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A View from the Past Into our Collective Future: The Oncofertility Consortium Vision Statement

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A View from the Past Into our Collective Future: The Oncofertility Consortium Vision Statement

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Abstract:	<p>Purpose: Today, male and female adult and pediatric cancer patients, individuals transitioning between gender identities, and other individuals facing health extending but fertility limiting treatments can look forward to a fertile future. This is, in part, due to the work of members associated with the Oncofertility Consortium. Methods: The Oncofertility Consortium is an international, interdisciplinary initiative originally designed to explore the urgent unmet need associated with the reproductive future of cancer survivors. As the strategies for fertility management were invented, developed or applied, the individuals for who the program offered hope, similarly expanded. As a community of practice, Consortium participants share information in an open and rapid manner to address the complex health care and quality-of-life issues of cancer, transgender and other patients. To ensure that the organization remains contemporary to the needs of the community, the field designed a fully inclusive mechanism for strategic planning and here present the findings of this process. Results: This interprofessional network of medical specialists, scientists, and scholars in the law, medical ethics, religious studies and other disciplines associated with human interventions, explore the relationships between health, disease, survivorship, treatment, gender and reproductive longevity. Conclusion: The goals are to continually integrate the best science in the service of the needs of patients and build a community of care that is ready for the challenges of the field in the future.</p>
Response to Reviewers:	<p>Hello, we have revised our manuscript to include information on the European efforts outside of the OC.</p> <p>Thank you so much for your consideration.</p>

A View from the Past Into our Collective Future:
The Oncofertility Consortium Vision Statement

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July 1, 2020

David F. Albertini, PhD
Journal of Assisted Reproduction and Genetics
Editor-in-Chief

Dear Dr. Albertini,

Enclosed please find a manuscript entitled: "A View from the Past Into our Collective Future: The Oncofertility Consortium Vision Statement" that was developed by a collaborative group of global leaders in the area of oncofertility that we are submitting to the *Journal for Assisted Reproduction and Genetics* for your consideration.

In this manuscript we provide a brief history of oncofertility and provide direction for the field in the next ten years and beyond. This paper outlines the strategic goals and collective priorities of our oncofertility leadership and represents thoughts and future directions from our global community of oncofertility professionals.

None of the authors have financial disclosures and all of the authors have contributed substantially to this manuscript and approved its submission.

We respectfully suggest the following individuals as reviewers:

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Given the commitment of JARG to covering issues relevant reproductive health specialists worldwide, we believe this article will be of interest to the journal's readership. We look forward to your timely and favorable consideration of our work. Please do not hesitate to contact me if you have any questions or require additional information.

Sincerely,

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A View from the Past Into our Collective Future:
The Oncofertility Consortium Vision Statement

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Abstract

Purpose: Today, male and female adult and pediatric cancer patients, individuals transitioning between gender identities, and other individuals facing health extending but fertility limiting treatments can look forward to a fertile future. This is, in part, due to the work of members associated with the Oncofertility Consortium. *Methods:* The Oncofertility Consortium is an international, interdisciplinary initiative originally designed to explore the urgent unmet need associated with the reproductive future of cancer survivors. As the strategies for fertility management were invented, developed or applied, the individuals for who the program offered hope, similarly expanded. As a community of practice, Consortium participants share information in an open and rapid manner to addresses the complex health care and quality-of-life issues of cancer, transgender and other patients. To ensure that the organization remains contemporary to the needs of the community, the field designed a fully inclusive mechanism for strategic planning and here present the findings of this process. *Results:* This interprofessional network of medical specialists, scientists, and scholars in the law, medical ethics, religious studies and other disciplines associated with human interventions, explore the relationships between health, disease, survivorship, treatment, gender and reproductive longevity. *Conclusion:* The goals are to continually integrate the best science in the service of the needs of patients and build a community of care that is ready for the challenges of the field in the future.

1 Introduction

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4 Since the term ‘oncofertility’ and the relatively small oncofertility consortium of research scientists and
5 allied clinicians was organized in 2006, the group has become a robust and productive community from
6 over 45 countries around the globe (1-12). Since its inception, there have been a number of scientific
7 advances, including sustained *in vitro* follicle growth in alginate hydrogels (with the achievement of live
8 birth in mice, the first metaphase II (MII) egg in human, and the first non-human primate embryo),
9 development of the first cryoprotectant
10 specifically designed for and tested on
11 non-human primate and human ovarian
12 tissue, and the first ovarian
13 bioprosthesis (with techniques
14 involving decellularization, 3-D printing,
15 and reconstituted tissue papers) and
16 autografting of cryopreserved
17 prepubertal rhesus testis to produce
18 sperm and offspring (1, 13-27). These
19 scientific discoveries have been
20 matched by clinical advances that
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Figure 1: Purple pins represent locations of the Oncofertility Professional Engagement Network (OPEN) member centers. OPEN consists of individuals or groups from 45 countries and are linked by basic and clinical research a high-level of shared protocols and experiences. Member leverage work done in affiliated centers to accelerate their formation and services offered. (1-7)

35
36 include expanding options to pediatric and adolescent and young adult populations and patients with
37 differences in sex development, transgender and gender-diverse populations, as well as the
38 development of optimized ovarian procurement and testicular biopsy sampling and documented
39 methods for tissue transport (12, 28-36). Prepubertal testicular tissue cryopreservation is now also
40 performed in a number of centers worldwide, although this technique still remain experimental (25, 37).
41 In addition, there has been a growing emphasis on the full range of patient, parent, and partner
42 considerations including questions of legal ramifications and religious and ethical concerns (28, 38-41).
43 Based on the extraordinary work from groups around the world, ovarian tissue cryopreservation (OTC)
44 is no longer designated experimental (42). Moreover, ten US states require insurers to cover fertility
45 preservation costs for cancer patients or any patients receiving gonadotoxic therapy. This change in
46 the US is being mirrored in other countries and the leverage created by having a globally linked
47 organization (Figure 1) allows for more rapid uptake of necessary procedures (4, 43, 44). In just over
48 ten years, the collective progress made by the broad and engaged stakeholders in this field has been
49 outstanding. Now, as we approach the next ten years of the field, our communal goal is to ensure that
50 similar progress will be made in the future and by this coordinated effort, patients' needs will continue
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1 to be prioritized and met. As such, in early November 2019, the Oncofertility Consortium introduced a
2 multi-month, multi-stakeholder discussion regarding the future of the field of oncofertility. Herein we
3 present the thoughts and conclusions of our engaged, global leadership.
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8 Beginning in 2007, a broadly attended annual meeting has been held that created context, community,
9 and critical mass for collaboration and increased momentum during a time frame when scientists and
10 clinicians were working largely on their own (45, 46). The meeting has served as a platform for
11 international collaboration and support in oncofertility program implementation. It has also served as a
12 training ground and mentorship for residents, fellows, early stage scientists, nurses and allied health
13 professionals from around the globe, as well as a pipeline for high school students (47-49). The 2019
14 meeting had record attendance, illustrating the interest to gather and collaborate as a field. However,
15 convening is only one dimension of our work. The community is thinking strategically about how to
16 facilitate this meeting and how to grow the field even more broadly to advance the science and its
17 clinical application for our patients. As such, all stakeholders were invited to participate in a strategic
18 planning process called *Vision 2030: A Roadmap for Oncofertility Research and Practices*.
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30 The strategic planning process began with an anonymized 'appreciative inquiry' survey sent to a group
31 of over 3000 oncofertility stakeholders in December 2019. Appreciative inquiry is a strengths-based,
32 positive approach to leadership development and organizational change (50). Survey recipients
33 included OC leadership, previous conference attendees, advocates, and other individuals who have all
34 interacted with the OC in some way since 2007. The ultimate goal of the short, four question
35 appreciative inquiry was to identify the OC's core strengths and to explore how to leverage these
36 strengths to redesign the organization to make it more effective and sustainable. Suggestions were
37 analyzed, and a summary document was provided to the members of the leadership group for their
38 review. Emerging themes included: diversity, collaboration, networking, the annual meeting, leadership,
39 team science, sharing, and bringing together stakeholders. (See **Figure 2** for complete appreciative
40 inquiry survey.)
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52 Following the appreciative inquiry, on February 7, 2020, a diverse group of leaders from the OC
53 participated in a day-long meeting, to review the appreciative inquiry responses and discuss the
54 resulting next steps for the field. This leadership group included clinicians and basic scientists, nurses,
55 patient navigators, social scientists, and advocates, from the USA and abroad. Disciplines represented
56 included oncology, urology, reproductive endocrinology and infertility, psychology, and specialists in
57 pediatric, adolescent and adult populations. Many of the participants serve as chairs of their respective
58 Oncofertility Professional Education Network (OPEN) subcommittees (1) and have exhibited exemplary
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1 leadership and engagement in the field. Together this group discussed the current state of the field, the
2 priorities for the next ten years, and the strategies to be used to ensure that the field is moving forward
3 in a productive and collaborative manner. The group was also tasked with developing the OC's vision,
4 mission, and value statements (**Figure 3**), and to identify four strategic goals for the field which were:
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8 1. Improve Access 2. Advance Research 3. Educate and 4. Collaborate.
9

10 11 Improve Access

12 Both nationally and internationally,
13 oncofertility professionals face common
14 challenges. These include a lack of
15 awareness among providers and
16 patients, a lack of appropriate
17 communication between provider and the
18 patient-parent dyad (particularly for
19 pediatric providers), a lack of referral
20 pathways with no standardized models of
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31 care, cultural and religious constraints, uncertainties regarding exact risks of cancer-related infertility,
32 insufficient funds to support oncofertility programs, a lack of insurance coverage, and high out-of-pocket
33 costs for patients (2, 51-53). As such, we believe in the next ten years, one major strategic goal of the
34 OC is to improve access to care. This can be facilitated in part by increasing oncofertility awareness
35 through expansion of OPEN (2). OPEN is a free, membership-based network comprised of oncofertility
36 professionals from 45 countries. It encourages members to share resources, methodologies and
37 experiences to collaboratively advance the field and break down barriers to access.
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46 First, we can continue to support new and existing centers with detailed roadmaps and patient
47 navigation expertise to develop, re-organize, and implement oncofertility programs (32, 54). The OC
48 has worked to provide centers with consent templates, protocols, business plans, and support, to
49 facilitate efficient program implementation. The OC's network of patient navigators provides
50 professional peer support and unprecedented opportunity for collaboration to serve both patients and
51 programs regardless of their location. Ideally, in the future, a team of patient navigators and oncofertility
52 experts would be equipped with standard operating procedures and guidelines and have the ability to
53 travel to rural, remote, or new clinics and centers to raise awareness, assist with leadership
54 engagement and subsequently help build robust oncofertility programs. Furthermore, the resources
55 provided by these teams would be in multiple languages, and they would be culturally adapted by local
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<p style="text-align: center;">Vision Statement</p> <p>The vision of the Oncofertility Consortium is for all patients facing loss of fertility due to medical conditions and/or gonadotoxic therapies to have access to oncofertility options and services.</p> <p style="text-align: center;">Mission Statement</p> <p>The mission of the Oncofertility Consortium is to convene the field to enable the essential conversations necessary to drive oncofertility research, clinical practice, and patient options forward.</p> <p style="text-align: center;">Value Statement</p> <p>The Oncofertility Consortium values collegiality, multi-disciplinary collaboration, inclusiveness, innovation, and altruism. All of its values are ultimately driven by patient-centeredness.</p>

Figure 3: Vision, Mission, and Value Statement issued by the oncofertility leadership team.

