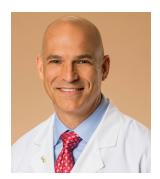


Request this Ebook (#)

Introduction

Miami Cancer Institute ADOLESCENT AND YOUNG ADULT (AYA) Cancer Survival Guide Part 1:Introduction to Oncofertility ADOLESCENT & YOUNG ADULT (AYA) **ONCOFERTILITY SURVIVAL GUIDE** (https://vimeo.com /173719996)

We suggest that you bring your ebook of this guide to meetings with Healthcare Professionals. You can get the ebook from the "Request this EBook" button above and will then be able to use it on your phone, tablet, computer, or print it out on paper.



Troy Gatcliffe, M.D.

surgical techniques including robotic with rapid recovery times allowing his surgery for all complex gynecologic and patients to return to their lives as quickly as women's reproductive cancer diagnoses as possible. well as chemotherapy expertise. He is a former Assistant Professor at the University Dr. Gatcliffe, "Fertility preservation is of School/Parkland Hospital in Dallas. He then often compromise your ability to have a went on to sub-specialty fellowship training child. So therefore, it's important to in gynecologic oncology. Dr. Gatcliffe consider fertility preservation at the time of formulates individualized treatment plans a cancer diagnosis." specifically tailored to each patient's needs.

Dr. Troy Gatcliffe offers minimally invasive His focus is on excellent surgical outcomes

Texas Southwestern Medical important because cancer treatment can

certified in Obstetrics and Gynecology and assistant professor of reproductive subspecialty the Endocrinology and Infertility, and is a of the Fertility Preservation Program at the Fellow of the American Congress of University of Colorado in Denver. I would Obstetricians and Gynecologists. At the describe myself as a physician/scientist. I time this Oncofertility eBook was created, see patients in a clinical setting, and I do a she was an Assistant Professor and lot of research looking closely at clinical Women's Reproductive Health Research outcomes." Scholar in the Division of Reproductive Endocrinology and Infertility at the University of Colorado.

Dr. Laxmi Kondapalli, MD MSCE is board "My name is Laxmi Kondapalli. I'm an Reproductive endocrinology and infertility and the director



Laxmi Kondapalli, MD MSCE

The Oncofertility Consortium

Dr. Kondapalli's research interests center on fertility Learn about the FIRST Registry preservation, ovarian response to medical therapies, and assisted reproduction outcomes. Her efforts in these fields are featured on the Oncofertility Consortium (http://oncofertility.northwestern.edu/) 's website.

What is the Oncofertility Consortium?



/177789700)

(http://oncofertility.northwestern.edu/resources/first-registry)



The Oncofertility Consortium is a group of basic scientists, clinical providers, and social scientists who are all committed to advancing the science in considering fertility preservation for cancer patients. The professionals involved in the Oncofertility Consortium seek to address a wide spectrum of issues, including:

- Mechanisms underlying the fertility threat of life-preserving cancer drugs.
- Methods for cryopreservation (freezing), storing and growing ovarian and gonadal tissue.
- In vitro follicle growth and oocyte maturation using a three-dimensional environment.
- Communication barriers between cancer patients and health care providers.
- Ethical and legal concerns regarding the use of fertility preservation technologies in cancer patients.

ONCOFERTILITY CONSORTIUM RESEARCH PROJECTS

- Novel Method for Cryopreservation and Recovery of Female Follicles (http://oncofertility.northwestern.edu/research/follicle-cryopreservation)
- Measures of Fertility in Young Cancer Patient (http://oncofertility.northwestern.edu/research/fertility-measures-after-cancer)
- Bioengineering Primate Follicles: From Immature Eggs to Live Births (http://oncofertility.northwestern.edu/research/bioengineering-primate-follicles)
- See more research projects... (http://oncofertility.northwestern.edu/research-projects)

Dr. Kondapalli, "I contribute to the Oncofertility Consortium by being a member of the National Physicians Cooperative (NPC), which is a conglomeration of institutions across the country that are committed to advancing the science in fertility preservation techniques and offering these methods to their patients."



- Learn about the NPC (http://oncofertility.northwestern.edu /resources/national-physicians-cooperative)

THE MOST IMPORTANT THING I'D SAY TO A NEWLY DIAGNOSED AYA CANCER PATIENT IS ...

