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Newsletter - FSP(I)

November 2021 (Volume 4)

A very good day to all of you reading this E-Newsletter. This is our 4th & final e-newsletter for this year from the Fertility Preservation Society of India (FPS(I)).

We hope you had good a Dasara

We are on the eve of Diwali and we wish you a fantastic, wonderful and safe festival and also a very very happy, prosperous and healthy New Year. I do hope you all go green this year have a green Diwali.

In the e-newsletters this year, we have been bringing you compilations from various articles, published in renowned journals throughout the world. We have covered the various aspects of fertility preservation in men and women, recommendations, guidelines and we are concluding with the ethics and morality of egg freezing both for medical and non-medical reasons as well as doctor's perspectives on the same.

In the coming year, we - will be changing the format of our e-newsletter, where we will be requesting the members from the various zones to contribute presentations of interesting cases or talk about their experiences with fertility preservation. This will help in sharing our experiences and will give us a lot of insight on the trends in cancers in our population and the acceptance of fertility preservation in the same.

We are getting ready for our two-day Annual Virtual Conference on 27th & 28th of November 2021. This is organized by the Tamil Nadu Chapter of FPS(I) under the able leadership of Dr. P.M. Gopinath and his team. We would like you all to register for this conference in large numbers and enrich your knowledge. We will be giving you the registration link as well as the various details of the programme at the end of this e-newsletter.

In our last edition, we brought to you about "Fertility Preservation in Childhood, Adolescent, and Young Adult Cancer". This time we are bringing to you:

- A synopsis of the "Fertility Preservation in Young Women with Cancer – Clinicians perspectives (Andrea Covelli, et al. JAMA Network Open | Oncology: November 6, 2019)".
- Ethics of social egg freezing and fertility preservation for nonmedical reasons - Excerpts from a review by Prof. Karey A Harwood, which we think is very relevant in the current scenario (Medicolegal and Bioethics 2015:5 59–67).

FIRST ARTICLE

CLINICIANS' PERSPECTIVES ON BARRIERS TO DISCUSSING INFERTILITY AND FERTILITY PRESERVATION WITH YOUNG WOMEN WITH CANCER

By

Andrea Covelli, MD, PhD; Marcia Facey, PhD; Erin Kennedy, MD, PhD; Christine Brezden-Masley, MD, PhD; Abha A. Gupta, MD, MSc; Ellen Greenblatt, MDCM; Nancy N. Baxter, MD,

Published in : JAMA Network Open | Oncology : November 6, 2019

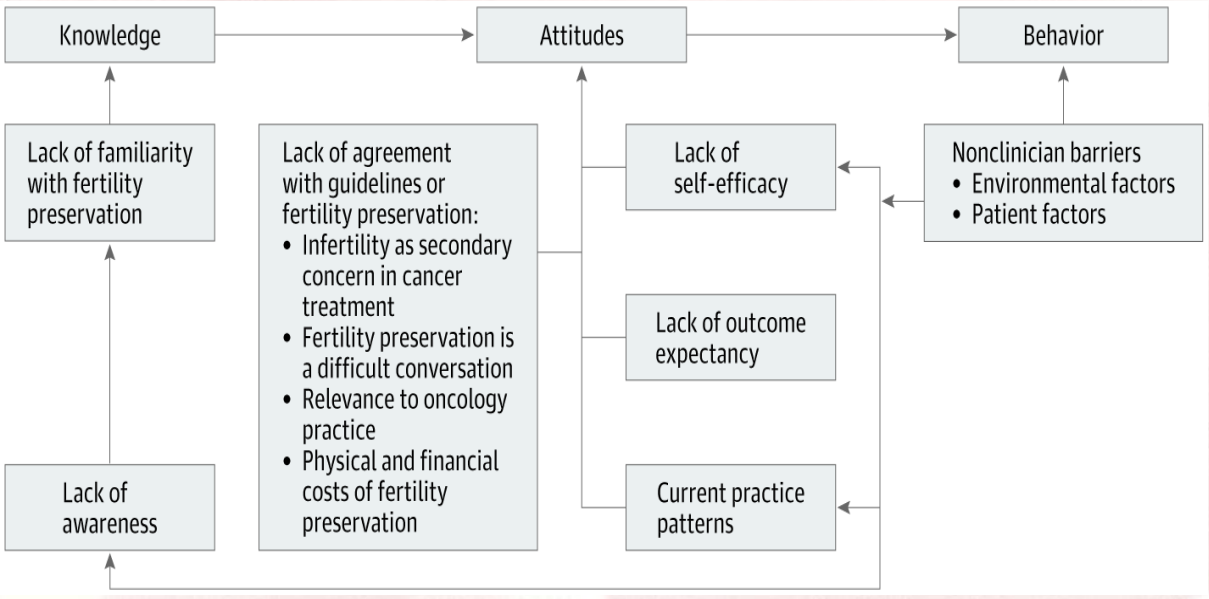
Context: ***American Society of Clinical Oncology guidelines recommend discussion of potential infertility in young women with diagnosed with cancer but nearly 50% of them with cancer remain uninformed.***