1 experts, who have a deeper insight on the local culture, and knowledge about local resources and
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3 processes.
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6 During the February meeting, the OC leadership team also explored the possibility of pursuing a center
7 of excellence designation for qualified member centers. Though time intensive to procure, this
8 designation may help enhance the depth and breadth of oncofertility services offered to patients. We
9 discussed the several advantages to establishing a center of excellence model, including lending further
10 credence to our work and credibility to an institution, clearly identifying high-level institutions for patients
11 seeking to identify a comprehensive oncofertility program at which to pursue care, as well creating a
12 continuum of success for our centers and further incentivizing member institutions to join the OC and
13 OPEN. We also considered, however, certain barriers to pursuing a center of excellence designation.
14 The OC is grounded in altruism, so affixing labels of quality may be exclusionary in some instances; we
15 would not want to disregard any centers, including those centers with limited resources. Moreover,
16 fertility preservation in the cancer setting is extremely time sensitive. In many instances, patients may
17 not have enough time to investigate a center's designation and respective outcome data. We would
18 never want a center of excellence designation, or lack thereof, to prevent a patient from pursuing family
19 building options. To achieve the full benefits of this model, proper assembly is required
20 (55) and the leadership team will need to further examine the benefits and risks associated with this
21 model. Ideally, as a group, we would need to determine how to create a designation that is customizable
22 and takes into account institutional variation so that it seeks to encourage and highlight positive change
23 and does not penalize or devalue programs that are simply resource poor.
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41 We can also improve access by optimizing internet-based resources and by utilizing telehealth
42 technologies to reach patients in remote locations or low-resource settings (56). As the working world
43 continues to evolve and patients face geographical and physical barriers to care, the utilization of
44 telehealth would improve awareness and access to oncofertility care (57). The transformation of clinical
45 care through the use of telehealth due to the COVID-19 pandemic has demonstrated that timely fertility
46 consultations can be provided remotely when patients otherwise may not have had the opportunity to
47 be counseled on fertility risk and preservation options before beginning cancer therapy. Telehealth
48 platforms that are Health Insurance Portability and Accountability Act (HIPAA) compliant are being
49 utilized to access vital healthcare services. Although many oncofertility procedures require in-person
50 care, the initial consultations prior to treatment could be performed remotely and the patient would then
51 be directed to the nearest clinic for treatment (58, 59). Telehealth services provide a centralized service
52 for initial consultation not just during trying times, but as a model for getting expertise to vulnerable or
53 remote communities, enabling more efficient initial first steps. In the US, the recent change in Medicare
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1 reimbursement rules to cover telemedicine consults has dramatically accelerated the financial feasibility
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3 of utilizing telemedicine for fertility preservation. Advocating for these changes to become permanent
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5 is a critical policy component for improving and maintaining access to fertility preservation expertise.
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7 Assembling a team of skilled patient navigators to conduct these remote consultations could be a
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9 priority in the field so we are able to nimbly adapt to current and future challenges.

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12 It is important to note that we must also be mindful of the economic and geographic hinderances of
13
14 oncofertility services while we explore approaches to improve access. While patients have struggled
15
16 with previously reported barriers to care, specifically high out-of-pocket costs, the COVID-19 pandemic
17
18 has shed light on geographic barriers to care. Although a patient can still receive timely intervention
19
20 and consultation through the use of telehealth technologies, they may not be able to travel to designated
21
22 centers for in-person care and procedures due to travel restrictions. The OC will continue to support
23
24 translation of innovation and cutting-edge clinical or research advances into tangible solutions at the
25
26 grassroot level. For example, in low resource settings, member institutions can provide training to the
27
28 local youth to access telemedicine technology and help set it up for patients. Similarly, member
29
30 institutions can channel philanthropic resources to provide transportation for patients requiring travel to
31
32 sites specializing in oncofertility procedures. The diversity of the OC membership provides us the
33
34 platform to understand needs of our community and effect change at local, regional, national, and
35
36 international level.

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38 One of the steepest barriers to care remains the high cost of fertility preservation services. This is both
39
40 because of the relatively high costs associated with the procedures themselves, as well as due to the
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42 lack of insurance coverage. The OC workw with other groups and professional societies, namely the
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44 Alliance for Fertility Preservation (the AFP), to advocate for improved insurance coverage. This has
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46 now been achieved in ten states, but much work remains. The OC can leverage its members'
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48 geographic diversity to form AFP "working groups" locally, to work both with their institutions and within
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50 their states toward the attainment of greater coverage. Existing template bills, sample private insurance
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52 policies, toolkits, and other materials can be shared to expedite legislative and regulatory initiatives in
53
54 several states.

55 56 Advance Research

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58 Our second strategic goal is to advance basic science research since this is the backbone of all that
59
60 we do. In 2007, when the OC was founded, we brought together numerous research projects with the
61
62 idea that this research would eventually translate to extraordinary clinical care for cancer patients who
63
64 face fertility loss. Additionally, we would have been unable to advance the field of oncofertility without
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1 establishing the current baselines of clinical need and patient outcomes. As such, it is crucial to continue
2
3 the support of basic science, clinical, and translational research projects throughout the OC.
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6 We have defined a field within science and medicine and created corridors of communication that have
7
8 led to options for fertility preservation and hormone restoration in pediatric, adolescent and young adult,
9
10 and adult cancer patients. We have disseminated our clinical research findings and taught our bench
11
12 technologies to enable additional resources and perspectives to expand and expedite our impact. We
13
14 are leading the field through team science and connected common goals and interests to enable a
15
16 network of engaged professionals and trainees, both in the USA and abroad, who share a passion for
17
18 oncofertility and reproductive health (60). These teams have created a series of key intellectual and
19
20 didactic products. Collectively, members of the OC have been involved with many of the ground-
21
22 breaking discoveries that have defined our field. We reported the first restoration of reproductive
23
24 function – endocrine hormone production and live birth – using engineered ovarian transplants in mice
25
26 (17). The OC has leveraged discoveries from advances in genomic medicine to improve oncofertility
27
28 care by collaboration with geneticists and genetic counselors. Researchers at the frontier of
29
30 bioengineering and 3-dimensional printing have enabled deployment of this exciting technology for
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32 development of the bioprosthesis ovary (61). Moreover, we reported the first human MII eggs developed
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34 after *in vitro* growth of early secondary human follicles (8, 21).
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36 Facilitating translational and clinical research is also a priority of the OC. Because the field is relatively
37
38 young, and impact of therapy on fertility is a late outcome, it is difficult to study and, as such,
39
40 comprehensive longitudinal data about oncofertility patients does not exist, but is critically needed. A
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42 number of international centers have already established registries and collaborative work with other
43
44 international registries could help to identify challenges in building such large registries (62, 63). As
45
46 such, a goal of the OC would be to work with a range of investigators to collaborate on an international
47
48 scale and establish a comprehensive oncofertility registry to investigate long-term outcomes in patients,
49
50 such as future fertility, pregnancy outcomes, and age at menopause. This registry could track baseline
51
52 data and longitudinal outcomes that can be used to guide oncofertility interventions. Though
53
54 aspirational, a central data coordinating center with the capability to automatically import data from
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56 participating institutions is the ideal. Such a platform will allow participating institutions to export their
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58 data to the centralized database without the need for additional human resources, minimizing cost and
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60 improving access for smaller institutions. Equal access to the collective, big data provided by
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62 participating institutions will allow multiple research questions to be addressed simultaneously, thus
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64 catapulting the field in key areas such as approaches to fertility preservation in vulnerable populations,
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1 long-term fertility outcomes, gynecologic and urologic late effects of cancer therapies, and barriers to
2 referral. This international database is long overdue and critical to advancing the field.
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6 We have been successful thus far because OC research teams have collaborated across institutions.
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8 Strengthening local, regional, and international ties and maximizing interaction among centers creates
9 synergistic opportunities for the field. We will continue to provide the forum and platform to enable these
10 connections through online forums and in-person conferences and training programs that expedite
11 research discovery and we will provide support to investigators in search of research funding.
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17 Additionally, the OC can help pursue opportunities to advocate for funding at the NIH and offer guidance
18 for particular requests for applications (RFAs). Whether this means providing a letter of support for an
19 NIH grant proposal or helping to identify and disseminate relevant grant and funding opportunities, the
20 OC is committed to the advancement of scientific research. Furthermore, we will utilize our network to
21 identify potential collaborators to enhance the scientific merit of proposals and grant applications. We
22 will disseminate these research findings in journals and via social media and other outlets to broaden
23 reach and keep the field connected through sustained engagement and an interdisciplinary approach.
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31 32 Educate 33

