research.

The Leukemia & Lymphoma Society

National Information Resource Center

www.LLS.org

800-955-4572

A national volunteer health organization dedicated to funding blood cancer research, education and patient support services, and providing low-income leukemia and lymphoma patients with funding for medical and drug costs.

The Ulman Cancer Fund for Young Adults

www.ulmanfund.org

A national organization providing education, resources, services, navigation, funding, advocacy, support groups, and general support for young adult cancer patients.

Together Rx Access

www.TogetherRXAccess.com

800-250-2839

National organization of 10 pharmaceutical companies providing free prescription savings cards.

U Compare Healthcare

www.ucomparehealthcare.com

Website offering comparative information on healthcare providers and facilities, including reproductive endocrinologists and fertility clinics.

United Way

www.liveunited.org

703-836-7112

National organization providing funding to agencies and information about local charities and programs.

Women 4 Women

www.women-4-women.org

502-561-8060

A national organization that provides health and wellness support, information and funding for women.

Women's Cancer Network

www.wcn.org

312.578.1439

A national organization providing information, support and awareness for women with gynecologic cancers.

Young Survival Coalition

www.youngsurvival.org

A national organization providing support for women under 40 years old with breast cancer.

Zichron Shlome Refuah Fund

www.zsrf.org

718-438-9255

A national fund providing assistance with medical costs for patients with chronic illnesses.

LOCAL FERTILITY RESOURCES
(complete these pages)

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