The key question was **"what do clinicians perceive as barriers to engaging in fertility preservation discussions with young women with cancer?"**

A qualitative study was conducted among clinicians of cancer centres and community hospitals in 5 Canadian provinces, 5 practice areas, and 12 practice sites in 2014. Interview included 22 clinicians (8 medical oncologists, 4 surgical oncologists, 4 fertility specialists, 3 haematology and oncology specialists, and 3 nurse practitioners or clinician nurse specialists) who regularly treat young women with cancer who might need fertility preservation.

The findings were drawn from the first phase of a 3-phase study aimed at understanding fertility preservation in the context of cancer treatment by exploring the experiences of clinicians and female and male patient with cancer.

Modified Cabana Framework as Applied to the Findings



Taken From: Andrea Covell et al. Clinicians' Perspectives on Barriers to Discussing Infertility and Fertility Preservation With Young Women With Cancer.

JAMA Netw Open. 2019;2(11):e1914511. doi:10.1001/jamanetworkopen.2019.14511

Main outcome measure was Clinician's experiences and perspectives regarding factors responsible for their non-adherence to American Society of Clinical Oncology guidelines of discussing fertility preservation with patients.

RESULTS:

CLINICIAN KNOWLEDGE – LACK OF FAMILIARITY WITH FERTILITY PRESERVATION

Most participants said that they were aware of ASCO guidelines, but many admitted to a general among clinicians. Clinician 6, a medical oncologist, stated that oncologists were "truly poorly informed" and "remarkably ignorant about it." Clinician 7 said clinicians were only aware of fertility "in a sort of theoretical way." Clinician 18, a surgeon, said, "I have slightly more information [about fertility preservation] than a layperson." Participants variously admitted that clinicians were insufficiently knowledgeable about the risks, did not understand fertility preservation processes, had no sense of timelines for how the processes work, had little or no understanding of the available technologies or their costs, and did not know where or how to refer patients for consultations.

CLINICIAN ATTITUDE: - LACK OF SELF EFFICACY

Clinicians' lack of self-efficacy or the absence of confidence in their ability to appropriately and correctly engage in fertility preservation discussions with patients was partly a function of their

- lack of preparation; and
- perceptions of fertility preservation discussions as difficult and complex, as "really sensitive," "awkward," "tricky," "a can of worms," as clinician 7 described them, and as a "Pandora's Box".

Some surgeons expressed fears about being asked fertility-related questions because they "might answer them wrong".

LACK OF AGREEMENT WITH ASCO GUIDELINES AND FERTILITY PRESERVATION

Participants all agreed in principle with the ASCO guidelines, but they also voiced skepticism about fertility preservation and its relevance to their practices. Clinicians conceived infertility as nonfatal and therefore fertility preservation was secondary to cancer treatments.

RELEVANCE TO ONCOLOGY PRACTICE

Cancer was diagnosed after surgery sometimes and there was no opportunity to discuss and it was irrelevant in advanced stages with high mortality

PHYSICAL AND FINANCIAL COSTS OF FERTILITY PRESERVATION

Physical recovery may be delayed due to hormones used for fertility preservation. This added financial costs and stress. Some of the clinicians were of this opinion – "You're paying for an unknown return on investment… with most fertility centers, they're going to underwrite everything and not make any promises that anything's going to work out, right, and then you've expensed x thousands of dollars, you've delayed your care and treatment for a hope."

LACK OF OUTCOME EXPECTANCY

Clinicians' lack of outcome expectancy or the expectation or belief that engaging patients in fertility preservation discussions and referring them for preservation would not result in successful outcomes was suggested in their negative assessments of and reservations about fertility preservation evidence. Others pointed to the experimental nature of technologies, such as ovarian tissue preservation, and in vitro maturation.