34 The third strategic goal of the OC is to educate the next generation of oncofertility leaders. To date, OC
35 leaders have trained numerous students, residents, and clinical and research fellows. Despite these
36 continuing efforts, creating new generations of oncofertility specialists remains an unmet need.
37 Treatment options in oncofertility are rapidly expanding, including the recent change to include ovarian
38 tissue cryopreservation as a part of the armamentarium of established care options (42). We expect
39 that as increasing numbers of medical centers and healthcare providers around the world will start to
40 offer oncofertility services, there will be a corresponding increase in the need for more oncofertility
41 education and training across disciplines. This is especially salient for healthcare providers to ensure
42 that fertility preservation technologies are offered safely and appropriately. Consideration should be
43 given to formal incorporation of oncofertility into the learning objectives and content for medical school,
44 residency, and fellowship curricula. In addition, nurses and advanced practice providers are an
45 increasingly important and engaged cohort among the community of medical providers. Prior research
46 among all of these groups has revealed not only oncofertility educational deficits, but also a strong
47 willingness among these cohorts to engage in oncofertility educational initiatives.
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61 We have a rich history in education ,and together with our collaborators, we created numerous
62 educational tools in various formats and multiple languages that have catalyzed the growth of
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1 oncofertility (1, 49, 64-66). These items include online patient and provider resources, the first
2 comprehensive oncofertility textbook, and educational training videos for a variety of different
3 audiences. We also created a free online certificate course as part of the American Society for
4 Reproductive Medicine's Air Learning platform, and an annual one-day course for trainees in a diverse
5 array of medical specialties including reproductive endocrinology and infertility, medical and pediatric
6 oncology, pediatric and adolescent gynecology, urology, breast oncology, rheumatology and radiation
7 oncology (47). The leaders in the field have provided mentorship and hands-on training to clinicians
8 and scientists who are interested in the creating or expanding oncofertility programs. Formal pathways
9 to connect mentees and mentors will drive expansion of this field.
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19 One of the great traditions of the OC is our work with high school students in local lab-based programs
20 complimented by the educational opportunity to participate in the annual meeting. We have combined
21 this educational opportunity with digital materials from early childhood to adults education in order to
22 ensure that reproductive health terms are as accessible as possible to the general public (65).
23 Educating the next generation of students is a core value of the OC and finding ways to connect
24 students to emerging health issues while informing them about their own health are dual wins for
25 society.
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34 Our goal has been to have educational resources that are enduring, but also easily updated.
35 Educational materials and seminars have been created by a team of experts to provide common patient
36 education materials, oncofertility program guidance, provider education materials, and core educational
37 guidelines for specialized training in oncofertility (67-70). Moving forward, we envision a strong
38 continuation and broad dissemination of existing resources and the development of new repositories,
39 didactic programs and partnerships to provide authoritative, comprehensive educational resources to
40 researchers, patients, and providers across pediatric and adult specialties.
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48 Collaborate

49 The fourth strategic goal is to continue to collaborate and connect members of the field. Even in the
50 earliest days of the OC, it was evident that the field would benefit greatly by including multiple disciplines
51 and expertise. We brought together a variety of medical disciplines, all with a vested interest in the field.
52 This included reproductive endocrinologists, oncologists, urologists, OBGYNs, allied health
53 professionals, psychologists, nurses, embryologists, and adult and pediatric specialists. We knew
54 ethicists and religious leaders would inevitably need to be included in the conversation. Most
55 importantly, patients and their partners and their families were included from the beginning to ensure
56 that all of our actions revolved around their care and ultimate well-being. Therefore, from the onset of
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1 the OC, we proactively included them as members of the field. These cross-cutting collaborations have
2 set the stage for ongoing partnerships, advancement of oncofertility care, and have become a hallmark
3 of the field.
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8 We will continue to convene annually at the Oncofertility Conference. The OC will serve as the great
9 facilitator of communications and collaboration among OPEN members and beyond. We will collaborate
10 with other professional societies and regional oncofertility organizations, including, but not limited to,
11 the International Society for Fertility Preservation (ISFP), FertiProtekt, the Japanese Society for Fertility
12 Preservation (JSFP), the Korea Society for Fertility Preservation (KSFP), the Australasian Oncofertility
13 Consortium, and many others (6). We will connect with advocacy groups to provide support to all
14 patients and make the critical connections to ensure their needs are being met and guarantee that the
15 patient's perspective remains a central, guiding force of the OC. There is great value in enhancing
16 international collaborations as we aim to gain important experiences from each other, and the OC
17 conference will continue to serve as the venue to do so.
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28 In addition, we must develop new ways to bring all OC communities together, especially across the
29 oncology services and their multidisciplinary teams, with the intention of providing updated information
30 in the field, jointly elaborating strategies for accessing options by patients and their families and, finally,
31 reducing the resistance to the fact that fertility is an aspect of the quality of survival. Although
32 oncofertility has gained space and prestige since its inception, as stated above, there remain concerns
33 about the effectiveness of communication between reproductive medicine professionals and
34 oncologists, which is evidenced by the absence of programs that offer both approaches in many clinics
35 and hospitals. In this sense, it is also important that there is an approximation of the OC with the clinical
36 and surgical oncology societies, which allows a joint action in the elaboration of comprehensive and
37 broadly applicable assistance protocols.
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48 Leadership is of paramount importance to sustain the OC for the next decade and beyond. Thus, one
49 of the early goals of the next phase will be to conceptualize a plan for leadership and structure. Together
50 we will develop a leadership steering committee model that involves members elected or selected from
51 the global OC community. In addition, the leadership plan should include methods of creating and
52 maintaining engagement, since this will positively affect every goal that the OC plans on achieving in
53 the future.
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1 Future Directions and Final Thoughts

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3 The Oncofertility Consortium was created out of the urgent unmet need of young female cancer patients
4 with limited options for fertility management prior to receiving gonadotoxic therapies. We now have an
5 evidence-based field of medicine that offers hope as well as real options that could only be imagined in
6 2006. Oncofertility has expanded from a field focused on the unmet need of young reproductive age
7 women undergoing cancer therapy into a discipline that provides fertility preservation options for people
8 of all ages and genders. The scope of our efforts has expanded beyond cancer to also provide options
9 for individuals at risk of infertility due to bone marrow transplantation (BMT) for benign diseases,
10 disorders of sexual development (DSD), autoimmune diseases, gender-affirming treatments for
11 transgender/gender-diverse populations, and other non-oncologic conditions, including rheumatology.
12 It has expanded beyond restoration of reproductive function to also include restoration of hormonal
13 function alone or in combination with reproduction. The key to the success of the field is to maintain the
14 level of cooperation and low barriers to communication between leaders and centers worldwide. The
15 multiple publications from the global team provides evidence that the world is ready for communal work
16 and elaborating on this opportunity is part of a successful future for the field and for the OC (1-7, 71).
17 This paper outlines the strategic goals and collective priorities of our leadership, however, the
18 implementation and tactics for achievement is up to the field. With this new strategic vision and the
19 broad global participation in the shaping of the Oncofertility Consortium's goals, we believe the time is
20 right for the next chapter of this organization to be written.
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1 **Figure 2:** Appreciative Inquiry Survey
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10 **Oncofertility Consortium Vision 2030: Appreciative Inquiry**

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12 Thank you in advance for taking the time to complete this survey. These answers will be used to
13 initiate the Oncofertility Consortium's Vision 2030 strategic planning process, and will help the
14 Oncofertility Consortium construct its mission, values, and goals for the next ten years.
15

16
17 The goal of this survey is to leverage the Oncofertility Consortium's positive core strengths (as
18 identified by all stakeholders) to design and redesign the organization to achieve a more effective
19 and sustainable future.
20

21
22 The questions in this survey will be split in four stages:

- 23 1. Discovery
 - 24 2. Dream
 - 25 3. Design
 - 26 4. Destiny
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29 Please be as detailed as possible when answering open ended questions. The more details you
30 can recall about a specific story, event, or anecdote, the better. Please focus on only
31 the *positive* core strengths of the Oncofertility Consortium as the goal is to understand what we do
32 well and how we can leverage these strengths in the future.
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35 **Question 1: Discovery: Appreciating and valuing the best of what is.**

36 What gives the Oncofertility Consortium life? What does the Oncofertility Consortium do best?
37 What are the strengths of the Oncofertility Consortium? What do you appreciate about the
38 Oncofertility Consortium? Include stories or information about what is working well.
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41 **Question 2: Dream: Envisioning what might be**

42 In a blue sky environment, how do you envision the impact of the Oncofertility Consortium?
43 Without any constraints, what results would you anticipate? What do you wish for the Oncofertility
44 Consortium? What would be your best aspirations for the Oncofertility Consortium in five and ten
45 years?
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48 **Question 3: Design: Determining what should be**

49 What is the ideal structure of the Oncofertility Consortium? What should the Oncofertility
50 Consortium be doing? How can we build even more on the way we collaborate? Include any ideas
51 for co-constructing this design.
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54 **Question 4: Destiny: Innovating what will be**

55 How can the Oncofertility Consortium innovate to sustain its efforts? How can teams and
56 individuals make the dream and design propositions a reality? How would you co-create the future
57 of the Oncofertility Consortium?
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A View from the Past Into our Collective Future:

The Oncofertility Consortium Vision Statement

Introduction

Since the term 'oncofertility' and the relatively small oncofertility consortium of research scientists and allied clinicians was organized in 2006, the group has become a robust and productive community from over 45 countries around the globe (1-12). Since its inception, there have been a number of scientific advances, including sustained *in vitro* follicle growth in alginate hydrogels (with the achievement of live birth in mice, the first metaphase II (MII) egg in human, and the first non-human primate embryo), development of the first cryoprotectant specifically designed for and tested on non-human primate and human ovarian tissue, and the first ovarian bioprosthesis (with techniques involving decellularization, 3-D printing, and reconstituted tissue papers) and autografting of cryopreserved prepubertal rhesus testis to produce sperm and offspring (1, 13-27). These scientific discoveries have been matched by clinical advances that



