

# IUSCC PINK

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*"Now mark me how I am undone."*

*-William Shakespeare, Richard II*

Dear Friends,

I've been thinking a lot about this lately. How a diagnosis of breast cancer can make our patients (and their families) lives come undone. A colleague likens this to the impact of the 9/11 attack – suddenly life changes and it seems like there is no safe place in the world. But women are resilient and frequently emerge as stronger versions of their former selves as Shelby and Lorri Mathias's essays attest (see the following pages).

I've also been thinking the many ways our therapies add to the 'undoing.' Hippocrates admonished physicians to 'First do no harm' but sometimes our therapies do cause harm. Though patients have complained about changes in cognitive function during chemotherapy for years, only recently has this area been subjected to careful study. How common is 'chemo brain'? Are the effects transient or permanent? Does hormonal therapy affect brain function? While this area of research remains in its infancy, preliminary results suggest the effects are quite real and important for some patients. We are delighted to join Drs. Saykin and McDonald in their hope to understand (and perhaps prevent or treat) chemobrain.



## *What is Oncotype DX?*

Oncotype DX™ is a test that measures the likelihood of disease recurrence in women with early stage breast cancer. With this information, it may be possible for doctors and patients to make more informed decisions about breast cancer treatment options.

Oncotype DX is only appropriate for newly diagnosed women with stage I and some stage II, ER+ and lymph node negative breast cancer.

Oncotype DX analyzes a specific set of genes within a tumor to determine a Recurrence Score™.

**Please talk with your Physician for more information.**

Perhaps most importantly, I've been thinking about how we can 'undo' breast cancer as a major cause of death. A monumental change is afoot in how we think about and treat breast cancer from a world where anatomy was king to a world where biology rules. In the past, treatment decisions were based on tumor size and whether any of the lymph nodes were involved. While these are still important considerations, our first questions now focus on the 'character' or 'biology' of the tumor. Women have long understood that 'one size NEVER fits all.' That's true in breast cancer therapy as well. For example, which women with estrogen receptor positive lymph node negative breast cancers truly need chemotherapy? A simple test using gene chip technology (Oncotype Dx Recurrence Score Assay) helps us clearly answer this question for three out of four women. At least partly individualized therapy in a sense we previously didn't dare dream is now routine.

We're not there yet but this is a tremendously exciting time. Decades of basic research has started to bear fruit in the clinic. We can finally start to imagine a day when little girls don't hate the sight of flowers.

**-Kathy Miller, MD**

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# The Hallway that Never Ended

Have you ever been in a situation that you just wanted to roll up in a ball and jump off the Empire State Building?

I have. I was eight. I thought 3rd grade would be the worst time of my life, boy was I wrong. It was a bright sunny fall day and school just let out. My stop was up next and I couldn't wait. I just wanted to go in the house as fast as I could and give my mom a big hug because I got an A+ on my social studies test that she helped me study for the whole entire week before. Mom would be so proud of me I thought. I ran in the house screaming MOM, MOM, I GOT A ... I just froze. My mom was lying on the couch wrapped up in the blanket that my grandma knitted. It looked like she was worried about something but I really didn't know what. Mom, who died? I said trying to lift up the moment with my humor. She looked at me like she always did when I was in trouble. No one Shelby, she said. I turned serious for her. Then what is it? I said, not really looking forward to the answer. I never look forward to bad news. Of course who does, but I'm different. At that time I still remembered the last bad news. Mom sat down and told me we would have to put down my beloved horse Buck. I cried for days. I may have cancer, she said. I was shocked. At that very moment in my head I went back to the time when I was three years old. Mom and I were outside on a warm sunny summer day. Mom and I were sitting on a big swing. I asked,

*"Mommy, will you ever get cancer"? Of course not she said.*

Mom sat down with me and talked to me about the situation. Truth be told, the doctors had to do lots of surgeries to determine if she did and what treatments to do. They ended up taking out a lot of lymphnodes to test. That alone caused lots of problems. She got lymphedema from it. Two months and seven surgeries later my mother was diagnosed with breast cancer. I was so scared because there was a chance of her dying. My parents told me it was nothing to worry about. For a while I actually believed them. For the next two months there were a lot of questions and crying in our family and our house smelled with flowers, all different kinds of them, blue ones, pink ones, and purple ones. All for my mom. It was very hard for me to except the fact that my mom had cancer. My mom was finally tested to see if she needed chemo, radiation, and a mastectomy. Two



