

Interview: Dr. Bohle

By Klaus Dragon Heiman

Our nine-year-old son, Klaus Dragon Heiman, has been a patient at MSKCC since 2009. Klaus is currently a third grader at Foothills Elementary School in Boulder, Colorado. Earlier this fall, he was given the assignment from his teacher to "interview an interesting person" and our son chose Dr. Bohle, formerly of MSKCC's Dental Services. In May of 2009 Klaus had his lower left mandible removed because of a sarcoma called plexiform fibrohistiocytic tumor. Since this major surgery, Klaus has been a regular visitor to the dental team — taking steps toward a complete and successful dental reconstruction. Klaus's experience as a child in a dental chair has only been a positive life experience and this interview with Dr. George Bohle is proof of it.



Tim and Tracy Heiman

Dentists help build new teeth
for people who need dentures
or fake teeth.

Dr. Bohle was born in Baltimore,
MD.

He went to dental school in
Kansas City, Mo. after he did 3
years of residency.

He has helped people from
2 years old to 101 years old.

His favorite tool is a laser,
it cuts better than a knife.

Doctors are nice people and they
help people. Dr. Bohle likes to
be a dentist because it is fun,
challenging and rewarding. He wanted
to be a dentist since the
8th grade.

by Klaus



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Memorial Sloan-Kettering
Cancer Center



This summer issue of *Bridges* begins the fifth year of publication of our newsletter for cancer survivors here at MSKCC. What started as a mere idea for a volunteer project has now grown into an amazing and rewarding experience for me as the patient editor of a very well-regarded and award-winning newsletter. It is truly exciting to achieve this milestone as we look forward to another year of publication.

We have had the opportunity to interact with inspiring patients, caregivers, clinicians, and staff of a premier and world-renowned cancer institution. Contributors to *Bridges* have included people of all ages and diseases. Some stories are written by individuals who are being published for the first time and others have already been published, including a Pulitzer Prize winner.

This newsletter has thrived because of advisory committee members who volunteer their time and energy as well as share their incredible and diverse expertise. From my perspective as a patient, volunteering has been an extraordinary experience as well as a privilege and it is also a way to “give back” in a meaningful way.

This newsletter remains a forum for cancer survivors to share their stories of hope and survival and also for clinicians to educate us about the latest in the world of cancer survivorship.

Cancer survivorship is an ever-evolving story. We would like to hear from you, so please share your story by e-mailing us at bridges@mskcc.org.

If you are interested in submitting your story or have suggestions for newsletter content, please e-mail bridges@mskcc.org.

My Journey By Kathryn Spata



For 20 years Kathryn enjoyed her career as an interior designer. Now she spends time gardening and painting at her house upstate in the Catskills. She is a seasoned traveler having visited 16 countries and counting!

In January of 2001 my mother was diagnosed with breast cancer. It had spread to her lungs, bones, and

brain. In February of 2003 my mother died of breast cancer. In October of 2009 I was diagnosed with stage III breast cancer at the young age of 46. The fear that had taken over me was unbearable. I came home and told my husband, and it was at that point that I decided I didn't care what it was, where it was, or how long it had been inside me, I was going to get rid of it and continue on with my life. And that's exactly what I did and never looked back. So starts my journey. The decision to go to MSKCC was simple. When the best cancer hospital in the country is in your backyard, you go there when you have cancer. The first appointment with my oncologist was comforting and non-threatening. I'm sitting in the exam room with my husband and in walks this young, vivacious blond attending. He proclaims, “YOU LOOK GREAT” and gives me a hug of all things! After the exam,

we discussed the treatment options: chemotherapy, mastectomy, radiation, reconstructive surgery, and five years of follow-up visits. Sounds easy enough; well, it wasn't. Losing your hair is the least of it. But after my first treatment I noticed the tumor had gotten smaller. The doctor agreed. And so I continued on with injections of this stuff that made me sick and tired and gain weight.