Figure 1: Purple pins represent locations of the Oncofertility Professional Engagement Network (OPEN) member centers. OPEN consists of individuals or groups from 45 countries and are linked by basic and clinical research a high-level of shared protocols and experiences. Member leverage work done in affiliated centers to accelerate their formation and services offered. (1-7)

include expanding options to pediatric and adolescent and young adult populations and patients with differences in sex development, transgender and gender-diverse populations, as well as the development of optimized ovarian procurement and testicular biopsy sampling and documented methods for tissue transport (12, 28-36). Prepubertal testicular tissue cryopreservation is now also performed in a number of centers worldwide, although this technique still remain experimental (25, 37). In addition, there has been a growing emphasis on the full range of patient, parent, and partner considerations including questions of legal ramifications and religious and ethical concerns (28, 38-41). Based on the extraordinary work from groups around the world, ovarian tissue cryopreservation (OTC) is no longer designated experimental (42). Moreover, ten US states require insurers to cover fertility preservation costs for cancer patients or any patients receiving gonadotoxic therapy. This change in the US is being mirrored in other countries and the leverage created by having a globally linked organization (Figure 1) allows for more rapid uptake of necessary procedures (4, 43, 44). In just over ten years, the collective progress made by the broad and engaged stakeholders in this field has been outstanding. Now, as we approach the next ten years of the field, our communal goal is to ensure that similar progress will be made in the future and by this coordinated effort, patients' needs will continue

1 to be prioritized and met. As such, in early November 2019, the Oncofertility Consortium introduced a
2 multi-month, multi-stakeholder discussion regarding the future of the field of oncofertility. Herein we
3 present the thoughts and conclusions of our engaged, global leadership.
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8 Beginning in 2007, a broadly attended annual meeting has been held that created context, community,
9 and critical mass for collaboration and increased momentum during a time frame when scientists and
10 clinicians were working largely on their own (45, 46). The meeting has served as a platform for
11 international collaboration and support in oncofertility program implementation. It has also served as a
12 training ground and mentorship for residents, fellows, early stage scientists, nurses and allied health
13 professionals from around the globe, as well as a pipeline for high school students (47-49). The 2019
14 meeting had record attendance, illustrating the interest to gather and collaborate as a field. However,
15 convening is only one dimension of our work. The community is thinking strategically about how to
16 facilitate this meeting and how to grow the field even more broadly to advance the science and its
17 clinical application for our patients. As such, all stakeholders were invited to participate in a strategic
18 planning process called *Vision 2030: A Roadmap for Oncofertility Research and Practices*.
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30 The strategic planning process began with an anonymized 'appreciative inquiry' survey sent to a group
31 of over 3000 oncofertility stakeholders in December 2019. Appreciative inquiry is a strengths-based,
32 positive approach to leadership development and organizational change (50). Survey recipients
33 included OC leadership, previous conference attendees, advocates, and other individuals who have all
34 interacted with the OC in some way since 2007. The ultimate goal of the short, four question
35 appreciative inquiry was to identify the OC's core strengths and to explore how to leverage these
36 strengths to redesign the organization to make it more effective and sustainable. Suggestions were
37 analyzed, and a summary document was provided to the members of the leadership group for their
38 review. Emerging themes included: diversity, collaboration, networking, the annual meeting,
39 leadership, team science, sharing, and bringing together stakeholders. (See **Figure 2** for complete
40 appreciative inquiry survey.)
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52 Following the appreciative inquiry, on February 7, 2020, a diverse group of leaders from the OC
53 participated in a day-long meeting, to review the appreciative inquiry responses and discuss the
54 resulting next steps for the field. This leadership group included clinicians and basic scientists, nurses,
55 patient navigators, social scientists, and advocates, from the USA and abroad. Disciplines represented
56 included oncology, urology, reproductive endocrinology and infertility, psychology, and specialists in
57 pediatric, adolescent and adult populations. Many of the participants serve as chairs of their respective
58 Oncofertility Professional Education Network (OPEN) subcommittees (1) and have exhibited exemplary
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1 leadership and engagement in the field. Together this group discussed the current state of the field, the
2 priorities for the next ten years, and the strategies to be used to ensure that the field is moving forward
3 in a productive and collaborative manner. The group was also tasked with developing the OC's vision,
4 mission, and value statements (**Figure 3**), and to identify four strategic goals for the field which were:
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8 1. Improve Access 2. Advance Research 3. Educate and 4. Collaborate.
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12 Improve Access

13 Both nationally and internationally,
14 oncofertility professionals face common
15 challenges. These include a lack of
16 awareness among providers and
17 patients, a lack of appropriate
18 communication between provider and the
19 patient-parent dyad (particularly for
20 pediatric providers), a lack of referral
21 pathways with no standardized models of
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<p style="text-align: center;">Vision Statement</p> <p>The vision of the Oncofertility Consortium is for all patients facing loss of fertility due to medical conditions and/or gonadotoxic therapies to have access to oncofertility options and services.</p> <p style="text-align: center;">Mission Statement</p> <p>The mission of the Oncofertility Consortium is to convene the field to enable the essential conversations necessary to drive oncofertility research, clinical practice, and patient options forward.</p> <p style="text-align: center;">Value Statement</p> <p>The Oncofertility Consortium values collegiality, multi-disciplinary collaboration, inclusiveness, innovation, and altruism. All of its values are ultimately driven by patient-centeredness.</p>

Figure 3: Vision, Mission, and Value Statement issued by the oncofertility leadership team.

30 care, cultural and religious constraints, uncertainties regarding exact risks of cancer-related infertility,
31 insufficient funds to support oncofertility programs, a lack of insurance coverage, and high out-of-pocket
32 costs for patients (2, 51-53). As such, we believe in the next ten years, one major strategic goal of the
33 OC is to improve access to care. This can be facilitated in part by increasing oncofertility awareness
34 through expansion of OPEN (2). OPEN is a free, membership-based network comprised of oncofertility
35 professionals from 45 countries. It encourages members to share resources, methodologies and
36 experiences to collaboratively advance the field and break down barriers to access.
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45 First, we can continue to support new and existing centers with detailed roadmaps and patient
46 navigation expertise to develop, re-organize, and implement oncofertility programs (32, 54). The OC
47 has worked to provide centers with consent templates, protocols, business plans, and support, to
48 facilitate efficient program implementation. The OC's network of patient navigators provides
49 professional peer support and unprecedented opportunity for collaboration to serve both patients and
50 programs regardless of their location. Ideally, in the future, a team of patient navigators and oncofertility
51 experts would be equipped with standard operating procedures and guidelines and have the ability to
52 travel to rural, remote, or new clinics and centers to raise awareness, assist with leadership
53 engagement and subsequently help build robust oncofertility programs. Furthermore, the resources
54 provided by these teams would be in multiple languages, and they would be culturally adapted by local
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1 experts, who have a deeper insight on the local culture, and knowledge about local resources and
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3 processes.
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6 During the February meeting, the OC leadership team also explored the possibility of pursuing a center
7 of excellence designation for qualified member centers. Though time intensive to procure, this
8 designation may help enhance the depth and breadth of oncofertility services offered to patients. We
9 discussed the several advantages to establishing a center of excellence model, including lending
10 further credence to our work and credibility to an institution, clearly identifying high-level institutions for
11 patients seeking to identify a comprehensive oncofertility program at which to pursue care, as well
12 creating a continuum of success for our centers and further incentivizing member institutions to join the
13 OC and OPEN. We also considered, however, certain barriers to pursuing a center of excellence
14 designation. The OC is grounded in altruism, so affixing labels of quality may be exclusionary in some
15 instances; we would not want to disregard any centers, including those centers with limited resources.
16 Moreover, fertility preservation in the cancer setting is extremely time sensitive. In many instances,
17 patients may not have enough time to investigate a center's designation and respective outcome data.
18 We would never want a center of excellence designation, or lack thereof, to prevent a patient from
19 pursuing family building options. To achieve the full benefits of this model, proper assembly is required
20 (55) and the leadership team will need to further examine the benefits and risks associated with this
21 model. Ideally, as a group, we would need to determine how to create a designation that is customizable
22 and takes into account institutional variation so that it seeks to encourage and highlight positive change
23 and does not penalize or devalue programs that are simply resource poor.
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41 We can also improve access by optimizing internet-based resources and by utilizing telehealth
42 technologies to reach patients in remote locations or low-resource settings (56). As the working world
43 continues to evolve and patients face geographical and physical barriers to care, the utilization of
44 telehealth would improve awareness and access to oncofertility care (57). The transformation of clinical
45 care through the use of telehealth due to the COVID-19 pandemic has demonstrated that timely fertility
46 consultations can be provided remotely when patients otherwise may not have had the opportunity to
47 be counseled on fertility risk and preservation options before beginning cancer therapy. Telehealth
48 platforms that are Health Insurance Portability and Accountability Act (HIPAA) compliant are being
49 utilized to access vital healthcare services. Although many oncofertility procedures require in-person
50 care, the initial consultations prior to treatment could be performed remotely and the patient would then
51 be directed to the nearest clinic for treatment (58, 59). Telehealth services provide a centralized service
52 for initial consultation not just during trying times, but as a model for getting expertise to vulnerable or
53 remote communities, enabling more efficient initial first steps. In the US, the recent change in Medicare
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1 reimbursement rules to cover telemedicine consults has dramatically accelerated the financial feasibility
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3 of utilizing telemedicine for fertility preservation. Advocating for these changes to become permanent
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5 is a critical policy component for improving and maintaining access to fertility preservation expertise.
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7 Assembling a team of skilled patient navigators to conduct these remote consultations could be a
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9 priority in the field so we are able to nimbly adapt to current and future challenges.

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12 It is important to note that we must also be mindful of the economic and geographic hinderances of
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14 oncofertility services while we explore approaches to improve access. While patients have struggled
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16 with previously reported barriers to care, specifically high out-of-pocket costs, the COVID-19 pandemic
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18 has shed light on geographic barriers to care. Although a patient can still receive timely intervention
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20 and consultation through the use of telehealth technologies, they may not be able to travel to designated
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22 centers for in-person care and procedures due to travel restrictions. The OC will continue to support
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24 translation of innovation and cutting-edge clinical or research advances into tangible solutions at the
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26 grassroot level. For example, in low resource settings, member institutions can provide training to the
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28 local youth to access telemedicine technology and help set it up for patients. Similarly, member
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30 institutions can channel philanthropic resources to provide transportation for patients requiring travel to
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32 sites specializing in oncofertility procedures. The diversity of the OC membership provides us the
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34 platform to understand needs of our community and effect change at local, regional, national, and
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36 international level.