Dr. Kondapalli, "When I see a newly diagnosed AYA cancer patient and meet with their family, one of the most important things that I want to get across in our first meeting is that they have choices, and many of these choices were not available even five years ago. The menu of choices and opportunities for fertility preservation, or for assessing a patient's fertility status and new fertility treatments that can be offered to them - even in the /177789009) survivorship period - has vastly increased and expanded over the last five years."



What is Oncofertility?



Oncofertility is an interdisciplinary field at the intersection of oncology and reproductive medicine that expands fertility options for cancer survivors.

(Source: http://oncofertility.northwestern.edu/ (http://oncofertility.northwestern.edu/))



/177832266)

Dr. Kondapalli, "My role as an oncofertility specialist is to think, one, about the fertility issues, but also to expand that to consider the whole host of long-term reproductive side effects that may result as an outcome of cancer treatment."



/177832794)

int for Pediactric and AYA Patients Be

HOW IMPORTANT IS IT TO HAVE **ONCOFERTILITY TRAINING?**

Dr. Kondapalli, "I think it's very important for providers who work with AYA patients to be aware of some of the oncofertility issues that their patients may face. Fertility is consistently considered to be one of the most important quality of life issues for many patients, particularly for AYA patients who are of reproductive age."

Fertility preservation is particularly important for AYA patients because some of the cancer treatments that they may receive may actually impair their ability to have children in the future. This consideration is of particular consequence for female cancer patients - natural fertility declines over time for women, even outside of a cancer diagnosis. And so, when you add to a natural decline in fertility these treatments that may actually accelerate that decline, then by the time a patient has completed their cancer treatment their fertility might be substantially reduced, or they may even enter into infertility and not be able to have biological children in the future. Therefore, being able to offer fertility preservation options before they go through their cancer treatment really optimizes the options that a patient has after their treatment.



To Learn More:



from The Ethics Committee of the American Society for **Reproductive Medicine**

How Cancer Treatments impact Fertility

FOR BOYS AND MEN

Chemotherapy kills rapidly dividing cells in the body. This targets cancer cells, but kills healthy ones as well. Some chemotherapy agents are more harmful than others, and a male's age, the type of chemotherapy, and the drug dosage can influence the fertility risk.

Radiation kills rapidly dividing cells in and around a target area. Radiation directed at or near the testicles can genetically damage a man's sperm or cause infertility. Radiation to the hormone-producing areas of the brain or the pituitary gland may also cause infertility by disrupting normal hormone production. However, radiation to other areas of the body will not affect fertility.

Bone Marrow/Stem Cell Transplants involve high doses of chemotherapy and sometimes, full body radiation. The combination of treatments and their intensity put the patient at high risk of infertility.



FOR GIRLS AND WOMEN

Chemotherapy kills rapidly dividing cells in the body, targeting cancer cells and healthy ones as well, which can damage or destroy eggs. Age, type of chemotherapy, and the medication dosage can affect risk.

Radiation kills rapidly dividing cells in and around a target area. This can damage the reproductive system when directed at or near the pelvic area. Radiation to the hormone-producing areas of the brain or the pituitary gland may also cause infertility by disrupting normal hormone production. Direction of the radiation and the dose impacts the risk level.

Bone Marrow/Stem Cell Transplants involve high doses of chemotherapy and sometimes, full body radiation. This poses a high infertility risk by damaging ovarian and uterine reproductive systems due to the amount and intensity of treatment. In some cases, the damage may

Medication targets certain cancer proteins or other eliminate future chances of carrying a pregnancy. cancer characteristics. While the protein-targeting medications may affect fertility, other medications appear to have no effect on male fertility.

Surgery removes cancer-ridden parts of the body. Infertility can result when parts of the reproductive system - such as one or both testicles - are removed.

Fertility and Men with Cancer (http://www.cancer.org/acs/groups/cid/documents /webcontent/acspc-041228-pdf.pdf)

Medication targets certain cancer proteins, which can affect fertility. Medications that target other cancer characteristics appear to have no effect on female fertility, but can impact pregnancy.

Surgery removes reproductive systems if they are found to contain gynecologic cancers, such as ovarian cancer, uterine cancer, or cervical cancer. Removing the ovaries, uterus, cervix or other reproductive organs can cause infertility and can eliminate chances of carrying a pregnancy.

