

Survivor Connection



An electronic newsletter from SurvivorConnect
A project of the Survivorship Clinic
Division of Pediatric Hematology/Oncology

- Did You Know?
- Childhood Cancer and Fertility
- A Cancer Survivor's Fertility Story

**MARK YOUR CALENDARS!
SURVIVOR SHINDIG!
Monday, Nov. 23, 2015,
5:30 pm - 8:30 pm**



SURVIVORS, FRIENDS, RELATIVES, NEIGHBORS!

Join us for a great evening at one of Pittsburgh's hottest new spots in the Strip District, Wigle Whiskey!

Find out what all the fun is about and eat some amazing food from the local Food Trucks!

Survivor parent, Val Prosser and the folks at Wigle

Did You Know?



Three out of five who survive children's cancer suffer late-effects, such as infertility, heart failure and secondary cancers. We have chosen the topic of infertility this month. Many of the questions we hear in clinic surround this topic. Hear from a survivor, Beth, who struggled with fertility, our own Nurse Aimee and a great resource, the Fertility Preservation Program at Magee Women's Hospital.

Childhood Cancer and Fertility

Infertility is a potentially unfortunate side effect of some cancer treatments. In those diagnosed with cancer during childhood, discussions about fertility are often lacking possibly because



Fall 2015

Fertility and the Cancer Survivor



by Aimee Costello, DNP

We've said it before... overall childhood cancer survival rates exceed 80%! However, many of you know that oftentimes cure does not come without its cost. For those exposed to certain chemotherapy drugs and radiation sites, infertility can be a significant risk; and that is a frequent topic discussed in Survivorship Clinic.

Females are born with a finite number of ovarian follicles or "eggs." As we naturally age, the number of follicles drops from about one million at birth to about 25,000 in our thirties. By our forties that

Whiskey have arranged for an evening to support SurvivorConnect and the programs of the Survivorship Clinic at Children's! 12% of the proceeds from the evening will be donated to the Survivorship program!

Wigle is a family owned and operated lark. The distillery became operational in December of 2011 and opened to the public in March 2012 after two years of lobbying to change the state laws to allow for an on-premise model of craft distillery to exist in Pennsylvania.

In 2015, Wigle became the most awarded craft whiskey distillery in the US by the American Craft Spirits Association and won Best Craft Rye Whiskey in America in the same double-blind competition of hundreds of whiskeys from around the country.

We hope to see you all there (over 21!)

Questions? Email survivorconnect@gmail.com.

Survivors - Find Us on FACEBOOK



We have a CLOSED Facebook group! If you want to join, send your email address to survivorconnect@gmail.com. We will send you an invitation to join!

Do you have a survivor story to share?

conversations about fertility can be uncomfortable or upsetting for patients and families. We believe that patients should be told about the risks associated with infertility and the options available to them.

In the past, little was known about how to protect cancer patients' fertility during treatment. While more recent research has been done in this area, childhood cancer survivors treated before these possibilities were available still have options that may be explored with a fertility specialist, while others choose to watch and wait.

The **Center for Fertility and Reproductive Endocrinology** in Pittsburgh of UPMC offers many procedures and fertility preservation options for adults. We refer several male patients for sperm analysis testing. Female patients have a variety of options to be explored with a fertility specialist depending on your specific risk for infertility or early menopause.

At a consult with the Fertility Preservation Program you can expect to have bloodwork done and to speak with a fertility specialist to receive a more definitive answer on your specific risk for infertility and what options you have for the future. It is important to note, however, that not all services offered may be covered by your insurance provider.

Others feel more comfortable with not seeking this information. With this approach, you may know that you have certain risk for infertility, but may choose to wait and see how things play out, not wishing to pursue workup and possible treatments listed above. We have had some patients with hormone levels that pointed to infertility but were still able to have children. This was to our great surprise! There is not a right or wrong way do this – it is what feels best for that person.

number is down to about 1000 and that is when menopause and permanent infertility most commonly occur. Female survivors may experience early menopause due to follicle destruction during treatment. Acute ovarian failure may occur within five years of treatment, but premature menopause may also occur, simply meaning that menopause may occur much earlier than age 40. Many of you participate in the Childhood Cancer Survivor Study (CCSS) and that research has revealed that premature menopause is 13 times higher among female survivors than the sibling control group.