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38 One of the steepest barriers to care remains the high cost of fertility preservation services. This is both
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40 because of the relatively high costs associated with the procedures themselves, as well as due to the
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42 lack of insurance coverage. The OC workw with other groups and professional societies, namely the
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44 Alliance for Fertility Preservation (the AFP), to advocate for improved insurance coverage. This has
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46 now been achieved in ten states, but much work remains. The OC can leverage its members'
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48 geographic diversity to form AFP "working groups" locally, to work both with their institutions and within
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50 their states toward the attainment of greater coverage. Existing template bills, sample private insurance
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52 policies, toolkits, and other materials can be shared to expedite legislative and regulatory initiatives in
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54 several states.

55 56 Advance Research

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58 Our second strategic goal is to advance basic science research since this is the backbone of all that
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60 we do. In 2007, when the OC was founded, we brought together numerous research projects with the
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62 idea that this research would eventually translate to extraordinary clinical care for cancer patients who
63
64 face fertility loss. Additionally, we would have been unable to advance the field of oncofertility without
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1 establishing the current baselines of clinical need and patient outcomes. As such, it is crucial to continue
2
3 the support of basic science, clinical, and translational research projects throughout the OC.
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6 We have defined a field within science and medicine and created corridors of communication that have
7
8 led to options for fertility preservation and hormone restoration in pediatric, adolescent and young adult,
9
10 and adult cancer patients. We have disseminated our clinical research findings and taught our bench
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12 technologies to enable additional resources and perspectives to expand and expedite our impact. We
13
14 are leading the field through team science and connected common goals and interests to enable a
15
16 network of engaged professionals and trainees, both in the USA and abroad, who share a passion for
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18 oncofertility and reproductive health (60). These teams have created a series of key intellectual and
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20 didactic products. Collectively, members of the OC have been involved with many of the ground-
21
22 breaking discoveries that have defined our field. We reported the first restoration of reproductive
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24 function – endocrine hormone production and live birth – using engineered ovarian transplants in mice
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26 (17). The OC has leveraged discoveries from advances in genomic medicine to improve oncofertility
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28 care by collaboration with geneticists and genetic counselors. Researchers at the frontier of
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30 bioengineering and 3-dimensional printing have enabled deployment of this exciting technology for
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32 development of the bioprosthesis ovary (61). Moreover, we reported the first human MII eggs developed
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34 after *in vitro* growth of early secondary human follicles (8, 21).
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36 Facilitating translational and clinical research is also a priority of the OC. Because the field is relatively
37
38 young, and impact of therapy on fertility is a late outcome, it is difficult to study and, as such,
39
40 comprehensive longitudinal data about oncofertility patients does not exist, but is critically needed. A
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42 number of international centers have already established registries and collaborative work with other
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44 international registries could help to identify challenges in building such large registries (62, 63). As
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46 such, a goal of the OC would be to work with a range of investigators to collaborate on an international
47
48 scale and establish a comprehensive oncofertility registry to investigate long-term outcomes in patients,
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50 such as future fertility, pregnancy outcomes, and age at menopause. This registry could track baseline
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52 data and longitudinal outcomes that can be used to guide oncofertility interventions. Though
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54 aspirational, a central data coordinating center with the capability to automatically import data from
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56 participating institutions is the ideal. Such a platform will allow participating institutions to export their
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58 data to the centralized database without the need for additional human resources, minimizing cost and
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60 improving access for smaller institutions. Equal access to the collective, big data provided by
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62 participating institutions will allow multiple research questions to be addressed simultaneously, thus
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64 catapulting the field in key areas such as approaches to fertility preservation in vulnerable populations,
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1 long-term fertility outcomes, gynecologic and urologic late effects of cancer therapies, and barriers to
2 referral. This international database is long overdue and critical to advancing the field.
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6 We have been successful thus far because OC research teams have collaborated across institutions.
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8 Strengthening local, regional, and international ties and maximizing interaction among centers creates
9 synergistic opportunities for the field. We will continue to provide the forum and platform to enable these
10 connections through online forums and in-person conferences and training programs that expedite
11 research discovery and we will provide support to investigators in search of research funding.
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17 Additionally, the OC can help pursue opportunities to advocate for funding at the NIH and offer guidance
18 for particular requests for applications (RFAs). Whether this means providing a letter of support for an
19 NIH grant proposal or helping to identify and disseminate relevant grant and funding opportunities, the
20 OC is committed to the advancement of scientific research. Furthermore, we will utilize our network to
21 identify potential collaborators to enhance the scientific merit of proposals and grant applications. We
22 will disseminate these research findings in journals and via social media and other outlets to broaden
23 reach and keep the field connected through sustained engagement and an interdisciplinary approach.
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32 Educate
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34 The third strategic goal of the OC is to educate the next generation of oncofertility leaders. To date, OC
35 leaders have trained numerous students, residents, and clinical and research fellows. Despite these
36 continuing efforts, creating new generations of oncofertility specialists remains an unmet need.
37 Treatment options in oncofertility are rapidly expanding, including the recent change to include ovarian
38 tissue cryopreservation as a part of the armamentarium of established care options (42). We expect
39 that as increasing numbers of medical centers and healthcare providers around the world will start to
40 offer oncofertility services, there will be a corresponding increase in the need for more oncofertility
41 education and training across disciplines. This is especially salient for healthcare providers to ensure
42 that fertility preservation technologies are offered safely and appropriately. Consideration should be
43 given to formal incorporation of oncofertility into the learning objectives and content for medical school,
44 residency, and fellowship curricula. In addition, nurses and advanced practice providers are an
45 increasingly important and engaged cohort among the community of medical providers. Prior research
46 among all of these groups has revealed not only oncofertility educational deficits, but also a strong
47 willingness among these cohorts to engage in oncofertility educational initiatives.
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61 We have a rich history in education ,and together with our collaborators, we created numerous
62 educational tools in various formats and multiple languages that have catalyzed the growth of
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1 oncofertility (1, 49, 64-66). These items include online patient and provider resources, the first
2 comprehensive oncofertility textbook, and educational training videos for a variety of different
3 audiences. We also created a free online certificate course as part of the American Society for
4 Reproductive Medicine's Air Learning platform, and an annual one-day course for trainees in a diverse
5 array of medical specialties including reproductive endocrinology and infertility, medical and pediatric
6 oncology, pediatric and adolescent gynecology, urology, breast oncology, rheumatology and radiation
7 oncology (47). The leaders in the field have provided mentorship and hands-on training to clinicians
8 and scientists who are interested in the creating or expanding oncofertility programs. Formal pathways
9 to connect mentees and mentors will drive expansion of this field.
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19 One of the great traditions of the OC is our work with high school students in local lab-based programs
20 complimented by the educational opportunity to participate in the annual meeting. We have combined
21 this educational opportunity with digital materials from early childhood to adults education in order to
22 ensure that reproductive health terms are as accessible as possible to the general public (65).
23 Educating the next generation of students is a core value of the OC and finding ways to connect
24 students to emerging health issues while informing them about their own health are dual wins for
25 society.
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34 Our goal has been to have educational resources that are enduring, but also easily updated.
35 Educational materials and seminars have been created by a team of experts to provide common patient
36 education materials, oncofertility program guidance, provider education materials, and core educational
37 guidelines for specialized training in oncofertility (67-70). Moving forward, we envision a strong
38 continuation and broad dissemination of existing resources and the development of new repositories,
39 didactic programs and partnerships to provide authoritative, comprehensive educational resources to
40 researchers, patients, and providers across pediatric and adult specialties.
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49 Collaborate

50 The fourth strategic goal is to continue to collaborate and connect members of the field. Even in the
51 earliest days of the OC, it was evident that the field would benefit greatly by including multiple disciplines
52 and expertise. We brought together a variety of medical disciplines, all with a vested interest in the field.
53 This included reproductive endocrinologists, oncologists, urologists, OBGYNs, allied health
54 professionals, psychologists, nurses, embryologists, and adult and pediatric specialists. We knew
55 ethicists and religious leaders would inevitably need to be included in the conversation. Most
56 importantly, patients and their partners and their families were included from the beginning to ensure
57 that all of our actions revolved around their care and ultimate well-being. Therefore, from the onset of
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1 the OC, we proactively included them as members of the field. These cross-cutting collaborations have
2 set the stage for ongoing partnerships, advancement of oncofertility care, and have become a hallmark
3 of the field.
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8 We will continue to convene annually at the Oncofertility Conference. The OC will serve as the great
9 facilitator of communications and collaboration among OPEN members and beyond. We will collaborate
10 with other professional societies and regional oncofertility organizations, including, but not limited to,
11 the International Society for Fertility Preservation (ISFP), FertiProtekt, the Japanese Society for Fertility
12 Preservation (JSFP), the Korea Society for Fertility Preservation (KSFP), the Australasian Oncofertility
13 Consortium, and many others (6). We will connect with advocacy groups to provide support to all
14 patients and make the critical connections to ensure their needs are being met and guarantee that the
15 patient's perspective remains a central, guiding force of the OC. There is great value in enhancing
16 international collaborations as we aim to gain important experiences from each other, and the OC
17 conference will continue to serve as the venue to do so.
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28 In addition, we must develop new ways to bring all OC communities together, especially across the
29 oncology services and their multidisciplinary teams, with the intention of providing updated information
30 in the field, jointly elaborating strategies for accessing options by patients and their families and, finally,
31 reducing the resistance to the fact that fertility is an aspect of the quality of survival. Although
32 oncofertility has gained space and prestige since its inception, as stated above, there remain concerns
33 about the effectiveness of communication between reproductive medicine professionals and
34 oncologists, which is evidenced by the absence of programs that offer both approaches in many clinics
35 and hospitals. In this sense, it is also important that there is an approximation of the OC with the clinical
36 and surgical oncology societies, which allows a joint action in the elaboration of comprehensive and
37 broadly applicable assistance protocols.
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48 Leadership is of paramount importance to sustain the OC for the next decade and beyond. Thus, one
49 of the early goals of the next phase will be to conceptualize a plan for leadership and structure.
50 Together we will develop a leadership steering committee model that involves members elected or
51 selected from the global OC community. In addition, the leadership plan should include methods of
52 creating and maintaining engagement, since this will positively affect every goal that the OC plans on
53 achieving in the future.
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1 Progress Made Outside of the OC