Fertility and Women with Cancer

(http://www.cancer.org/acs/groups/cid/documents /webcontent/acspc-041244-pdf.pdf)





How has Fertility Preservation Changed in the Last 3-5 Years

Over the past few years, we have had great advances in technology, and we are able to offer even newer fertility preservation options for patients. For example, up until last year, oocyte cryopreservation, or what is traditionally known as egg banking, was considered experimental, however, given the advances in the way that we freeze eggs, the pregnancy rates have drastically improved, and the experimental label was taken off of egg banking - it's (177839753) now considered standard of care. In June 2015, the first birth was recorded from transplanted ovarian tissue. There have been successful pregnancies for women with grafts of ovarian tissue, but this is the first for ovarian tissue removed before the woman started menstruating. These are examples of how our delivery of fertility preservation has changed even in the last three to five years, and research in this area is active and ongoing.

How has fertility preservation changed in the last 3-5 years?

(https://vimeo.com

To Learn More:

- The First Birth from Transplanted Tissue (http://www.popsci.com/woman-transplanted-ovarian-tissue-gives-birthbaby)

INFORMATION ON EGG BANKING:

- Egg Freezing Changing Fertility Treatments (http://www.cnn.com/2012/10/22/health/frozen-egg-banks/)

- Egg Freezing Puts the Biological Clock on Hold (http://www.npr.org/2011/05/31/136363039/egg-freezing-puts-thebiological-clock-on-hold)

- Egg Freezing: A New Frontier In Fertility

(http://health.usnews.com/health-news/health-wellness/articles/2013/07 /11/egg-freezing-a-new-frontier-in-fertility)

What Fertility Options are Available?



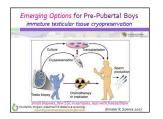


/177832323)

For post-pubertal males (men who have gone through puberty), the mainstay fertility preservation method is sperm cryopreservation, or sperm banking. Pre-pubertal boys (boys who have not gone through puberty) are not yet producing sperm, so research is focused on using testicular tissue. We are studying the best ways to freeze and store that tissue and how to use it in the future to restore the boy's fertility.

To Learn More:

- Fertility and Men With Cancer (http://www.cancer.org/treatment /treatmentsandsideeffects/physicalsideeffects/sexualsideeffectsinmen /fertilityandmenwithcancer/fertilityandmenwithcancertoc)





For post-pubertal girls, we can freeze eggs, we can freeze embryos, and an experimental procedure that we can now offer is ovarian tissue transplantation. Pre-pubertal girls (girls who have not begun menstruating) do not produce mature eggs, so they are candidates for ovarian tissue cryopreservation (freezing). This ovarian tissue can be transplanted back after cancer treatment. Though still experimental, this procedure looks very hopeful.

To Learn More:

- Fertility and Women With Cancer (http://www.cancer.org/treatment/treatmentsandsideeffects/physicalsideeffects/sexualsideeffectsinwomen/fertilityandwomenwithcancer /fertilityandwomenwithcancercoc)





Dr. Kondapalli, "When I counsel AYA patients about maximizing their future fertility potential, my first approach is to discuss and review with them the fertility preservation options that are available even before they undergo their cancer treatment. In addition, I also share with them that there are many different ways of making a family - sometimes it is using your own eggs and sperm, and sometimes there are opportunities to use donor occytes or donor sperm or even adoption as alternative options for parenthood."



Diagnosis

The <u>Diagnosis</u> Phase

In the diagnosis phase, pediatric and AYA patients and Fertility Preservation at a Glance their parents may have some time pressure to make decisions - momentous decisions about future fertility and their reproductive choices. Oftentimes, they may have an aggressive disease, and our oncology colleagues may feel motivated to initiate chemotherapy or radiation quickly, and patients are left having to make very big decisions in a very short period of time.

Dr. Kondapalli, "In my role as an oncofertility specialist, I do my best to provide patients with information without overwhelming them, and the most important thing that I try to convey is that they have options. They're in a situation where many of the things that they're facing are out of their control, but they do have a very specific decision that they can make and that they have a right to make, and that's about their fertility."