As we know, males are very different. They continue producing sperm across the lifespan and do not have a window of child-bearing potential. However, they do carry a significant risk of sperm abnormalities (particularly low or undetectable levels of viable sperm) following certain cancer treatments that may also result in infertility. Risk may be up to 4 times higher in survivors compared to sibling controls.

Common chemotherapy agents that carry infertility risk in males and females include busulfan, cytoxan, ifosfamide, procarbazine, carboplatin and cisplatin. Radiation sites include the head, nasopharyngeal, abdomen, bladder, pelvis, spine, prostate and total body irradiation. Higher



Contact Noelle at survivorconnect@gmail.com if you would like to share your story!

KENNYWOOD PHOTOS

Here are some photos from our recent Celebrate Survivorship Picnic held on National Cancer Survivors Day on Sunday, June 7 at Kennywood Park! Mark your calendars for next year - **Sunday, June 5, 2016**



For more information about the Fertility Preservation Program in Pittsburgh, you may visit their website:

<http://www.mwrif.org/220>, or contact Katherin Gassei (Program Coordinator) by calling the dedicated phone line at 412-641-7475 or email them at fertilitypreservation@upmc.edu.

Contact:

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[Website](#) [Info](#) [Orwig Lab](#) [Facebook](#)

A Cancer Survivor's Fertility Story

by **Beth Luptak**

I love numbers and patterns. It's natural, I'm a math teacher. It also seemed natural to start a family with my husband after being married for several years. I used my love for numbers and patterns to determine possible conception and birthdates, maternity leave, budgets, and saving for a minivan.

Then the numbers started to betray me:

- 2 years of being unable to conceive naturally, led to...
- 6 IUI (inner uterine insemination) sessions with one miscarriage
- then 24 eggs collected and 18 fertilized with one failed IVF transfer of 2 embryos



risk is experienced based on dosing and combination therapy.

Some common labwork associated with infertility testing includes LH (lutening hormone), FSH (follicle stimulating hormone), testosterone, estradiol and AMH (anti-mullerian hormone). Males are frequently referred for semen analysis. We are fortunate to have an excellent working relationship with [The Center for Fertility and Reproductive Endocrinology](#) department at Magee Hospital in Oakland.

For more information, contact:

Center for Fertility and Reproductive Endocrinology
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Suite 5150
Pittsburgh, PA 15213

Phone: 412-641-7475
Fax: 412-641-1077





- which was 5 years total of trying to conceive.

We pursued treatment with a reproductive specialist because I am a survivor. I was diagnosed with Acute Lymphocytic Leukemia (ALL) at age 13 and had three years of chemotherapy. At that young age I just wanted to survive and have my hair back, then again, putting my wig on in the morning did save me a ton of time each day! ***As a teenager, I didn't consider the possibility of infertility as an adult.***

When I realized my infertility issues may be related to my ALL diagnosis, I consulted my oncologist, my OB/GYN and then a reproductive specialist. After completing various levels of tests, they all agreed – my ALL diagnosis shouldn't be inhibiting my chance of conceiving. It was a relief to know the choices made over twenty years ago were not to blame. Then again, who wants to be labeled with “unexplained infertility?”

So, back to the numbers – our second round of IVF had a 48% chance of conceiving a singleton and 16% chance of twins. It turns out 16% was all we needed. Our sons were born just shy of 37 weeks gestation, after 20 days of bed rest, and weighed in at a hefty 6lbs 10oz and 5lbs 12oz, and spent 0 days in the NICU. They are now 4 years old and take 0 naps during the day. But that's fine with me, our love for them is infinite!



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