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3 We would be remiss if we did not discuss all of the progress made in the field outside the confines of
4 the Oncofertility Consortium. Our colleagues in Europe specifically, many of whom are not formally part
5 of the OC, have made groundbreaking discoveries and many of the most notable advances in
6 oncofertility and fertility preservation. This includes live births following fertility preservation using in-
7 vitro maturation of ovarian tissue oocytes and live births reported using cryopreserved and transplanted
8 ovarian tissue (71-75). The progress made by these centers has been outstanding and we continue to
9 applaud their work. We believe that if we further coalesce as a field and come together to better enable
10 collaboration and team science, we will rapidly improve the pace of research thereby accelerating
11 clinical breakthroughs that ultimately improve the lives of our patients.
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21 Future Directions and Final Thoughts

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23 The Oncofertility Consortium was created out of the urgent unmet need of young female cancer patients
24 with limited options for fertility management prior to receiving gonadotoxic therapies. We now have an
25 evidence-based field of medicine that offers hope as well as real options that could only be imagined
26 in 2006. Oncofertility has expanded from a field focused on the unmet need of young reproductive age
27 women undergoing cancer therapy into a discipline that provides fertility preservation options for people
28 of all ages and genders. The scope of our efforts has expanded beyond cancer to also provide options
29 for individuals at risk of infertility due to bone marrow transplantation (BMT) for benign diseases,
30 disorders of sexual development (DSD), autoimmune diseases, gender-affirming treatments for
31 transgender/gender-diverse populations, and other non-oncologic conditions, including rheumatology.
32 It has expanded beyond restoration of reproductive function to also include restoration of hormonal
33 function alone or in combination with reproduction. The key to the success of the field is to maintain the
34 level of cooperation and low barriers to communication between leaders and centers worldwide. The
35 multiple publications from the global team provides evidence that the world is ready for communal work
36 and elaborating on this opportunity is part of a successful future for the field and for the OC (1-7, 76).
37 This paper outlines the strategic goals and collective priorities of our leadership, however, the
38 implementation and tactics for achievement is up to the field. With this new strategic vision and the
39 broad global participation in the shaping of the Oncofertility Consortium's goals, we believe the time is
40 right for the next chapter of this organization to be written.
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Figure 2: Appreciative Inquiry Survey



Oncofertility Consortium Vision 2030: Appreciative Inquiry

Thank you in advance for taking the time to complete this survey. These answers will be used to initiate the Oncofertility Consortium's Vision 2030 strategic planning process, and will help the Oncofertility Consortium construct its mission, values, and goals for the next ten years.

The goal of this survey is to leverage the Oncofertility Consortium's positive core strengths (as identified by all stakeholders) to design and redesign the organization to achieve a more effective and sustainable future.

The questions in this survey will be split in four stages:

1. Discovery
2. Dream
3. Design
4. Destiny

Please be as detailed as possible when answering open ended questions. The more details you can recall about a specific story, event, or anecdote, the better. Please focus on only the *positive* core strengths of the Oncofertility Consortium as the goal is to understand what we do well and how we can leverage these strengths in the future.

Question 1: Discovery: Appreciating and valuing the best of what is.

What gives the Oncofertility Consortium life? What does the Oncofertility Consortium do best? What are the strengths of the Oncofertility Consortium? What do you appreciate about the Oncofertility Consortium? Include stories or information about what is working well.

Question 2: Dream: Envisioning what might be

In a blue sky environment, how do you envision the impact of the Oncofertility Consortium? Without any constraints, what results would you anticipate? What do you wish for the Oncofertility Consortium? What would be your best aspirations for the Oncofertility Consortium in five and ten years?

Question 3: Design: Determining what should be

What is the ideal structure of the Oncofertility Consortium? What should the Oncofertility Consortium be doing? How can we build even more on the way we collaborate? Include any ideas for co-constructing this design.

Question 4: Destiny: Innovating what will be

How can the Oncofertility Consortium innovate to sustain its efforts? How can teams and individuals make the dream and design propositions a reality? How would you co-create the future of the Oncofertility Consortium?

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Figure 1: Purple pins represent locations of the Oncofertility Professional Engagement Network (OPEN) member centers. OPEN consists of individuals or groups from 45 countries and are linked by basic and clinical research a high-level of shared protocols and experiences. Member leverage work done in affiliated centers to accelerate their formation and services offered. (1-7)



Oncofertility Consortium Vision 2030: Appreciative Inquiry

Thank you in advance for taking the time to complete this survey. These answers will be used to initiate the Oncofertility Consortium's Vision 2030 strategic planning process, and will help the Oncofertility Consortium construct its mission, values, and goals for the next ten years.

The goal of this survey is to leverage the Oncofertility Consortium's positive core strengths (as identified by all stakeholders) to design and redesign the organization to achieve a more effective and sustainable future.

The questions in this survey will be split in four stages:

1. Discovery
2. Dream
3. Design
4. Destiny

Please be as detailed as possible when answering open ended questions. The more details you can recall about a specific story, event, or anecdote, the better. Please focus on only the *positive* core strengths of the Oncofertility Consortium as the goal is to understand what we do well and how we can leverage these strengths in the future.

Question 1: Discovery: Appreciating and valuing the best of what is.

What gives the Oncofertility Consortium life? What does the Oncofertility Consortium do best? What are the strengths of the Oncofertility Consortium? What do you appreciate about the Oncofertility Consortium? Include stories or information about what is working well.

Question 2: Dream: Envisioning what might be

In a blue sky environment, how do you envision the impact of the Oncofertility Consortium? Without any constraints, what results would you anticipate? What do you wish for the Oncofertility Consortium? What would be your best aspirations for the Oncofertility Consortium in five and ten years?

Question 3: Design: Determining what should be

What is the ideal structure of the Oncofertility Consortium? What should the Oncofertility Consortium be doing? How can we build even more on the way we collaborate? Include any ideas for co-constructing this design.

Question 4: Destiny: Innovating what will be

How can the Oncofertility Consortium innovate to sustain its efforts? How can teams and individuals make the dream and design propositions a reality? How would you co-create the future of the Oncofertility Consortium?

Figure 2: Appreciative Inquiry Survey

Vision Statement

The vision of the Oncofertility Consortium is for all patients facing loss of fertility due to medical conditions and/or gonadotoxic therapies to have access to oncofertility options and services.

Mission Statement

The mission of the Oncofertility Consortium is to convene the field to enable the essential conversations necessary to drive oncofertility research, clinical practice, and patient options forward.

Value Statement

The Oncofertility Consortium values collegiality, multi-disciplinary collaboration, inclusiveness, innovation, and altruism. All of its values are ultimately driven by patient-centeredness.

Figure 3: Vision, Mission, and Value Statement issued by the oncofertility leadership team.

A View from the Past Into our Collective Future: The Oncofertility Consortium Vision Statement

Introduction

Since the term ‘oncofertility’ and the relatively small oncofertility consortium of research scientists and allied clinicians was organized in 2006, the group has become a robust and productive community from over 45 countries around the globe (1-12). Since its inception, there have been a number of scientific advances, including sustained *in vitro* follicle growth in alginate hydrogels (with the achievement of live birth in mice, the first metaphase II (MII) egg in human, and the first non-human primate embryo), development of the first cryoprotectant specifically designed for and tested on non-human primate and human ovarian tissue, and the first ovarian bioprosthesis (with techniques involving decellularization, 3-D printing, and reconstituted tissue papers) and autografting of cryopreserved prepubertal rhesus testis to produce sperm and offspring (1, 13-27). These scientific discoveries have been matched by clinical advances that



Figure 1: Purple pins represent locations of the Oncofertility Professional Engagement Network (OPEN) member centers. OPEN consists of individuals or groups from 45 countries and are linked by basic and clinical research a high-level of shared protocols and experiences. Member leverage work done in affiliated centers to accelerate their formation and services offered. (1-7)

include expanding options to pediatric and adolescent and young adult populations and patients with differences in sex development, transgender and gender-diverse populations, as well as the development of optimized ovarian procurement and testicular biopsy sampling and documented methods for tissue transport (12, 28-36). Prepubertal testicular tissue cryopreservation is now also performed in a number of centers worldwide, although this technique still remain experimental (25, 37). In addition, there has been a growing emphasis on the full range of patient, parent, and partner considerations including questions of legal ramifications and religious and ethical concerns (28, 38-41). Based on the extraordinary work from groups around the world, ovarian tissue cryopreservation (OTC) is no longer designated experimental (42). Moreover, ten US states require insurers to cover fertility preservation costs for cancer patients or any patients receiving gonadotoxic therapy. This change in the US is being mirrored in other countries and the leverage created by having a globally linked organization (Figure 1) allows for more rapid uptake of necessary procedures (4, 43, 44). In just over ten years, the collective progress made by the broad and engaged stakeholders in this field has been outstanding. Now, as we approach the next ten years of the field, our communal goal is to ensure that similar progress will be made in the future and by this coordinated effort, patients’ needs will continue

to be prioritized and met. As such, in early November 2019, the Oncofertility Consortium introduced a multi-month, multi-stakeholder discussion regarding the future of the field of oncofertility. Herein we present the thoughts and conclusions of our engaged, global leadership.

Beginning in 2007, a broadly attended annual meeting has been held that created context, community, and critical mass for collaboration and increased momentum during a time frame when scientists and clinicians were working largely on their own (45, 46). The meeting has served as a platform for international collaboration and support in oncofertility program implementation. It has also served as a training ground and mentorship for residents, fellows, early stage scientists, nurses and allied health professionals from around the globe, as well as a pipeline for high school students (47-49). The 2019 meeting had record attendance, illustrating the interest to gather and collaborate as a field. However, convening is only one dimension of our work. The community is thinking strategically about how to facilitate this meeting and how to grow the field even more broadly to advance the science and its clinical application for our patients. As such, all stakeholders were invited to participate in a strategic planning process called *Vision 2030: A Roadmap for Oncofertility Research and Practices*.