- Fertility Preservation Options Before Cancer Treatment (https://arm.coloradowomenshealth.com/services/cancer/preservation/)

- · Before undergoing cancer treatment, men and women can preserve their reproductive potential through cryopreservation: men may freeze a sample of their sperm, and women can preserve their eggs or create and freeze embryos
- · Women may also surgically reposition their ovaries to avoid radiation, depending on the area of the body being targeted
- There are also fertility preservation options for children who will be going through cancer treatments.

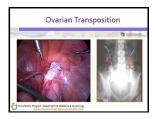


Different Cancers and Oncofertility Consideration

Dr. Kondapalli, "Depending on the type of cancer a patient has, their fertility preservation options and the way that I approach them from an oncofertility standpoint can be quite different. For example, patients who have a large abdominal or pelvic tumor may require pelvic radiation. With these patients, I would discuss a procedure called ovarian transposition, where we can actually surgically suspend the ovaries to try and remove them outside of the radiation field."



/177840400)



"For a patient who has a hematologic cancer such as leukemia or lymphoma, the options that I discuss with them might be a little bit different. For example, ovarian tissue freezing is an option that is available for leukemia or lymphoma patients, even in a pediatric population. However, the successful pregnancies that have occurred from using frozen tissue have resulted from transplantation. Unfortunately, patients who have bloodborne malignancies really aren't candidates for transplantation. The last thing that we would want is for an AYA patient to overcome their cancer and then potentially reintroduce those malignant cells through the transplanted tissue."

Having a Fertility Conversation With Your Doctor

Dr. Kondapalli, "Conversations about reproductive issues and fertility concerns are often challenging when discussing them with a newly diagnosed patient and their family. One of the ways that I approach it is that I often ask if I can speak with the patient by him or herself so that we can have a private conversation. Then, patients, especially the young adolescents, will oftentimes have incredibly smart questions that they feel free to ask. I /177840946) discuss with them any concerns that they have - not just about fertility, but also about safe sex practices, about contraception, and about reproductive health. Patients will often feel comfortable speaking with me privately about those issues and the other things that are on their minds, where they may not feel as comfortable discussing those issues in front of their families. At the end of that conversation, I always regroup with the family as a whole and summarize the points that we discussed during the



consultation. However, patients do know that they have a confidential relationship with me as their provider."

- 5 Questions to Ask Your Child's Doctor Before Starting

Treatment (http://www.myoncofertility.org/documents /5_questions_ask_your_childs_doctor/)

- 5 Questions to Ask Your Partner's Doctor Before Starting

Treatment (http://www.myoncofertility.org/documents /5_questions_ask_your_partners_doctor/)

Goals to consider during the Diagnosis Phase: 1. Think about what your desires are for children in the future

2. Ask questions about the impact of your cancer treatment on long term fertility

3. Talk to a support network about fertility preservation



/177840948)

Dr. Kondapalli, "The kinds of goals that I would ask my patients to consider, especially in the diagnosis phase, are, one, to really consider what their desires are for children in the future; two, to seek as much information and ask as many questions as they can about the specific impact of their particular cancer treatment on long-term fertility; and, three, to make time to talk with friends and family and loved ones or partners who are their support network to communally come to a decision about fertility preservation and how to proceed with fertility preservation."

NOTE: The general Health Goals at the end of each phase are suggestions only. Develop specific goals in collaboration with your patient care team.

Click here to learn more about setting achievable health goals. (https://www.mybridge4life.com/node/7623)

Treatment

The Treatment Phase

During the treatment phase, consideration of oncofertility issues can be quite difficult. The best opportunity for patients to optimize their fertility preservation options is to pursue some sort of banking prior to starting chemotherapy or radiation.

Dr. Kondapalli, "The way that I approach patients who are currently in treatment and desire fertility preservation is not through thinking about the cancer subtype itself, but about what treatment they've received. One example would be a patient who receives cyclophosphamide, an alkylating chemotherapeutic agent that is widely used in a variety of different cancers. Cyclophosphamide can have an impact on the eggs that remain within the ovary. So, regardless of the type of cancer a patient has, a woman who has been exposed to cyclophosphamide may not respond to fertility medications once she's initiated that cancer therapy."