*Shelby Mathias pictured with her mom, Lorri.*

weeks later the truth arrived. Yes was the answer. We cried for hours. The day of the surgery mom dropped me over at Rachel's house to get on the bus to go to school. She was my best friend at the time. After school my grandma was in the driveway waiting to take me to the hospital. When we got to the hospital my family was all waiting in the waiting room. I only waited ten minutes before being called into the recovery room to see her. She was in pain. Barely opening her eyes, Mom looked at me. It wasn't just any look, it was the look of pain and fear. That was so hard to see my mom in so much discomfort. At least she was comforted by family and of course flowers. The following three days I spent most of my time by her side. Sometimes I crawled in bed with her and found comfort under the flat pillows, sanitized bed sheets and multi-colored wires. The fact that I was with her was the only thing I needed to fall asleep. On the second to the last day of her hospital stay they made her walk. My mom was not looking forward to that. I didn't understand why that was such a big deal. Once my mom got up she was screaming in pain. I started crying, make her stop, Mama make her stop. Then my dad shushed at me. She needs to do this. She was walking out of the room with tears filling both mine and her eyes. It was the hardest thing to see her like that, screaming and crying at every step the nurse pushed her into. It seemed like the hall never ended with it's light baby blue walls and tan floor that looked like upchuck. It seemed like it could go on forever. There were two nurses at the counter over looking the evil hallways. Oh poor little girl, one of them said. It's sad how one little innocent child has to deal with all of this.

*By Shelby Mathias, March 2007, 5th grade*

## *The Journey*

My mom was going at a very slow pace but I still wasn't allowed near her because she could have fallen at any moment. The next day, it was time for her leave. She waddled her way out of the hospital even in a wheelchair she was still in pain. She was so happy to get home to see my animals. Dad and I unloaded all the flowers from the trunk while mom rested on the couch. After Dad and I were done we helped mom into the bedroom so she could take a long nap. She spent a whole month in that very same spot. Occasionally she got up to watch Dr. Quinn in the living room, but not often.

*She still was comforted with her stinky pretty flowers.*

People made lots of dinners for us. Right when things were settling down they had to start back up again. Mom would soon have to start chemo, radiation and fill-ups. I wasn't ready for her to lose her hair. In fact I wasn't fond of a bald-headed mom at all. Mom didn't absolutely love it either. The day of the first chemo treatment mom was scared and I was too. It took a few weeks for mom to start thinning out. One night after I took my bath I got out and cleaned out my newly pierced ears. After I used the cotton ball, I threw it in the trash and that is when I saw it. Mom's hair! It was all bundled up in a little ball. I showed Daddy and he freaked out. The next morning Mom walked out crying with her little bald head. She still had a little hair, but not much. I told her not to cry and I comforted her. Later that day all three of us had a ball shaving her head. That was probably the first time in months that we laughed. A few weeks after it was time to start fill ups. I got to go with her. What they did was stick a humongo needle into her flesh and injected this liquid. Six months later she was done with chemo and started radiation. Six weeks after she ended radiation. She had a year of fill-ups so do the math. Since then we've gone to a lot of survivor banquets and stuff. We've been invited to dinners and other festivals. My mom was even invited to speak in front of our church. It's amazing that we've become accustomed to hospitals and stuff. I love my mom. She is my ROCK that stands tall and proud! She is the strongest person I know. I am so thankful to say that my mom is a survivor. Our experience has brought us closer together and closer to GOD. I am so lucky to have her.

*She is indeed my hero!*

I truly feel God has allowed me to go through my cancer journey to come out blessed on the other side. That may be hard for some to understand, but I know there are those who will understand what I'm saying. I still have struggles, but I'm never alone in those struggles.