I only needed eight treatments — how bad could that be? Before my sixth visit I said to my husband, “I think the tumor is gone. I can't feel it!” He was dealing with this in his own way and patting me on the head, said, “Sure it is.” During my exam the doctor confirmed my belief; she couldn't feel the tumor. She was so excited, but we needed to be certain there was no microscopic disease, and only surgery could make that determination. I only

■ *Continued on page 6*

That Moment in Time: Realizing the Good from Cancer

By Patrick Dooley

Patrick Dooley is a 45-year-old, 18-year survivor of synovial sarcoma from Mount Sinai, New York. He works for North Shore Neon, the company responsible for the installation of a majority of the spectacular signage you see in Times Square. He has been married for 26 years to his high school sweetheart, Nancy, and has four amazing daughters: Erin, 24, Rebecca, 23, Jillian, 18, and Sarah, 16. He volunteers at MSKCC and has recently started competing in amateur triathlons.

Cancer – malignant, rare, highly aggressive, terminal – you hear these ominous words and at that moment in time your life changes forever. In our case it has changed for good. Although the cancer was mine, we as a family were the collective patient. Each of us became the heart, or the soul, the sense of humor, or the brain, as required. We approached it as a team effort, a competition, and a fight that we refused to lose. As a result, not only are we better people today, but our immediate world is a better, broader place. Cancer reconfigured our perspective, made us socially aware, and today every event we volunteer for, every fundraiser we organize or participate in, stems from that moment in time.

I became an active volunteer at MSKCC when my oldest daughter Erin was searching for volunteer work to do (because most 24-year-olds are sitting around thinking about how they can help others) and came across the Patient-to-Patient program at Memorial. Since I became involved, it has brought up memories and emotions that had lingered, just below the surface. It has also made me reflect on where we have been since that moment in time, and how we got here. At eight years old, Jillian (who was one month old when we received the diagnosis) gave up her seat as the elementary school concertmistress to a

friend whose father had recently been diagnosed with Hodgkin's disease. This innocent act of compassion, which still gives me goose bumps, had a dramatic effect on an entire community. She spent the spring break of her freshman year at NYU going to New Orleans and assisting in the continuing cleanup efforts for Hurricane Katrina.

Rebecca organized a teddy bear drive for Schneider Children's Hospital and collected personal goods for families staying at Ronald McDonald House. While a college business major, she organized a clothing drive, collecting



Patrick's daughters

suits and office wear and distributing them to homeless shelters, to be used for job interviews.

Our youngest, Sarah, has organized "Relay for Life" in our community since she was 13 (because teenage kids care about finding a cure for cancer). She jumps into every cause with a boundless energy and encourages her

peers to get involved. She volunteers at a food pantry and at a local doctor's office. Now 16, Sarah wouldn't be here today if we had not survived. She plans on starting college in a pre-med program in the fall.

My amazing wife, Nancy, ran the local "Adopt a Family" program even when we were quite possibly as needy as the families she was helping to have a joyous holiday. She is the go-to mom when our children's friends need help, or a shoulder to cry on, a secret to be shared, or a fear worked out.

These are just a few examples of things they have done – we don't keep a list, we just say: Here is a need, how do we help? Are we without flaws? Well, we are not overly concerned with saving money. We may crack an inappropriate joke when co-workers think they are "in crisis." We are impatient with those who grumble about petty things. Complain to us about your wait at Starbucks and it is sure to fall on deaf ears. We tend

to push the limits of life, we do the things we enjoy in excess, and we may eat, drink, and party a little more as well as take walks, watch sunsets, and marvel at rainbows. All with the subconscious knowledge that tomorrow is not guaranteed. We live, we do, we participate, and we want the world to be better because we were in it.

Ask the Survivor: Lymphedema

Q *How has being diagnosed with lymphedema impacted your breast cancer journey?*

A I was first diagnosed with truncal lymphedema on the day I had my last chemo treatment. I was concerned that the swelling and heaviness I was feeling in my breast was a recurrence so, initially, I was relieved that that wasn't the case. As I began treatment for the lymphedema I learned that managing it required many new skills and a great deal of time each day. I would also have to wear special compression garments. I began to understand that this was a potentially serious and, worst of all, chronic condition. This was a game changer. Until that point my treatment was focused on curing me and I hoped that I would be able to return to my "old life."