The strategic planning process began with an anonymized 'appreciative inquiry' survey sent to a group of over 3000 oncofertility stakeholders in December 2019. Appreciative inquiry is a strengths-based, positive approach to leadership development and organizational change (50). Survey recipients included OC leadership, previous conference attendees, advocates, and other individuals who have all interacted with the OC in some way since 2007. The ultimate goal of the short, four question appreciative inquiry was to identify the OC's core strengths and to explore how to leverage these strengths to redesign the organization to make it more effective and sustainable. Suggestions were analyzed, and a summary document was provided to the members of the leadership group for their review. Emerging themes included: diversity, collaboration, networking, the annual meeting, leadership, team science, sharing, and bringing together stakeholders. (See **Figure 2** for complete appreciative inquiry survey.)

Following the appreciative inquiry, on February 7, 2020, a diverse group of leaders from the OC participated in a day-long meeting, to review the appreciative inquiry responses and discuss the resulting next steps for the field. This leadership group included clinicians and basic scientists, nurses, patient navigators, social scientists, and advocates, from the USA and abroad. Disciplines represented included oncology, urology, reproductive endocrinology and infertility, psychology, and specialists in pediatric, adolescent and adult populations. Many of the participants serve as chairs of their respective Oncofertility Professional Education Network (OPEN) subcommittees (1) and have exhibited exemplary

leadership and engagement in the field. Together this group discussed the current state of the field, the priorities for the next ten years, and the strategies to be used to ensure that the field is moving forward in a productive and collaborative manner. The group was also tasked with developing the OC's vision, mission, and value statements (**Figure 3**), and to identify four strategic goals for the field which were: 1. Improve Access 2. Advance Research 3. Educate and 4. Collaborate.

Improve Access

Both nationally and internationally, oncofertility professionals face common challenges. These include a lack of awareness among providers and patients, a lack of appropriate communication between provider and the patient-parent dyad (particularly for pediatric providers), a lack of referral pathways with no standardized models of

care, cultural and religious constraints, uncertainties regarding exact risks of cancer-related infertility, insufficient funds to support oncofertility programs, a lack of insurance coverage, and high out-of-pocket costs for patients (2, 51-53). As such, we believe in the next ten years, one major strategic goal of the OC is to improve access to care. This can be facilitated in part by increasing oncofertility awareness through expansion of OPEN (2). OPEN is a free, membership-based network comprised of oncofertility professionals from 45 countries. It encourages members to share resources, methodologies and experiences to collaboratively advance the field and break down barriers to access.

First, we can continue to support new and existing centers with detailed roadmaps and patient navigation expertise to develop, re-organize, and implement oncofertility programs (32, 54). The OC has worked to provide centers with consent templates, protocols, business plans, and support, to facilitate efficient program implementation. The OC's network of patient navigators provides professional peer support and unprecedented opportunity for collaboration to serve both patients and programs regardless of their location. Ideally, in the future, a team of patient navigators and oncofertility experts would be equipped with standard operating procedures and guidelines and have the ability to travel to rural, remote, or new clinics and centers to raise awareness, assist with leadership engagement and subsequently help build robust oncofertility programs. Furthermore, the resources provided by these teams would be in multiple languages, and they would be culturally adapted by local

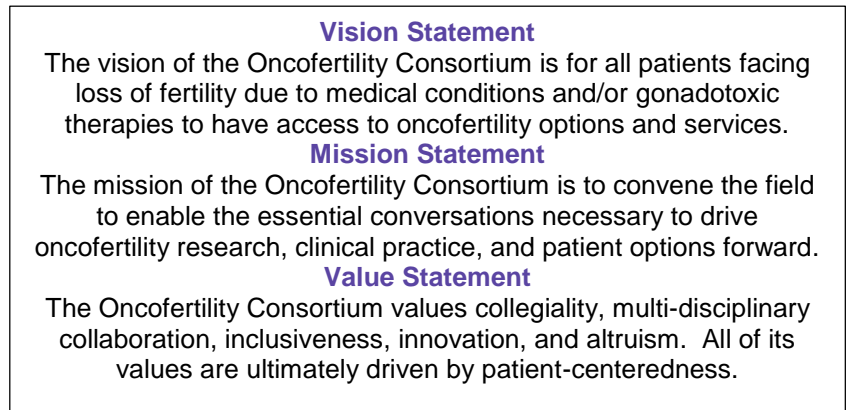


Figure 3: Vision, Mission, and Value Statement issued by the oncofertility leadership team.

experts, who have a deeper insight on the local culture, and knowledge about local resources and processes.

During the February meeting, the OC leadership team also explored the possibility of pursuing a center of excellence designation for qualified member centers. Though time intensive to procure, this designation may help enhance the depth and breadth of oncofertility services offered to patients. We discussed the several advantages to establishing a center of excellence model, including lending further credence to our work and credibility to an institution, clearly identifying high-level institutions for patients seeking to identify a comprehensive oncofertility program at which to pursue care, as well creating a continuum of success for our centers and further incentivizing member institutions to join the OC and OPEN. We also considered, however, certain barriers to pursuing a center of excellence designation. The OC is grounded in altruism, so affixing labels of quality may be exclusionary in some instances; we would not want to disregard any centers, including those centers with limited resources. Moreover, fertility preservation in the cancer setting is extremely time sensitive. In many instances, patients may not have enough time to investigate a center's designation and respective outcome data. We would never want a center of excellence designation, or lack thereof, to prevent a patient from pursuing family building options. To achieve the full benefits of this model, proper assembly is required (55) and the leadership team will need to further examine the benefits and risks associated with this model. Ideally, as a group, we would need to determine how to create a designation that is customizable and takes into account institutional variation so that it seeks to encourage and highlight positive change and does not penalize or devalue programs that are simply resource poor.

We can also improve access by optimizing internet-based resources and by utilizing telehealth technologies to reach patients in remote locations or low-resource settings (56). As the working world continues to evolve and patients face geographical and physical barriers to care, the utilization of telehealth would improve awareness and access to oncofertility care (57). The transformation of clinical care through the use of telehealth due to the COVID-19 pandemic has demonstrated that timely fertility consultations can be provided remotely when patients otherwise may not have had the opportunity to be counseled on fertility risk and preservation options before beginning cancer therapy. Telehealth platforms that are Health Insurance Portability and Accountability Act (HIPAA) compliant are being utilized to access vital healthcare services. Although many oncofertility procedures require in-person care, the initial consultations prior to treatment could be performed remotely and the patient would then be directed to the nearest clinic for treatment (58, 59). Telehealth services provide a centralized service for initial consultation not just during trying times, but as a model for getting expertise to vulnerable or remote communities, enabling more efficient initial first steps. In the US, the recent change in Medicare

reimbursement rules to cover telemedicine consults has dramatically accelerated the financial feasibility of utilizing telemedicine for fertility preservation. Advocating for these changes to become permanent is a critical policy component for improving and maintaining access to fertility preservation expertise. Assembling a team of skilled patient navigators to conduct these remote consultations could be a priority in the field so we are able to nimbly adapt to current and future challenges.

It is important to note that we must also be mindful of the economic and geographic hinderances of oncofertility services while we explore approaches to improve access. While patients have struggled with previously reported barriers to care, specifically high out-of-pocket costs, the COVID-19 pandemic has shed light on geographic barriers to care. Although a patient can still receive timely intervention and consultation through the use of telehealth technologies, they may not be able to travel to designated centers for in-person care and procedures due to travel restrictions. The OC will continue to support translation of innovation and cutting-edge clinical or research advances into tangible solutions at the grassroots level. For example, in low resource settings, member institutions can provide training to the local youth to access telemedicine technology and help set it up for patients. Similarly, member institutions can channel philanthropic resources to provide transportation for patients requiring travel to sites specializing in oncofertility procedures. The diversity of the OC membership provides us the platform to understand needs of our community and effect change at local, regional, national, and international level.

One of the steepest barriers to care remains the high cost of fertility preservation services. This is both because of the relatively high costs associated with the procedures themselves, as well as due to the lack of insurance coverage. The OC workw with other groups and professional societies, namely the Alliance for Fertility Preservation (the AFP), to advocate for improved insurance coverage. This has now been achieved in ten states, but much work remains. The OC can leverage its members' geographic diversity to form AFP "working groups" locally, to work both with their institutions and within their states toward the attainment of greater coverage. Existing template bills, sample private insurance policies, toolkits, and other materials can be shared to expedite legislative and regulatory initiatives in several states.

Advance Research

Our second strategic goal is to advance basic science research since this is the backbone of all that we do. In 2007, when the OC was founded, we brought together numerous research projects with the idea that this research would eventually translate to extraordinary clinical care for cancer patients who face fertility loss. Additionally, we would have been unable to advance the field of oncofertility without

establishing the current baselines of clinical need and patient outcomes. As such, it is crucial to continue the support of basic science, clinical, and translational research projects throughout the OC.

We have defined a field within science and medicine and created corridors of communication that have led to options for fertility preservation and hormone restoration in pediatric, adolescent and young adult, and adult cancer patients. We have disseminated our clinical research findings and taught our bench technologies to enable additional resources and perspectives to expand and expedite our impact. We are leading the field through team science and connected common goals and interests to enable a network of engaged professionals and trainees, both in the USA and abroad, who share a passion for oncofertility and reproductive health (60). These teams have created a series of key intellectual and didactic products. Collectively, members of the OC have been involved with many of the groundbreaking discoveries that have defined our field. We reported the first restoration of reproductive function – endocrine hormone production and live birth – using engineered ovarian transplants in mice (17). The OC has leveraged discoveries from advances in genomic medicine to improve oncofertility care by collaboration with geneticists and genetic counselors. Researchers at the frontier of bioengineering and 3-dimensional printing have enabled deployment of this exciting technology for development of the bioprosthesis ovary (61). Moreover, we reported the first human MII eggs developed after *in vitro* growth of early secondary human follicles (8, 21).

Facilitating translational and clinical research is also a priority of the OC. Because the field is relatively young, and impact of therapy on fertility is a late outcome, it is difficult to study and, as such, comprehensive longitudinal data about oncofertility patients does not exist, but is critically needed. A number of international centers have already established registries and collaborative work with other international registries could help to identify challenges in building such large registries (62, 63). As such, a goal of the OC would be to work with a range of investigators to collaborate on an international scale and establish a comprehensive oncofertility registry to investigate long-term outcomes in patients, such as future fertility, pregnancy outcomes, and age at menopause. This registry could track baseline data and longitudinal outcomes that can be used to guide oncofertility interventions. Though aspirational, a central data coordinating center with the capability to automatically import data from participating institutions is the ideal. Such a platform will allow participating institutions to export their data to the centralized database without the need for additional human resources, minimizing cost and improving access for smaller institutions. Equal access to the collective, big data provided by participating institutions will allow multiple research questions to be addressed simultaneously, thus catapulting the field in key areas such as approaches to fertility preservation in vulnerable populations,

long-term fertility outcomes, gynecologic and urologic late effects of cancer therapies, and barriers to referral. This international database is long overdue and critical to advancing the field.