My family and friends have been with me every step of the way, and I love them for that. Worrying my family and friends has been one of the most difficult parts of my journey. Watching my young daughter grow up much faster than she should have is also difficult. I have met and become friends with so many good people.

I would have missed these friendships if it weren't for my journey. I work with a team of wonderful people at Riley Hospital. They were and continue to be a huge support system to me. Each year, we have a team in The Komen Race for the Cure. We always have a large number of participants and enjoy the day.

The care I received and continue to receive at the Indiana University Melvin and Bren Simon Cancer Center is second to none. I thank you one and all for that. Barbara (Thompson, RN) you ROCK!!

I see things differently now. As I walk by the oncology unit daily at Riley Outpatient Center, I see more than little bald heads. Some I've talked to, others I say a prayer for. This journey is not over by a long shot. I plan on enjoying every moment that I've been given.

By Lorri Mathias, 2 1/2 year survivor

You may have noticed our name is a little different on this issue. As the Indiana University Cancer Center begins to transition into its new name, the Indiana University Melvin and Bren Simon Cancer Center, we've also changed to Indiana University Simon Cancer Center (IUSCC) Pink.

# When a Parent Has Cancer: Helping Kids Cope

A diagnosis of cancer affects the whole family. For the person diagnosed, it's difficult enough for them to process their own feelings about your cancer, let alone think about how they will tell their children. One of the most important things to remember is that kids are more resilient than we may give them credit! I want to share some ideas that you may find helpful.

Use clear, simple, and appropriate language with children. Years ago, it was not as socially acceptable to use the actual term "cancer." However, using appropriate terms and language is very important with kids. A few years ago, I was working in the chemotherapy area at Cedars Sinai Cancer Center, when I came across a female patient crying. When I approached her and asked if I may help, she shared how close she was with her 6 year old granddaughter and yet the previous night, her granddaughter ignored her and wouldn't go near her. As I explored further, I found out her granddaughter was not told she had "cancer," she was told her grandmother was "sick." As we talked more, her granddaughter was only responding in a way she had learned – to stay away from someone who is sick because she may catch it. This is a great example of why being clear and using appropriate language is so important.

Keep the kid's age in mind when sharing about cancer. Be mindful of your kid's age when talking with them about your cancer. Depending upon your child, you may choose to share more detail for example with an inquisitive twelve-year-old than a five-year-old.

Encourage your kids to talk about and express their feelings. For younger children, you may want to let them use drawing and coloring as a way to express feelings. If your children are a little older, you may want to frequently give them permission to talk and ask questions. Another good thing to do is role model. For example, when you are with the kids you may share something like "daddy's cancer makes me feel sad sometimes." This helps them to identify a feeling and learn that it's okay and safe to talk about.

Let teachers or other important figures in your kid's life know what is going on. Many times it helps to let teachers, coaches and babysitters know what is happening with a cancer diagnosis in the family. It may help alert them to behavioral changes and help with knowing how they can be there for the kids.

Take your kids with you to your medical appointment. By taking your kids to a medical appointment and even touring the cancer center, their concern and fears of the unknown will be lessened. As an oncology social worker, I always encouraged parents to bring kids in so I could provide a tour. It helps to see the physical space, as well as meeting the medical team involved with your care. As an example, when your child knows you are going to chemotherapy, when they think of you during that time, they can actually picture where you will be and know that the kind staff will be taking good care of you. Just be sure to talk with your medical team first to identify the best time for such a tour.

Keep schedules and routines as "normal" as possible. Kids actually tend to do best when kept to some schedule. It can be difficult to juggle cancer treatments with activities such as soccer and music lessons. If you know that you will have a schedule conflict, ask a friend or relative to take your child. This will keep some normalcy and helps keep your kids engaged with activities and people that are helpful for them too.

## Celebrating Life 2007



In April, we had the first Breast Cancer Update 2007: Celebrating Life. This was an educational event designed specifically for our patients. To our surprise, what started out as a small local event grew to approximately 500 attendees from all over the state. The IU doctors, nurses, and staff enjoyed catching up with all of you. Due to the success of this first event, we have decided to make it a regular affair and invite all of our IU breast cancer patients. Please check out the Q & A section of the newsletter as these are your questions from the Celebrating Life Event.

