

Summer 2020

Karen Kinahan: A passion for survivorship

Karen Kinahan, FNP, started her nursing career in 1987 at Children's Memorial Hospital in Chicago, where she cared for children during and after their treatment for cancer. "Back then, not as much was going on in survivorship," she recalls.

She had an "aha" moment at a conference in 1997 when she met with the founders of Dallas Children's Hospital ACE Program, the first program for adult survivors of childhood cancer transitioning to an adult medical setting and primary care physician for follow-up care. Returning home, she successfully advocated for the establishment of a similar program in the Robert H. Lurie Comprehensive Cancer

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The STAR Program received the FIERCE Award for Survivorship from the Biden Cancer Initiative in 2018. Left to right: Dr. Jill Biden; Aarati Didwania, MD, Medical Director, STAR Program; Karen Kinahan, FNP, Coordinator, STAR Program; former Vice President Joseph Biden

Julia Stepenske: Survivor and survivorship nurse

In 1989, when Julia Stepenske was an adolescent, she was diagnosed with anaplastic large cell lymphoma. "Karen Kinahan was my primary nurse at Children's Memorial Hospital. She really got to know me and my family, helping us through a difficult time," Julia recalls. "She's been my nurse ever since. When

she piloted the STAR Program, I was one of the first patients to go to Northwestern for adult survivorship care."

A few years later, Julia was a college freshman who thought she was headed for medical school until she realized that she wanted to give patients the kind of support

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A NOTE FROM US

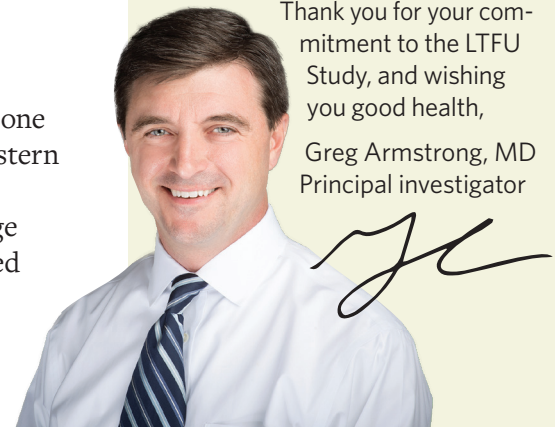
Year of the Nurse

2020 was declared "Year of the Nurse and Midwife" by the World Health Organization. In this issue we focus on two outstanding examples of the importance of nurses in survivorship. Julia Stepenske, a member of the LTFU Study Education Committee, is a nurse and cancer survivor. When she suggested featuring Karen Kinahan, who pioneered one of the earliest survivorship programs, she didn't realize we would want to tell her story as Karen's patient too. Thank you to Julia, Karen, and all the nurses and Advanced Practice Providers (APPs) who help adult survivors of childhood cancer thrive throughout their lives.

COVID-19 and LTFU

To help you keep informed during this challenging time, we have added up-to-date resources to ltfu.stjude.org and the myLTFU portal. Stay-at-home orders for LTFU staff have paused our mailing of paper surveys, so myLTFU has become the main tool for study participation. You can activate your account here: ltfu.stjude.org/myltfu.

Thank you for your commitment to the LTFU Study, and wishing you good health,
Greg Armstrong, MD
Principal investigator



LTFU research addresses fertility outcomes of childhood cancer survivors

Late effects of childhood cancer treatment on reproductive function can pose long-term psychosocial and health-related challenges for some survivors.

Here are two examples of how the LTFU Study is helping to improve survivors' fertility-related quality of life.

Predicting acute ovarian failure risk

Based on data from female LTFU participants, researchers have developed a simple online tool to identify risk of acute ovarian failure (AOF) among childhood cancer patients. AOF, which is the loss of ovarian function during or shortly after cancer treatment, affects more than 6% of women treated for childhood cancer.

The new tool offers health care providers a rapid and precise calculation of a patient's risk so they can discuss fertility preservation options, or help patients at low risk to avoid unnecessary procedures.

"Predicting acute ovarian failure in female survivors of childhood cancer: a cohort study in the Childhood Cancer Survivor Study (CCSS) and the St Jude Lifetime Cohort (SJLIFE)." Lancet Oncology, Feb. 2020

Measuring male perceptions of infertility

Understanding the risk of infertility is important. Men who do not know their infertility risk may be less likely to consider fertility testing or seek reproductive assistance. Men who overestimate their infertility risk may not use contraceptives, resulting in unplanned pregnancy.

More than 12,000 male survivors rated their risk of infertility compared to other men their age without cancer. LTFU researchers then assessed their risk based on their cancer treatment ("gonadotoxic" treatments are those that affect fertility):

- 311 of 857 survivors (36.3%) who received gonadotoxic treatment perceived no increased risk of infertility.
- 132 of 376 survivors (35.1%) believed they were at increased risk although they did not receive gonadotoxic treatment.

Overall, nearly 36% of the 12,000 survivors reported perceptions of infertility risk that were not consistent with the treatments they received. The study's authors emphasize the need for accurate, individualized health information regarding risks of infertility for all survivors of childhood cancer.