To Learn More:

- More information on Cyclophosphamide and its Effects (https://medlineplus.gov/druginfo/meds/a682080.html)



Counseling Patients About Pregnancy

/177841656)

Dr. Kondapalli, "One of the challenges that I face is counseling patients about the interval of time to delay pregnancy or consider beginning pregnancy after they finish their cancer therapy. Unfortunately, we don't have a lot of data about what the optimal time period is. Oftentimes, oncologists and reproductive medicine specialists like myself advise patients to wait 12 to 24 months after finishing therapy before thinking about pregnancy. One of the challenges, though, is that we don't have specific data to support that recommendation."





/177842237)

NOTE: The general Health Goals at the end of each phase are suggestions only. Develop specific goals in collaboration with your patient care team.

Click here to learn more about setting achievable health goals. (http://www.mybridge4life.com/node/7623)



Healing



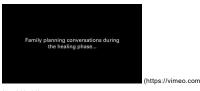
After a patient has completed their therapy and is in the healing phase, from a reproductive standpoint they may still be facing some of the long-term side effects of their cancer therapy.

Dr. Kondapalli, "For many of my female young adolescent and young adult patients, they may stop getting their period during chemotherapy or radiation, and their period (177843017) may not come back for 6 to 12 months after their therapy. During the time when their periods have not started again they don't feel like a normal patient or a normal peer, and so they may have undue or unnecessary concern or anxiety about the fact that their body hasn't gotten back to normal.'

- Perception of Fertility Affects Quality of Life in Young, Female Cancer Survivors (http://www.coloradocancerblogs.org /perception-of-fertility-affects-quality-of-life-in-young-female-cancersurvivors/)

- Life After Cancer Treatment & Ways to Manage Physical Changes (http://www.cancer.gov/publications/patient-education /facing-forward)

Family Planning Conversations During the Healing Pha



/177842708)

Dr. Kondapalli, "Patients do come see me after they've completed their therapy so that we can regroup and talk about their reproductive concerns and their reproductive goals now that they're in the survivorship period. For example, we may readdress issues about fertility, and whether there are fertility treatments that we can offer to a survivor after they've overcome their cancer. I also discuss with them contraceptive concerns and contraceptive options, particularly since many oncologists advise patients to postpone pregnancy for about one to two years after completion of their therapy. That can be a challenging conversation to have because some of the contraceptive options may not be appropriate for a particular AYA patient. In particular, patients who have had different types of chemotherapy may not be appropriate candidates for certain types of contraceptive methods."

The Healing Phase

(https://vimeo.com

- Pregnancy & Children After Cancer (http://www.cancer.net /survivorship/life-after-cancer/having-baby-after-cancer-pregnancy) - Managing Pregnancy After a Cancer Diagnosis (http://oncofertility.northwestern.edu/blog/2013/02/managing-pregnancyafter-cancer-diagnosis)



Dr. Kondapalli, "Health goals that I would like patients to consider in the healing phase are, one, to really think about what their family goals are for the future and to seek information about fertility options if that's something that they'd like to pursue; two, is to meet with either their primary care physician or another provider and discuss family planning contraceptive options as well; and three is to really consider their sexual wellbeing, as well."

NOTE: The general Health Goals at the end of each phase are suggestions only. Develop specific goals in collaboration with your patient care team.



/177843309)

Click here to learn more about setting achievable health goals. (http://www.mybridge4life.com/node/7623)

Wellbeing



In the wellbeing phase, I would advise patients to consider identifying what their current fertility status is.

Dr. Kondapalli, "They can get information from their primary care physician or seek a fertility specialist to find out and assess what long-term impact their cancer treatment may have had on their fertility. If a patient has (177844894) pursued fertility preservation methods prior to their cancer therapy, the wellbeing phase may be an opportunity for them to actually utilize some of their banked eggs or embryos or sperm. In that stage, I would advise my female patients to follow up with their obstetrician, and for some of them, I recommend seeking the advice and consultation of a maternal fetal medicine doctor. These are doctors who specialize in high-risk obstetrics and really specialize in thinking about how patients who have a whole host of medical illnesses might still have a safe pregnancy.