## Breast Cancer Q & A

Identify resources for you and your kids. Check out what resources are available to you and your children in your community. Here are three key resources that I use in my practice:

-There is a great book, "Helping your Children Cope with your Cancer" by Peter Van Dernoort. This book offers great tips and inspirational stories.

-Visit [www.kidskonnected.org](http://www.kidskonnected.org). I have used Kids Kon-nected for several years at various cancer centers. It's a wonderful free Web site that offers information for parents and kids. You can even order free age-appropriate educational materials as well as a teddy bear!

-Kids/Parents Connect at The Wellness Community-Central Indiana. We offer a program called Kids/Parents Connect that is free and open to kids ages 5 to 14. We meet on the second and fourth Wednesday of each month from 4:30 p.m. to 6:00 p.m. While the kids do art therapy with a licensed play therapist, I meet with the adults to discuss how their kids are doing and appropriate ways to intervene. Please call 317-257-1505 or visit our website [www.twc-indy.org](http://www.twc-indy.org) for further information.



Dwayne A. Kniola, LCSW, OSW-C  
Clinical Program Director  
The Wellness Community-  
Central Indiana

## Nutrition & Breast Cancer

Please join our group nutrition education program for patients with breast cancer.

**Where:** IU Simon Cancer Center, Rm 102,  
(Education Center, 1st floor)

**Date:** Monday, September 10, 2007

**Time:** 1:30-3:30 p.m.

**Facilitator:** Anna Zufall, MMSc, RD, CD  
Oncology/Hematology Dietitian

This class will explore healthy eating, low-fat diets, and activity guidelines. Please join us as we discuss the Women's Intervention Nutrition Study (WINS)-reduced fat may decrease breast cancer recurrence. Parking will be free, bring your ticket for validation.

**Q: Is the medical profession taking "chemo brain" as a serious complaint by survivors?**

**A:** Absolutely. We recognize this to be a real and important problem in many survivors. Some very elaborate research is currently being conducted to understand why this happens and potential ways to prevent/minimize this side effect.

**Q: Do all patients with cancer get depressed?**

**A:** Most patients with cancer react to the bad news with fear, a sense of loss, feelings of anxiety, inability to think about much else, worry, and tearfulness. But, for the majority of the patients, these feelings go away over time and fighting spirits emerge along with a desire to normalize life as much as possible. However, the two best studies done show that for 1/3 of patients with cancer, these feelings of distress persist and cause levels of depression and anxiety that can impair a person's ability to function and meet all the demands of their usual roles and the management of the cancer.

**Q: Will there be a way to "cure" lymphedema?**

**A:** We hope so. There have been very few trials to date evaluating therapies for this disease. The Indiana University Breast Care and Research team is currently studying the effects of an anti-angiogenic drug, Bevacizumab (Avastin) on lymphedema.

**Q: Does reconstruction for nipples really work? I have had two failed surgeries.**

**A:** Reconstruction of the nipple areolar complex does work. If you have had two failed attempts, then it may be time for a second opinion.

**Q: What is the most effect way to check for any recurrence with a double mastectomy?**

**A:** After mastectomy, the most effective way of screening for recurrence is clinical examination. If focal tenderness is encountered then a chest CT scan or bone scan may be necessary.

**Q: What role does alcohol play in breast cancer?**

**A:** Moderate alcohol intake increases the body's estrogen levels, and thus increases breast cancer risk.

# Update on Cognitive Changes in Breast Cancer and Chemotherapy

Cognitive problems have long been known to occur in some individuals following cancer treatment. In some cancers, these difficulties can be attributed to tumor location and/or to brain radiation. However, over time it has been recognized that patients with non-brain cancers such as breast cancer, who do not receive radiation to the brain, may also report cognitive changes, suggesting that chemotherapy may also play a role in these problems. These cognitive changes experienced by some individuals following chemotherapy have received much attention recently in the popular press, and are commonly described as “chemobrain” or “chemofog”. While first recognized in the early 1980s, these concerns have received increasing scientific attention. Several research teams, including our group at IU, are now investigating the frequency of cognitive changes following chemotherapy, which cognitive areas are most likely to be affected, how severe changes may be, what the biological mechanisms for these changes are, and how they might be treated or even prevented.

