

# BCFR NEWSLETTER

Keeping you up to date on the Breast Cancer Family Registry

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## PUBLICATIONS & NEWS

### *Adolescent and Young Adult Female Cancer Survivors and Fertility*

**“Looking at future cancer survivors, give them a roadmap”: addressing fertility and family-building topics in post-treatment cancer survivorship care**

Fertility is an important issue among adolescent and young adult female cancer survivors. Although patients are increasingly being counseled about infertility risks and fertility preservation options before treatment begins, follow-up fertility counseling after treatment ends is often lacking. The majority of young survivors are uncertain of their fertility status and reproductive potential after treatment, receive limited reproductive health care, and report high levels of fertility distress, which is associated with lower quality of life. In a study published in *Supportive Care in Cancer*, researchers examined young cancer survivors’ unmet needs and recommendations for care to address fertility and family-building after treatment.

Researchers conducted interviews with 25 young female survivors, aged 15-39 years. The interviews explored themes related to fertility and family-building after cancer, primarily focused on the survivorship time period after treatment. The participants were on average 5.81 years post-treatment, and 32% had undergone fertility preservation before or after treatment.

Results identified six recommendations for improving young adult cancer care related to fertility and family-building: improving patient-provider communication, and providing better informational, emotional, and peer support, including financial information, and offering decision-making support. Ultimately, survivors wished they had access to informational and supportive resources that they could access when they felt ready to address fertility concerns, and also wished that doctors would initiate discussions regularly over time. A combined approach was preferred such that information (via web-based communication) should be provided first, with follow-up in-person visits and referrals when needed.

The finding suggests that to improve care, better communication that allows young survivors to feel supported but also in control of information delivery, while connecting them with peer support outlets, may be important. In addition, future work should evaluate how to best support oncology providers in meeting the needs of young survivors concerned about fertility and family-building, including referral to clinical specialties and supportive resources. *To read the full article, click [here](#).* Dr. Catherine Benedict, the lead researcher of this study, is highlighted in this month's *Meet a Researcher* section on the next page.

### **COVID-19 Vaccine Information for Cancer Patients, Survivors, and Caregivers**

As vaccines are now widely available to help protect against COVID-19, you may have questions as a cancer patient, survivor, or caregiver. Please visit the [American Cancer Society](#) for more information about the vaccine.

## PARTICIPANT RESEARCH HUB

### STUDY UPDATES

#### YOUNG WOMEN'S STUDY UPDATE



The BCFR continues to enroll participants to our Young Women's Study.

We have enrolled **773** young women across all of our BCFR sites.

If you have a female relative 18-39 years old who may be interested or wants to learn more, please contact your BCFR site under the “CONTACT US” section on the bottom of the next page.

#### 25-YEAR FOLLOW-UP UPDATE



The 25-year follow-up is still underway! We have received over **8,400** completed surveys!

Once again, we send a huge 'Thank-You' to those who have already completed the survey! You and your family have played an important role in building and expanding the Family Registry resources.

If you have not yet received the survey, you may contact your BCFR site under the “CONTACT US” section on the bottom of the next page.

## MEET A RESEARCHER

Catherine Benedict, PhD



To view Dr. Benedict's full profile, click [here](#).

Dr. Benedict is a Clinical Psychologist, Clinical Assistant Professor in the Department of Psychiatry and Behavioral Sciences - Medical Psychiatry of Stanford Medicine, and a co-investigator in the Young Women's Study. Her clinical focus is the treatment of cancer survivors coping with late or long-term effects, including physical, emotional, and interpersonal difficulties, particularly within the adolescent and young adult population. Young people affected by cancer face a number of unique, age-specific issues such as disruption to education and early career achievements, issues surrounding dating and disclosure, relationships with peers, and feeling socially isolated. Questions about fertility, reproductive potential, and family building are also major concerns that can be quite distressing. Survivors may need to pursue alternative family-building options to have a child (or more children) after cancer, including the use of reproductive medicine and adoption or fostering, and there is a lot of uncertainty about what those entail. Dr. Benedict's research focuses on building patient-focused resources to support young people in managing the long-term effects of cancer and being able to achieve important life goals such as parenthood.

If you or someone you know is interested in learning more about fertility and family building after cancer, Dr. Benedict is conducting a study to test an informational website designed to make women feel empowered to make decisions and plan for future parenthood. To learn more, click [here](#).



Other great resources to learn about cancer and fertility are the [Oncofertility Consortium](#) and the [Alliance for Fertility Preservation](#).

## HEALTHY TIPS

### May is Skin Cancer Awareness Month

Skin cancer is the **most common cancer** in the United States and worldwide, with 1 in 5 Americans who will develop skin cancer by age of 70 years. The good news is that 99 percent of all cases are curable if they are diagnosed and treated early enough. But in order to stop skin cancer, we have to spot it on time.

**Skin cancer is the cancer you can see.** Unlike cancers that develop inside the body, skin cancers form on the outside and are usually visible. That is why skin exams, both at home and by a dermatologist, are especially important.

**Early detection saves lives.** Learning what to look for on your own skin gives you the power to detect cancer early when it is easiest to cure. The Skin Cancer Foundation recommends that you perform a thorough skin self-exam once a month. If you see something NEW, CHANGING or UNUSUAL, get checked by a dermatologist right away.

Source: [Skin Cancer Foundation](#)



To learn more about skin cancer screening, prevention, causes, or treatment, please visit National Cancer Institute's page [here](#).

### How to perform a skin self-exam:

*What you'll need:* a bright light, a full-length mirror, a hand mirror, two chairs or stools and a blow-dryer. Be sure to document your findings by writing them down, or use your phone to take picture.

 <p><b>1. Examine your face</b></p> <p>Especially your nose, lips, mouth and ears — front and back. Use one or both mirrors to get a clear view.</p>	 <p><b>2. Inspect your scalp</b></p> <p>Thoroughly inspect your scalp, using a blow-dryer and mirror to expose each section to view. Get a friend or family member to help, if you can.</p>	 <p><b>3. Check your hands</b></p> <p>Palms and backs, between the fingers and under the fingernails. Continue up the wrists to examine both the front and back of your forearms.</p>	 <p><b>4. Scan your arms</b></p> <p>Standing in front of the full-length mirror, begin at the elbows and scan all sides of your upper arms. Don't forget the underarms.</p>
 <p><b>5. Inspect your torso</b></p> <p>Next, focus on the neck, chest and torso. Lift the breasts to view the undersides.</p>	 <p><b>6. Scan your upper back</b></p> <p>With your back to the full-length mirror, use the hand mirror to inspect the back of your neck, shoulders, upper back and any part of the back of your upper arms you could not view in step 4.</p>	 <p><b>7. Scan your lower back</b></p> <p>Still using both mirrors, scan your lower back, buttocks and backs of both legs.</p>	 <p><b>8. Inspect your legs</b></p> <p>Sit down; prop each leg in turn on the other stool or chair. Use the hand mirror to examine the genitals. Check the front and sides of both legs, thigh to shin. Then, finish with ankles and feet, including soles, toes and nails (without polish).</p>

Source: [Skin Cancer Foundation](#)

## CONTACT US

Select your BCFR site to be directed to your Research Team. Or, select BCFR to visit our website.



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Ontario



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