Before starting radiation therapy I had another breast biopsy after which the lymphedema spread to my arm. I also understood that the radiation therapy would likely make the lymphedema worse. It was the straw that broke the camel's back. I was overwhelmed and emotionally spent from the diagnosis and treatment I was undergoing. I was trying to battle the fatigue and get back to work and so on. I couldn't see how I could possibly make the many modifications in my life the ongoing management of lymphedema required.

Thankfully, my lymphedema therapist was an angel. During the intensive



By Christine Quinn

Christine is a 51-year-old healthcare professional who lives and works on Long Island. She was diagnosed with breast cancer (and lymphedema) in 2009. She enjoys traveling and spending time with her family and friends.

phase of my lymphedema treatment we spent many hours together over several weeks. She was compassionate and supportive in helping me cope with this new challenge. I felt completely overwhelmed trying to learn the multistep bandaging process, but she was creatively able to help manage the swelling in other ways.

Around the time I finished radiation therapy two things happened. First, my MSKCC treatment center at Commack started a lymphedema support group. I was initially hesitant to join a support group, but I went anyway hoping to learn more about dealing with this chronic condition. The group is co-led by a lymphedema specialist, who provides

guidance to help us better manage our condition, and a social worker, who is not afraid of the intense emotions we express in the safe haven of our group. Being a member of this group has been an unexpected blessing on my journey. I have met such wonderful ladies with whom I share a bond like no other in my life. We are soul sisters in the sense that no one else can really understand the challenges lymphedema brings to daily life. The leaders have created a sacred and constructive space where we can share the frustration, anger, sadness, and fear that lymphedema has brought to all of our lives. We also learn from one another and laugh a lot.

Around the time I joined the group a colleague of mine lost his beloved wife (who was close to my age) to pancreatic cancer. I realized that Maureen probably would have been grateful to survive her disease and deal with lymphedema. That insight helped me put in perspective the many challenges of dealing with lymphedema.

With my lymphedema therapist's encouragement, I began to add weight training to my routine. Even though I was intimidated at first, I joined a gym and worked closely with an experienced trainer to improve my strength. Now I work out six days a week and my arms are stronger than they have ever been! There continue to be days when the time it takes to manage my swelling is burdensome and I still wish I didn't have it — but my lymphedema is stable and I am back to living a full life.

Ask the Professional: Exercise and Lymphedema

Q Can you tell us a little about how exercise recommendations for managing lymphedema have evolved?

A Lymphedema is one of the many challenges faced by cancer survivors, particularly those with breast cancer. For many years patients treated for breast cancer were counseled not to lift more than ten to 20 pounds, carry their purse on the affected side, or engage in heavy work for fear of causing or worsening lymphedema. Though these dogmatic recommendations were not based on scientific evidence, strict adherence to them served to severely limit the quality of life for countless survivors who were reminded daily of the costs of survivorship.

In 1998, sports medicine doctor Donald McKenzie published a rousing account of a breast cancer patient's valiant attempts to get back to "real life" through the grueling sport of competitive dragon boat racing. He also wrote that his patients who trained exhaustively with their upper bodies and arms suffered no ill effects in terms of lymphedema development or exacerbations. This non-scientific letter served as a rallying cry and sparked something of a rebellion as women across North America picked up paddles to spread the simple message that "there is life after breast cancer."