## What cognitive functions are affected?

The most common problems noted by patients following chemotherapy involve cognitive processes like attention, concentration, processing speed, and short-term and working memory.

**-Attentional functions** include things like the ability to focus attention on a topic or activity, ignore distractions, sustain attention to complete a task, or pay attention to more than one thing at once (for example, when trying to “multitask”). Experiencing difficulty with such functions may result in being more easily distracted or only being able to do one thing at a time, rather than being able to juggle multiple tasks simultaneously.

**-Processing speed** is the rate at which a person can process or think through information or complete a task. After chemotherapy, some people feel it takes them much longer to complete tasks than it used to, or that they have to “work harder” to finish things that previously were routine.

**-Short-term memory** is the ability to learn, retain, and recall new information, such as new facts, or how to do new tasks. Symptoms include having increased difficulty learning new tasks, for example new programs at work, or increased forgetting of things discussed in a meeting.

**-Working memory** is the ability to keep information “on-line” while it is needed to complete a task or activity; for example, looking up a phone number and remembering it long enough to go to the phone and make the

call. Patients commonly report difficulty with this kind of “on-line” processing during and after chemotherapy. The good news is that these problems seem to improve over time for the majority of patients. While many patients notice such problems during chemotherapy and/or for several months after treatment is completed, they tend to resolve over time, with most people regaining their prior level of functioning at work and at home. However, for 17 to 34% of patients, some level of cognitive problems may persist even years after treatment has been completed. Recent research also suggests that between 20 to 35% of breast cancer patients may show some areas of cognitive difficulty before chemotherapy. This suggests that some of these concerns may be related to other biological factors which are part of the cancer disease process, not just to chemotherapy.

## Why do these changes occur?

Understanding the biological causes for cognitive changes related to breast cancer and its treatment is a critical area for research. At present, we simply don’t have the answer. Scientists have several theories about the causes for these problems. It is likely that genetic risk factors play a role, perhaps related to the body’s DNA repair mechanisms or ineffective immune system functioning. It is also thought that chemotherapy and hormone treatments may interact with these genetic risks in some individuals.

## Can cognitive problems be improved?

Both behavioral and medication treatments are being studied, to see if they can improve persistent cognitive changes after chemotherapy. Again, it should be noted that for most people, these difficulties seem to improve naturally over time as part of the recovery process. For those people who experience persistent problems, though, one possible treatment strategy is cognitive behavioral therapy, or CBT. CBT is a focused, short-term psychotherapy method, which targets specific issues for treatment. Usually, therapists who specialize in CBT will help a patient work to improve functions like memory and attention, as well as to develop strategies to compensate for or work around their areas of weakness. Medications are also being explored as a potential option for treating cognitive problems following chemotherapy. A recent open-label trial using modafinil (Provigil) in breast cancer patients about two years after completion of chemotherapy showed treatment-related improvements on attention and memory measures. A trial of dexamethylphenidate

(Focalin) also reported improvement in fatigue and a trend toward improvement in cognitive functioning. It should be noted that both of these studies reflect preliminary findings only, and have not yet been published as complete reports. However, these data suggest that medication treatment is an important area of further study.

### *What local research is being conducted?*

An ongoing study sponsored by the National Cancer Institute, and led by Dr. Andrew Saykin, director of IU's Center for Neuroimaging, is examining changes in brain structure and function that may be related to chemotherapy for breast cancer. Genetic testing is also being conducted to investigate possible risk factors that may predict which patients will develop cognitive symptoms following chemotherapy. In this study, patients who have recently been diagnosed with breast cancer (both those who receive chemotherapy and those who do not) and healthy volunteers participate in cognitive testing and structural and functional MRI scans three times: before beginning chemotherapy, radiation, or hormone therapy, about six months later (one month after finishing chemotherapy for those who receive this treatment), and about 18 months after the first visit. This study is currently enrolling participants and interested individuals can receive more information by contacting Dr. Brenna McDonald at 317-278-8878. A multidisciplinary team of IU Simon Cancer Center researchers is also planning future integrative studies on this topic.