Citation: "Perceptions of risk of infertility among male survivors of childhood cancer." Cancer, June 2018.

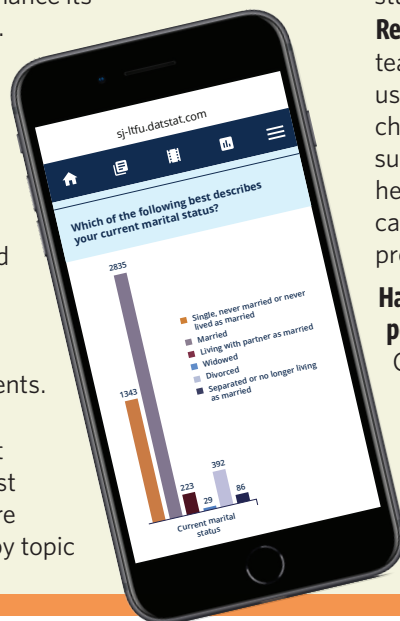
The LTFU Study Community

In addition to providing quick and easy access to the latest LTFU Study survey, the myLTFU portal offers additional features that enhance its usefulness for participants.

Real-time data about the LTFU Study community:

After they finish their surveys, participants can see, in real time, how other participants who completed the survey answered selected questions, including marital status (shown here), education, employment, and living arrangements.

Newsletters: LTFU Study newsletters, from the most recent issue back to the first issue, published in 1996, are available and are indexed by topic



so you can browse for useful information, resources, and study results.

Resources: The LTFU Study team has compiled links to useful, reliable information about childhood cancer survivorship, support, and recommendations for healthy living after treatment for cancer. Resources for health care providers are also included.

Haven't activated your myLTFU portal yet?

Go here to get started:

<https://ltfu.stjude.org/myltfu.html>

If you don't have a key code, just let us know and we'll be happy to help.

Call: 800-775-2167 Email: LTFU@stjude.org



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Center of Northwestern University. By 2001 the STAR (Survivors Taking Action and Responsibility) Program was offering survivorship care to adults in a comprehensive setting.

Julia Stepenske (see accompanying story), a survivor of childhood cancer who is Karen's patient and also a survivorship nurse, emphasizes Karen's contributions to the field: "She's been doing this her entire career, trying to streamline and improve care for survivors. She started one of the first long-term follow-up clinics for children, and then she realized that adult patients needed help navigating their follow-up care too. Survivorship is Karen's passion."

Karen Kinahan, FNP (left), Coordinator of the STAR Program at Northwestern University's Lurie Comprehensive Cancer Center, and Julia Stepenske, RN, a childhood cancer survivor and nurse coordinator in the POST program at Advocate Children's Hospital.



Nurses' role in survivorship

"Nurses are key to survivorship care," Karen explains. "Nurses and other Advanced Practice Providers ask about what's going on in a survivor's life, and educate patients about how they can protect their health. They are really an important part of the survivor's team during and after treatment."

"About 60% of our patients are transitioning from the pediatric STAR Program at Lurie Children's Hospital," she says. "Younger survivors may be concerned about fertility, while older survivors may be grappling with a second malignancy or chronic health condition. Sometimes the challenges are psychosocial, like body image or depression. A survivor may become anxious about upcoming breast imaging, or upset by an abnormal result. Supporting these patients is vital."

Know your risk

Karen encourages survivors to learn as much as possible about the potential effects of their treatment. "Knowledge is very important," she says. "It can be scary but it can also be empowering. There are two sides to the survivor role: Knowing your risks and educating your providers, who may not have cancer survivorship expertise."

Whatever it is, talk about it

"If something is on your mind, write it down, make a list of your questions, and bring it up with someone on your healthcare team," she advises. "Whether it is a physical or emotional issue, let's talk about it and address it. Survivors may feel stigmatized, or guilty about surviving. Sexual health, mental health—there are so many important topics. We are here to help our patients."

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and compassion that Karen and other nurses had given her. "Karen's one of the reasons I wanted to do survivorship," she says.

Julia became a nurse and focused on cancer care. "Bone marrow transplantation was my special passion," she recalls. In 2008, when she was pregnant with her second daughter, she had a late recurrence of cancer. "If I hadn't had Karen to coordinate everything I needed, my care would have been delayed. Having an advocate to help navigate the adult health system is so important."

Today, Julia is a nurse coordinator in the Pediatric Oncology Survivors in Transition (POST) clinic at Advocate Children's Hospital in Park Ridge, IL.

"I will sometimes share with a patient that I'm a survivor, especially if someone has a lot of distress and is thinking, 'I just don't think I can do this.' We can get what I call 'survivor fatigue.' The journey doesn't end, it's lifelong. As soon as I get all my tests done, I start all over. Sometimes you just want to be normal and not worry about all this stuff. It can be exhausting. I can empathize with my patients."

Oncofertility Consortium

Fertility-related resources for survivors.
www.oncofertility.northwestern.edu

Get Empowered videos

Produced by the STAR Program for adult survivors of childhood cancer.

www.cancer.northwestern.edu/cancer-care/survivorship/star-program/get-empowered.html

Resources