In time, serious investigations followed the path blazed by the dragon



Michael D. Stubblefield, MD,
*Chief, Rehabilitation Medicine Service,
is a physiatrist who specializes in
enhancing and restoring patients'
functional abilities and quality of life.*

boat racers. The most important study concerning exercise and lymphedema is the Physical Activity and Lymphedema (PAL) Trial conducted by epidemiologist Katie Schmitz of the University of Pennsylvania. This study compared a program of slowly progressive weight lifting for 141 women who had lymphedema and for 154 women who were at risk for lymphedema. The main goal of the study for patients with preexisting lymphedema was to determine if slowly progressive weight lifting was safe and did not worsen their lymphedema. For the women at risk for lymphedema, the goal of the study was to confirm that progressive weight lifting would not cause the development of lymphedema. Additional goals included evaluating the participants' changes in body image, quality of life, muscle strength, and body fat. The results of

the PAL Trial suggested that progressive weight lifting is not only safe for both women with lymphedema and women who are at risk for lymphedema, but is actually helpful!

The trial demonstrated:

- A 50 percent reduction in the likelihood of lymphedema worsening in women with lymphedema
- A 70 percent reduction in the likelihood of arm swelling increases in women who had five or more lymph nodes removed

Not surprisingly, slowly progressive weight lifting also produced increased strength, improved body image, and reduced body fat for both the women with lymphedema and the women at risk for lymphedema. While all the patients in the PAL Trial wore a compression garment during exercises, other studies with positive results did not require a garment so it remains unclear whether it is really needed.

The pivotal PAL Trial has successfully overturned decades of dogma concerning weight lifting, exercise, and lymphedema. Lymphedema patients, like anyone who hasn't exercised in a while, are at risk for injury, in some cases more so. They are also more susceptible to infections. While exercise is strongly advised, patients should remember that the PAL Trial's exercise program was very slowly progressive and supervised. It's always a good idea to talk to your doctor before starting a new exercise program after cancer treatment.



Resource Review

ART EXPRESSIONS

Some of the current arts and crafts being taught are watercolor painting, collage, paper crafts, knitting, and acrylic painting. The workshops are four to six weeks long and meet once each week for two or three hours. All levels of artistic skills are welcome and no prior experience is required. The teachers are aided by volunteers in each of the classes.

Art Expressions is a series of imaginative art work shops designed for Memorial Sloan-Kettering Cancer Center outpatients and their caregivers. The program is volunteer driven and takes place in a bright and sunny open space on the 11th floor of the Rockefeller Outpatient Pavilion, on East 53rd Street. All workshops are free of charge. Participants may be current or former patients, caregivers or family members.

The artists-in-residence are volunteers and all the art supplies are provided free of charge to the participants. The program was started as a pilot program in the fall of 2011, continuing into the spring and fall months of 2012.



In addition to the workshops, Art Expressions has introduced the ArtKart, which is a colorful rolling cart filled with artistic and creative projects that services the waiting areas and chemotherapy suites of the Rockefeller Outpatient Pavilion. Patients and family can enjoy creating small portable projects such as bead jewelry,



wish dolls, and scratch art, for example, while they wait for their appointments. Two ArtKart volunteers assist people in the waiting areas with these craft projects.

Art can be both therapeutic and healing while also reducing stress. Art Expressions provides a welcomed distraction for participants and can help to restore their creativity during a very challenging time in their lives. The workshops also provide a forum for participants to connect with others in similar situations while developing or rediscovering their self-expression skills through art and creativity.

Please contact Volunteer Services at 212-639-5980 with questions or to register for future classes.

■ *Continued from page 2*
had three more treatments left and I just knew good things were ahead of me.

I completed all of my treatments and underwent a mastectomy. Believe it or not, it was a walk in the park com-

pared to the chemotherapy. A week after surgery I went back to the surgeon. She removed the drains and read the pathology report. After conveying the medical jargon, she concluded with, "We found no cancer. Go celebrate!!" The magnitude of what had happened didn't sink in until later in the evening.

Having cancer profoundly changes you, beating it humbles you.

My journey with cancer isn't over yet, but because of my fabulous team of doctors, strong belief in myself, and love from my family and friends, I am confident I will beat this monster.