-Brenna C. McDonald, PsyD and Andrew J. Saykin, PsyD



Living Beyond Breast Cancer

### *Featured Web site*

This Web site is part of a nonprofit organization dedicated to empowering all women affected by breast cancer to live as long as possible with the best quality of life. It offers educational information and free programs. Its next teleconference covers Follow-up testing: What you need to know. The Stay Informed section has all the latest news on breast cancer and clinical trials. This is a great section to read more about something that you heard about on the news or from a friend. For more specific information, you can click on the quick links for Newly Diagnosed and Advanced Breast Cancer. Visit this Web site to always be informed!

[www.lbbc.org](http://www.lbbc.org)

## *In the News...*

### *Mary Ellen's Tissue Bank*

You may have heard that Susan G. Komen for the Cure recently awarded IU Simon Cancer Center with funds geared towards expanding from a local bank to a national repository for tissue. We are so excited to receive such a wonderful gift. This is a project that would have never been a success without many of you! Thank you for participating in the Friends for Life events that help create Mary Ellen's Tissue Bank. Currently, we are working hard at organizing, planning and deciding on a name for this new bank. Watch for the announcement of our inaugural event in future editions of IUSCC Pink. In the meantime, if you haven't donated visit us at the Indiana State Fair on Aug. 11th in the Clarian Building to contribute.

### *Vera Bradley Foundation for Breast Cancer*

The 14th annual Vera Bradley Classic raised \$1,045,250 during a women's golf and tennis tournament, held in Fort Wayne. Players and volunteers came together to have fun, increase breast cancer awareness and raise funds for research on behalf of the Vera Bradley Foundation. All money raised at the event supports breast cancer research at the Indiana University Melvin and Bren Simon Cancer Center. The funds raised will advance promising breast cancer research through recruitment of the best scientific investigators and support of state-of-the-art shared facilities that make research possible

### *Daniela Matei, MD*

Dr. Matei, assistant professor of medicine, has received the 2007 Department of Medicine Young Investigators Award in recognition of her basic and clinical research in ovarian cancer clinical and laboratory research. The Young Investigator Award is chosen annually by the Department of Medicine. It is based on outstanding achievements in research and evidence of emerging excellence in the investigators' chosen field.

### *Kathy Miller, MD*

Dr. Miller, associate professor of medicine and breast cancer researcher, has received the Young Investigator Award from the Eastern Cooperative Oncology Group (ECOG), a network of researchers and clinicians that conduct cancer clinical trials. ECOG presents the award each year to recognize outstanding contributions to research in the cooperative group, which is one of the largest clinical research organizations.

## ARE YOU INTERESTED IN LEARNING MORE ABOUT BREAST CANCER?

Sign up to receive the *IUSCC Pink* Newsletter

Name: \_\_\_\_\_ \*E-mail: \_\_\_\_\_

Street: \_\_\_\_\_ City/Zip: \_\_\_\_\_

\*Newsletters will be sent by e-mail when applicable.

Return to Casey Allen at:

IU Simon Cancer Center  
535 Barnhill Drive, RT 473  
Indianapolis, IN 46202

INDIANA UNIVERSITY  
MELVIN AND BREN SIMON  
CANCER CENTER



Or send an e-mail to [calallen@iupui.edu](mailto:calallen@iupui.edu) with the above information.

Do you have a story idea or just something to say about a story you've read in *IUSCC Pink*? Tell us about it! Would you like to share a personal experience? Contact us via e-mail [calallen@iupui.edu](mailto:calallen@iupui.edu), call 317-274-0594 or send mail to the address above.

Past editions of *IUSCC Pink* can be viewed at the IU Simon Cancer Center Web site, [cancer.iu.edu](http://cancer.iu.edu), by selecting breast cancer in the cancer type section (<http://cancer.iu.edu/programs/breast/iuccpink/>).