Wellbeing Phase for Different Cancer Subtype



/177846017)

Dr. Kondapalli, "Some of my young Hodgkin's/lymphoma patients have been exposed to certain types of chemotherapy that can have toxic effects either on their lungs or even on their heart. During pregnancy, the blood volume is increased by fifty percent because so much of that blood volume and nutrients are there to support the growing pregnancy. And for my young patients who have been exposed to Adriamycin, there are baseline tests that we can do to assess their cardiac function even before considering pregnancy so that we can be sure to monitor them and be aware of any complications that they may be at risk for during their pregnancy. In addition, for my patients who have had pelvic radiation, one thing that I discuss with them is that radiation exposure can predispose them to certain pregnancy complications, such as pre-term birth or having a small baby, and those are pregnancy complications that patients need to be aware of before even embarking on their fertility journey."

WILL THE LIVES OF AYA PATIENTS EVER BE THE SAME AGAIN?

Dr. Kondapalli, "For AYA patients in the wellbeing phase, they may have trouble resuming their normal lives because they've undergone a tremendous experience. My goal as a fertility specialist is to provide them fertility options to normalize their lives as much as possible and enable them to achieve their goal of having a family if that is what they want."



Dr. Kondapalli, "During the wellbeing phase, I would advise patients to maintain certain health goals. One is to maintain a healthy lifestyle. So eating well, exercising, and making sure that they are able to enjoy doing their normal activities. Two, I would advise patients to find out their fertility status if pregnancy and future fertility are of concern to them. And three would be to seek out information - there are phenomenal web resources, they can discuss next steps with their primary care physician, and they can also seek the expertise of a fertility specialist. I would also advise patients to join support groups or get involved in their community.



/177844890)

NOTE: The general Health Goals at the end of each phase are suggestions only. Develop specific goals in collaboration with your patient care team.

There are phenomenal peer-to-peer programs where they Click here to learn more about setting achievable health can also shepherd another young person who's newly goals. (http://www.mybridge4life.com/node/7623) diagnosed and has been through or will go through many of the same experiences that they have. It's a great opportunity for those young people to provide that same type of support to future patients."

- National Cancer Institute Organizations & Resources for AYA Patients (http://www.cancer.gov/types/aya)

Looking Toward the Future

Looking Toward the Future

Dr. Kondapalli, "There are promising future fertility preservation options that are coming down the pike. For example, we are now able to isolate individual eggs from the outer layer of the ovary, which is called the cortex, and there are opportunities to actually grow those immature eggs completely in an in vitro or lab system. That is a technology that has advanced over the last three to five years, and great advancements are continuing to happen in this area. In addition, on the male side, there are new technologies to actually biopsy or remove portions of the testes in prepubertal young males, and then that tissue can be frozen and then transplanted back into the testes, and mature human sperm can be created. Both of these treatment options are still experimental, and there are institutions that are making great headway, and I do believe that over the next few years these options are going to be a reality."



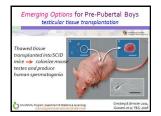
/177848177)



MOST EXCITING WORK ...

Dr. Kondapalli, "The most exciting work that I am aware of is the emergence of science and research into the longterm side effects of cancer therapy. While we've made great strides in providing new technology for fertility preservation, one of the questions that still remains unanswered is what the long-term impact is of many of the chemotherapies and radiation therapies that we are utilizing now. There are new studies that are looking at some of the longterm side effects, not only on fertility and reproductive function, but also on the impact on hormonal production and how that may predispose young patients to early diabetes or early heart disease, as well as the impact on bone health. Researchers are really thinking from a fertility standpoint about how the area of hormonal production can impact other important body systems."

- So Others May Benefit: Young Cancer Patients and Survivors Take Part in Oncofertility Research (http://www.cancer.gov/about-cancer/treatment/research/young-adultsfertility-research)



MY DREAM IN 10 YEARS ...

Dr. Kondapalli, "The most exciting work that I am aware of is the emergence of science and research into the longterm side effects of cancer therapy. While we've made great strides in providing new technology for fertility preservation, one of the questions that still remains unanswered is what the long-term impact is of many of the



/177848178)

(https://vimeo.com

Closing



Dr. Kondapalli, "As an oncofertility specialist, the most important thing to communicate to a newly diagnosed patient is that they have options available to them, and these options are choices we can work on together to make really informed decisions about their reproductive health in the future; and that there are experts and professionals available to help them and shepherd them through a very difficult process."



(https://vimeo.com/174882845)