The other factors cited are environmental factors of lack of infrastructure and facility and Patient factors such as geographic location and non-accessibility and no immediate necessity for having a pregnancy or baby

CURRENT PRACTICE PATTERNS

Although clinicians acknowledged that infertility was important and a significant adverse effect of cancer treatments, they also asserted that most clinicians were on board with fertility preservation in theory only; in other words, if they do not have responsibility for it.

Moreover, clinicians admitted that some oncology clinicians tended to focus only on the part of the body they are treating and did not see preservation as their responsibility.

CONCLUSION

Medical education regarding fertility preservation has not kept pace with fertility preservation technologies, which has left many clinicians uninformed about them.

Awareness of the ASCO guidelines has not translated into increased discussions about fertility preservation

RECOMMENDATION:

Creating resource tools (eg, posters, decision aids) for clinicians and patients to improve levels of fertility-related discussions.

Implementation of active knowledge translation strategies, such as inter-professional collaborations and communications, identification of local opinion leaders or champions, society endorsements, continuing medical education opportunities, dedicated fertility preservation programs, referral networks, and decision support systems, might keep to increase patient engagement by clinicians regarding fertility preservation methods.

ACKNOWLEDGEMENT

The first article is a compilation from "CLINICIANS' PERSPECTIVES ON BARRIERS TO DISCUSSING INFERTILITY AND FERTILITY PRESERVATION WITH YOUNG WOMEN WITH CANCER" Andrea Covelli, MD, PhD; Marcia Facey, PhD; Erin Kennedy,MD, PhD; Christine Brezden-Masley, MD, PhD; Abha A. Gupta, MD, MSc; Ellen Greenblatt, MDCM; Nancy N. Baxter,MD, PhD, *JAMA Network Open.* 2019;2(11):e1914511. doi:10.1001/jamanetworkopen.2019.14511

SECOND ARTICLE

We are bringing to you a summary of an article written by Dr. Karey A Harwoo in Medicolegal and Bioethics 2015:5 59–67 issue, addressing – "On the ethics of social egg freezing and fertility preservation for nonmedical reasons". He has reviewed this paper and we are sharing some of the excerpts of the same. You can read more about it @ https://www.dovepress.com/getfile.php?fileID=26602, published in August 2015 issue.

ON THE ETHICS OF SOCIAL EGG FREEZING AND FERTILITY PRESERVATION FOR NONMEDICAL REASONS-REVIEW ARTICLE

By

Karey A Harwood, Department of Philosophy and Religious Studies, North Carolina State University, Raleigh, NC, USA. Published in: Medicolegal and Bioethics. 2015:5

CONTEXT

The practice of egg freezing reached a new milestone in 2012, when the American Society for Reproductive Medicine removed its designation as "experimental". Studies of the safety and efficacy of egg freezing led the ASRM to recommend egg freezing for patients facing infertility due to gonadotoxic therapies, but prompted continued caution against egg freezing when undertaken for nonmedical reasons. The European Society of Human Reproduction and Embryology has more explicitly supported nonmedical egg freezing.

Nonmedical egg freezing is also referred to as "elective" or "social" egg freezing.

Oocyte freezing is now considered as a standard procedure like embryo freezing and it is no longer "experimental". It is advised for women of reproductive age with cancer but the indication of social egg freezing is not yet accepted and it is a debatable issue.

THE ETHICAL DEBATE

- Age-related fertility decline should count as a medical justification for fertility preservation
- Honoring the principle of autonomy
- Limits of individual autonomy when a medical technology is used for an elective reason.
- ***The "perfect" biological time for reproducing is thought to be between the ages of 25 and 35 years for women and this may not align with a woman's preferences***
- Egg freezing should be viewed as the ***alternative to using a donor egg*** when age related infertility is later encountered

CONCERNS

- Leads to commercial exploitation,
- Women will be pressurised to use egg freezing
- The overall impact of egg freezing on sex inequality and professional norms will emerge
- Commercial egg banks (CEBs) also make frozen donor eggs widely available