We have been successful thus far because OC research teams have collaborated across institutions. Strengthening local, regional, and international ties and maximizing interaction among centers creates synergistic opportunities for the field. We will continue to provide the forum and platform to enable these connections through online forums and in-person conferences and training programs that expedite research discovery and we will provide support to investigators in search of research funding.

Additionally, the OC can help pursue opportunities to advocate for funding at the NIH and offer guidance for particular requests for applications (RFAs). Whether this means providing a letter of support for an NIH grant proposal or helping to identify and disseminate relevant grant and funding opportunities, the OC is committed to the advancement of scientific research. Furthermore, we will utilize our network to identify potential collaborators to enhance the scientific merit of proposals and grant applications. We will disseminate these research findings in journals and via social media and other outlets to broaden reach and keep the field connected through sustained engagement and an interdisciplinary approach.

Educate

The third strategic goal of the OC is to educate the next generation of oncofertility leaders. To date, OC leaders have trained numerous students, residents, and clinical and research fellows. Despite these continuing efforts, creating new generations of oncofertility specialists remains an unmet need. Treatment options in oncofertility are rapidly expanding, including the recent change to include ovarian tissue cryopreservation as a part of the armamentarium of established care options (42). We expect that as increasing numbers of medical centers and healthcare providers around the world will start to offer oncofertility services, there will be a corresponding increase in the need for more oncofertility education and training across disciplines. This is especially salient for healthcare providers to ensure that fertility preservation technologies are offered safely and appropriately. Consideration should be given to formal incorporation of oncofertility into the learning objectives and content for medical school, residency, and fellowship curricula. In addition, nurses and advanced practice providers are an increasingly important and engaged cohort among the community of medical providers. Prior research among all of these groups has revealed not only oncofertility educational deficits, but also a strong willingness among these cohorts to engage in oncofertility educational initiatives.

We have a rich history in education ,and together with our collaborators, we created numerous educational tools in various formats and multiple languages that have catalyzed the growth of

oncofertility (1, 49, 64-66). These items include online patient and provider resources, the first comprehensive oncofertility textbook, and educational training videos for a variety of different audiences. We also created a free online certificate course as part of the American Society for Reproductive Medicine's Air Learning platform, and an annual one-day course for trainees in a diverse array of medical specialties including reproductive endocrinology and infertility, medical and pediatric oncology, pediatric and adolescent gynecology, urology, breast oncology, rheumatology and radiation oncology (47). The leaders in the field have provided mentorship and hands-on training to clinicians and scientists who are interested in the creating or expanding oncofertility programs. Formal pathways to connect mentees and mentors will drive expansion of this field.

One of the great traditions of the OC is our work with high school students in local lab-based programs complimented by the educational opportunity to participate in the annual meeting. We have combined this educational opportunity with digital materials from early childhood to adults education in order to ensure that reproductive health terms are as accessible as possible to the general public (65). Educating the next generation of students is a core value of the OC and finding ways to connect students to emerging health issues while informing them about their own health are dual wins for society.

Our goal has been to have educational resources that are enduring, but also easily updated. Educational materials and seminars have been created by a team of experts to provide common patient education materials, oncofertility program guidance, provider education materials, and core educational guidelines for specialized training in oncofertility (67-70). Moving forward, we envision a strong continuation and broad dissemination of existing resources and the development of new repositories, didactic programs and partnerships to provide authoritative, comprehensive educational resources to researchers, patients, and providers across pediatric and adult specialties.

Collaborate

The fourth strategic goal is to continue to collaborate and connect members of the field. Even in the earliest days of the OC, it was evident that the field would benefit greatly by including multiple disciplines and expertise. We brought together a variety of medical disciplines, all with a vested interest in the field. This included reproductive endocrinologists, oncologists, urologists, OBGYNs, allied health professionals, psychologists, nurses, embryologists, and adult and pediatric specialists. We knew ethicists and religious leaders would inevitably need to be included in the conversation. Most importantly, patients and their partners and their families were included from the beginning to ensure that all of our actions revolved around their care and ultimate well-being. Therefore, from the onset of

the OC, we proactively included them as members of the field. These cross-cutting collaborations have set the stage for ongoing partnerships, advancement of oncofertility care, and have become a hallmark of the field.

We will continue to convene annually at the Oncofertility Conference. The OC will serve as the great facilitator of communications and collaboration among OPEN members and beyond. We will collaborate with other professional societies and regional oncofertility organizations, including, but not limited to, the International Society for Fertility Preservation (ISFP), FertiProtekt, the Japanese Society for Fertility Preservation (JSFP), the Korea Society for Fertility Preservation (KSFP), the Australasian Oncofertility Consortium, and many others (6). We will connect with advocacy groups to provide support to all patients and make the critical connections to ensure their needs are being met and guarantee that the patient's perspective remains a central, guiding force of the OC. There is great value in enhancing international collaborations as we aim to gain important experiences from each other, and the OC conference will continue to serve as the venue to do so.

In addition, we must develop new ways to bring all OC communities together, especially across the oncology services and their multidisciplinary teams, with the intention of providing updated information in the field, jointly elaborating strategies for accessing options by patients and their families and, finally, reducing the resistance to the fact that fertility is an aspect of the quality of survival. Although oncofertility has gained space and prestige since its inception, as stated above, there remain concerns about the effectiveness of communication between reproductive medicine professionals and oncologists, which is evidenced by the absence of programs that offer both approaches in many clinics and hospitals. In this sense, it is also important that there is an approximation of the OC with the clinical and surgical oncology societies, which allows a joint action in the elaboration of comprehensive and broadly applicable assistance protocols.

Leadership is of paramount importance to sustain the OC for the next decade and beyond. Thus, one of the early goals of the next phase will be to conceptualize a plan for leadership and structure. Together we will develop a leadership steering committee model that involves members elected or selected from the global OC community. In addition, the leadership plan should include methods of creating and maintaining engagement, since this will positively affect every goal that the OC plans on achieving in the future.

Progress Made Outside of the OC

We would be remiss if we did not discuss all of the progress made in the field outside the confines of the Oncofertility Consortium. Our colleagues in Europe specifically, many of whom are not formally part of the OC, have made groundbreaking discoveries and many of the most notable advances in oncofertility and fertility preservation. This includes live births following fertility preservation using in-vitro maturation of ovarian tissue oocytes and live births reported using cryopreserved and transplanted ovarian tissue (71-75). The progress made by these centers has been outstanding and we continue to applaud their work. We believe that if we further coalesce as a field and come together to better enable collaboration and team science, we will rapidly improve the pace of research thereby accelerating clinical breakthroughs that ultimately improve the lives of our patients.

Future Directions and Final Thoughts

The Oncofertility Consortium was created out of the urgent unmet need of young female cancer patients with limited options for fertility management prior to receiving gonadotoxic therapies. We now have an evidence-based field of medicine that offers hope as well as real options that could only be imagined in 2006. Oncofertility has expanded from a field focused on the unmet need of young reproductive age women undergoing cancer therapy into a discipline that provides fertility preservation options for people of all ages and genders. The scope of our efforts has expanded beyond cancer to also provide options for individuals at risk of infertility due to bone marrow transplantation (BMT) for benign diseases, disorders of sexual development (DSD), autoimmune diseases, gender-affirming treatments for transgender/gender-diverse populations, and other non-oncologic conditions, including rheumatology. It has expanded beyond restoration of reproductive function to also include restoration of hormonal function alone or in combination with reproduction. The key to the success of the field is to maintain the level of cooperation and low barriers to communication between leaders and centers worldwide. The multiple publications from the global team provides evidence that the world is ready for communal work and elaborating on this opportunity is part of a successful future for the field and for the OC (1-7, 76). This paper outlines the strategic goals and collective priorities of our leadership, however, the implementation and tactics for achievement is up to the field. With this new strategic vision and the broad global participation in the shaping of the Oncofertility Consortium's goals, we believe the time is right for the next chapter of this organization to be written.

Figure 2: Appreciative Inquiry Survey



Oncofertility Consortium Vision 2030: Appreciative Inquiry

Thank you in advance for taking the time to complete this survey. These answers will be used to initiate the Oncofertility Consortium's Vision 2030 strategic planning process, and will help the Oncofertility Consortium construct its mission, values, and goals for the next ten years.

The goal of this survey is to leverage the Oncofertility Consortium's positive core strengths (as identified by all stakeholders) to design and redesign the organization to achieve a more effective and sustainable future.

The questions in this survey will be split in four stages:

1. Discovery
2. Dream
3. Design
4. Destiny

Please be as detailed as possible when answering open ended questions. The more details you can recall about a specific story, event, or anecdote, the better. Please focus on only the *positive* core strengths of the Oncofertility Consortium as the goal is to understand what we do well and how we can leverage these strengths in the future.

Question 1: Discovery: Appreciating and valuing the best of what is.

What gives the Oncofertility Consortium life? What does the Oncofertility Consortium do best? What are the strengths of the Oncofertility Consortium? What do you appreciate about the Oncofertility Consortium? Include stories or information about what is working well.

Question 2: Dream: Envisioning what might be

In a blue sky environment, how do you envision the impact of the Oncofertility Consortium? Without any constraints, what results would you anticipate? What do you wish for the Oncofertility Consortium? What would be your best aspirations for the Oncofertility Consortium in five and ten years?

Question 3: Design: Determining what should be

What is the ideal structure of the Oncofertility Consortium? What should the Oncofertility Consortium be doing? How can we build even more on the way we collaborate? Include any ideas for co-constructing this design.

Question 4: Destiny: Innovating what will be

How can the Oncofertility Consortium innovate to sustain its efforts? How can teams and individuals make the dream and design propositions a reality? How would you co-create the future of the Oncofertility Consortium?

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