ARGUMENTS FAVOURING EGG FREEZING

- Success rates appeared to be significantly lower for women who freeze their eggs over the age of 38 years.
- The timing of fertilization and implantation can be controlled when the woman is ready for motherhood.
- A woman at risk for premature menopause (or for premature ovarian failure due to a number of genetic conditions) might be motivated to freeze her eggs.
- A woman who discovers she has a BRCA mutation might choose to undergo a prophylactic oophorectomy to decrease her risk of cancer. Egg retrieval and egg freezing in advance of the removal of her ovaries can be a means of preserving potential future fertility.
- Lack of a suitable partner, sometimes combined with concern about advancing age
- A desire to postpone childbearing while completing one's education or while focusing on career advancement.
- A desire to postpone childbearing until women feel they have reached a sufficient level of maturity, financial stability, or emotional support
- Egg freezing can play a role in enabling childbearing for gays, lesbians, and unmarried persons
- 30-year-old who has the foresight to freeze her eggs before experiencing any sign of infertility is to be considered as undertaking "preventive medicine"
- If biological difference is the root of inequality between men and women, then egg freezing can help level the playing field by lengthening the time during which a woman can become pregnant.
- Egg freezing for nonmedical reasons promotes sex equality. Among its many benefits, egg freezing promotes equal participation in employment, equal participation in educational endeavors, and a more equal amount of time to find a partner (Savulescu , Imogen & Goold)

COSTS

- Retrieval and freezing-US$10,000–$15,000 per cycle.
- Safe storage- $900 per year
- Parents undertake Payment
- In the USA, health insurance does not pay for "social" egg freezing

FINANCIAL ASSISTANCE FOR FERTILITY PRESERVATION FOR CANCER

1. LIVESTRONG Fertility foundation
2. Heartbeat Programme by-Ferring Pharmaceuticals --"select fertility medications at no cost"
3. Recently, Facebook and Apple made headlines by offering to give female employees $20,000 of egg-freezing benefits

- UK offers coverage for infertility treatment through its National Health Service, including egg freezing **only for medical reasons**
- The Israel National Bioethics Council (INBC) recommended permitting egg freezing for disease as well as **age-related fertility decline as early as 2009**

POLICIES

Currently, the average reported age of women who freeze their eggs is 38 years, but that may be too late as the quality of eggs is already in decline and success of achieving a pregnancy is low.

The ideal age for egg freezing is reportedly 30–35 years

Egg freezing for women aged over 40 years becomes the ultimate snake oil: an expensive procedure that is not much more than an empty promise.

RECOMMENDATIONS:

The Centres for Disease Control and Prevention could begin compiling data on egg freezing as part of its annual assisted reproductive technology report

The European Society of Human Reproduction and Embryology: Fertility specialists should leave the option to the women themselves to make their own informed decisions.

ACKNOWLEDGEMENT

The second article is a compilation from "ON THE ETHICS OF SOCIAL EGG FREEZING AND FERTILITY PRESERVATION FOR NONMEDICAL REASONS" Karey A Harwood. Medicolegal and Bioethics 2015:5.

For further reading one can download the article @ https://www.dovepress.com/getfile.php?fileID=26602.

FERTIPROTECT ANNUAL CONFERENCE 2021 (VIRTUAL)

NOVEMBER 27-28, 2021

The 8th annual conference, Fertiprotect 2021, organized by Tamil Nadu Chapter of FPS(I) aims to fulfill these core objectives by reaching out to a wide global audience and bring together the pioneers in the field of onco-fertility. This academic event will be conducted as a two-day virtual conference on November 27-28th 2021.

This is a web based conference, amidst the pandemic, will ensure safety while giving the delegates, a comfortable visual experience. The sessions have been specially selected to bridge gaps between awareness and clinical know-how and finally summing it all up with safe laboratory techniques that spell success. Clear cut take home messages and the ability to embark on a safe onco-fertility practice is our end goal.

Eminent speakers from all over the world will be delivering the talks on various topics.

PROGRAMME

DAY 1 (27/11/2021)		
TIME	**TOPIC**	**SPEAKER**
1.00pm to 1.40 pm	**Inauguration** Prayer song Welcome address President's address Address by President ASFP Address by ISFP President Vote of thanks	 Mrs. Sreedevi Karthick Mrs.Padma Rekha Jirghe Dr.P.M. GOPINATH Dr Nalini Kaul - Mahajan Dr Marie-Madeleine Dolmans Dr Priya Selvaraj
1.40 pm -2.10pm	**Invited oration** - FP in children with non-iatrogenic POI	Prof Dror Meirow
2.10 PM TO 2.30 PM	**SPECIAL GUEST LECTURE** Fertility Preservation in Borderline Ovarian Tumors	Dr Nalini Kaul - Mahajan
SESSION I - MALE FERTILITY PRESERVATION		
2.30 PM TO 3.00 PM	**SESSION IA** **ORATION - I** Research & Developments in Male fertility preservation	Dr Ranjith Ramasamy
3.00 PM TO 3.15 PM	**SESSION I B** Male Fertility Preservation -Indian Scenario	Dr SS Vasan
3.15 PM TO 3.30 PM	Counselling Young Adolescent and Prepubertal Male	Dr Poonam Nayar
3.30 PM TO 3.45 PM	Consents And Legal Issues In Male Fertility Preservation	Dr Hithesh Bhat
3.45 PM TO 4.00 PM	Basics of Bioprinting with 3D implantable scaffolds (ovaries)	Dr. Shantanu Patil
4.00 PM TO 4.15 PM	Follow Up Of Male Fertility Preservation	Dr Tanya Bakshi Rohatgi

SESSION II - HEMATOLOGICAL MALIGNANCIES		
4.15PM TO 4.45 pm	**SESSION II A** **ORATION -II** Oocyte Vitrification For Fertility Preservation: How Many Eggs Do We Need?	Dr. Javier Domingo
4.45 pm TO 5.05 pm	**SESSION II B** **Keynote 1** Fertility Protective Chemotherapy In Children	Dr Ponni Sivaprakasam
5.05pm TO 5.25 pm	**Keynote 2** Preventive Measures In Radiotherapy In Children	Dr.Sanjay Chandrasekar
SESSION II C		
5.25 pm TO 5.40 pm	Psychological Aspects Of Children With Malignancies	Dr Surendram Veeraiah
5.40 pm TO 5.55 pm	Counselling The Parents Of Children With Malignancy	Dr Smitha Ruckmani
5.55 pm TO 6.10 pm	Gamete collection issues in prepubertal children	Dr Priya Kannan
6.10 pm TO 6.25 pm	How To Screen For Malignancy In Stored Tissue	Dr Devika Gunasheela
SESSION III - FERTILITY PRESERVATION IN BREAST MALIGNANCIES		
6.25PM TO 6.55PM	**SESSION III A** **ORATION -III** An Overview Of Breast Reconstruction After Breast Cancer Surgery	Dr. Venkat Ramakrishnan
6.55PM TO 7.15PM	**SESSION III B** **Keynote 1** Breast cancer screening And Recommendations for Indian women	Dr. Vani Parmar
7.15PM TO 7.35PM	**Keynote 2** Breast cancer in Young women	Dr. Bhawna Sirohi
7.35PM TO 7.50PM	**SESSION III C** An Overview Of Oncoplastic Breast Surgery	Dr. Nita Nair
7.50PM TO 8.05PM	Hereditary Breast and ovarian cancers	Dr. Bhargavi Ilangovan
8.05PM TO 8.20PM	Fertility preservation in breast cancer patients	Dr.G Buvaneswari
8.20PM TO 8.40PM	Challenges In Fertility Preservation In Patients With Breast Cancer.	Dr. Ramesh Raja
8.40PM TO 9.00 PM	**ORATION -IV** Current updates on fertility preservation on young adolescent	Dr Denis Vaughan
DAY 2 (28/11/2021)		
1.30 PM to 2.00 PM	General Body Meeting	
2.00pm to 2.30pm	Stimulation protocols in fertility preservation	Dr. Madhuri Patil
SESSION IV - Embryological Aspects of FP		
2.30 pm to 3.00pm	**SESSION IV A** **ORATION -V** The Lab Journey Of Fertility Preservation- Then And Now - Have We Improved Outcomes?	Dr.Ethiraj Balaji Prasath

3.00 pm to 3.20pm	**SESSION IV B** **Keynote 1** Ensuring Follicle Survival In Frozen Ovarian Tissue And Optimizing Transplantation Outcomes	Dr. Stine Gry kristensen
3.20 pm to 3.40 pm	**Keynote 2** Critical parameters to achieve high survival with oocyte vitrification	Dr. Debra Gook S
3.40 pm to 3.55 pm	**SESSION IV C** Sperm Vitrification And Outcomes Compared To Slow Freeze	Dr. Pankaj Talwar
3.55 pm to 4.10 pm	Ovarian Tissue Cryopreservation – Laboratory Protocols	Dr. Christiani Amorim
4.10 pm to 4.25 pm	Does IVM Have A Role In Improving Available Numbers Of Embryos?	Dr. Varsha Samson Roy
4.25 pm to 4.40 pm	Fertility Outcomes in Cancer Survivors after IVF	Dr Richa Jagtap
SESSION V – Fertility Preservation in Young and Adolescents Patient		
4.40pm to 5.10pm	**SESSION V- A** **ORATION –VI** Fertility Preservation In Patients With Endometriosis	Dr Juan Velasco
5.10 to 5.40 pm	**ORATION -VII** Setting Up A Fertility Preservation Service	Dr. Abha Maheswari
5.40pm to 6.00pm	**SESSION V- B** **Keynote 1** Oocyte Cryopreservation For Nonmalignant Conditions	Dr.Hemashree Rajesh
6.00 pm to 6.15 pm	**SESSION V- C** What Adolescents And Young Adults Need To Know After Cancer Diagnosis?	Dr.Vinotha Thomas
6.15 pm to 6.30 pm	Gynaec Malignancies And Fertility Preservation	Dr.Kavitha Sukumar
6.30pm to 6.45 pm	Precautions during OPU In Fertility Preservation	Dr Abha Majumdar
6.45 pm to 7.00 pm	Counselling For Obstetrics And Future Fertility Risks In Young Cancer Survivors	Dr.Padmarekha Jirge
7.00 pm	**VALEDICTORY**	

We are offering this academic visual extravaganza completely free of charge. Only registration details will be required without a fee. If you are an aspiring or an established reproductive specialist, embryologist or gynecologist who has a keen interest in oncofertility, becoming a member should be your first objective towards updating, networking and enhancing your clinical and lab skills. The registration link is as follows :

https://virtualconnect.chkdin.com/login/16612488

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Membership Request Form

Fertility Preservation Society (India)
Registered Office & Secretariat:
D-59, Defence Colony, New Delhi - 110024

Name : _____

Qualification : _____

Designation : _____

Address :

Workplace : _____

Residence : _____

Address to be used for correspondence ☐ Workplace ☐ Residence

Telephone No. : Workplace: _____ Residence : _____

Mobile : _____ Email address : _____

Amount : _____

Cash / Cheque / Demand Draft No / Online Transfer Details :

Date : _____ Bank : _____

Signature : _____ Name : _____

Please make cheque . Draft in favour of
FERTILITY PRESERVATION SOCIETY
A/C No-914020019747855 (Axis Bank)
Please attach two recent passport size photographs

Mailing address
SECRETARIAT
Fertility Preservation Society (India)
D-59, Defence Colony, New Delhi – 110024
Website : www.fpsind.com
Email Address : rebecca@fpsind.com/helpdesk@fpsind.com/
fertilitypreservationsociety@gmail.com

We do hope you have enjoyed reading this compilation and found it useful. We encourage all of you to become members of FPS(I) as cancer is a now a household name and there are not many families who do not have or have heard of someone near or dear who have been afflicted with cancer. So we are going to be confronted with these problems increasingly and we being part of the society will help you to widen your knowledge horizon and also have a healthy discussion when in doubt as to the way forward in any solution…….. So do join us.

The membership form can be downloaded by clicking the following link.

Membership Form - ***http://www.FPS(I)nd.com/membership.php***

We would also like to encourage you to talk about you experience dealing with cancer patients in the form of case reports, case series and review articles and submit them to TOGF on the below link.

https://www.tofjonline.org/

Thank you for spending your valuable time reading this newsletter.

Last but not least, some food for thought:

"At the end of the day all you need is
HOPE & STRENGTH.
hope that it will get better
&
strength to hold on until it does"

So let us pray that we can offer some hope and make a difference in the lives of our cancer survivors

- FPS(I) Team

The Onco Fertility Journal

Offical publication of the Fertility Preservation Society

Scope of the Journal

The Onco Fertility Journal covers technical and clinical studies related to health, ethical and social issues in the field of Fertility preservation, Protection for cancer patients, women with severe endometriosis, Haematological and Immunological Disease. Articles with clinical interest and implications will be given preference.

Indexing Information

The Journal is registered with the following abstracting partners: Baiciu Scholar, CNKI (China National Knowledge Infrastructure), EBSCO Publishing's Electronic Databases, Ex Libris – Primo Central, Google Scholar, Hinari, Infotrieve, Netherlands ISSN center , ProQuest, TdNet, Wanfang Data

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