Full Body Scan

By AnneMarie Ciccarella

AnneMarie is a breast cancer survivor who currently resides on Long Island. As an MSKCC Patient-to Patient volunteer, she visits surgical patients to share her own experiences. In addition, she volunteers her time with other organizations that support research toward finding a cure for breast cancer. AnneMarie is a participant in the Visible Ink program. With the help of her writing coach she has launched a blog that has now been read in more than 50 countries.



I can't complain about the way the agent approached me. I don't recall any discomfort. I do recall her saying she would "need to do a pat down" and she would be using the back of her hands. After the fact? I realized she specifically noted the area of my body that was being scrutinized. And the only area that she would be touching.....

My brain is on a time delay so nothing registered until I was well beyond the security area waiting at the gate to board my flight. I've flown a number of times since my mastectomy. I've strolled barefoot through screening areas in at least eight different airports while my carry-on bags took a ride through the x-ray conveyor. On this day, I would be visiting a full-body scanner for the very first time.

I think I was stunned by the swiftness. I was waved to proceed through the metal detector by a male officer and it was a man who escorted me to the body scanner. Suddenly, appearing from nowhere, there was a pleasant woman donning blue gloves explaining the pat down process.

Following the "pat down," which was in full view of four very crowded security lines, I was told my hands need to be tested for resin. HUH? Now I am searching in my already challenged chemobrain to recall what I might have touched that would show up as some type of suspicious residue.

She passed a wand over my palms and fingers. Flashing back to the operating room, I remember a wand similar in appearance being passed under my arm. I still had my own body parts and the surgeon was demonstrating how to locate the sentinel nodes. Jeez. This flashback could have triggered a PTSD meltdown!

Apparently, they believed I might actually have explosive implants and would be doing a self-surgery to remove said implants and use the contents to assemble a bomb. Did they presume I inserted the implants just prior to hitting the security line and that is what the hand residue check was all about?

I was NEVER pulled off a security line. I follow the rules: three-ounce containers, one-quart Ziploc, and I

make sure the chargers/wires are attached to the electronic devices when I toss them in those gray bins. That wire stuff isn't even a rule. I just always figured a tangled mess of wires inside my bag would resemble a bomb. Airport security is one thing I know how to do and I do it rather well if I must say so myself.

The gummy bears used for my reconstruction are cohesive gel implants. They are foreign objects. Ergo, the Wizard behind the curtain who was looking at the screen sent an immediate radio alert to the kind female agent.

I am 100 percent behind anything that is being done to keep us safe. I have no attachment or modesty issues surrounding my amputated body parts or their replacements. I hope, however, for the sake of those who may not be as nonchalant, TSA finds a better way to deal with the breast cancer crowd. There are enough body image issues swirling within that group. Maybe the airport shouldn't be yet one more reminder of club membership?

Surviving Together

By Christine Arundel

Christine is a 38-year-old New York City teacher and a five-year thyroid cancer survivor. Her husband, Keith, a 44-year-old Long Island postal plant supervisor, is recently in remission for non-Hodgkin lymphoma. They are raising their family and consider themselves lucky and thankful to have each other and their faith and be survivors together.



I figure that my husband and I must be either the unluckiest of people or the luckiest of people, depending on how you look at our situation. We choose to look at ourselves as the luckiest even though sometimes it doesn't feel that way. My name is Christine Arundel and my husband, Keith, and I have been married 17 years. We have three children: Monica, 15, Erica, 13, and Steven, 11. Like many families, we struggle with demanding jobs, finances, and raising our three children. I am 38 years old and teach the third grade in a New York City public school.

Keith is 44 years old and is a supervisor at a US Postal Service plant on Long Island. Unlike our friends, we are also both patients at Memorial Sloan-Kettering. In May of 2007 I was lucky enough to be diagnosed with papillary thyroid cancer. I say lucky because the cancer was contained to my thyroid gland and removed via a total thyroidectomy. I have since only needed to follow up with annual checkups. In April of 2011, my husband suddenly grew a mass on his neck. We tried to find out what the mass was through our primary doctor and hospital system.

We were dismayed to learn that we had to wait several weeks for tests and appointments. I called Memorial Sloan-Kettering and the staff was very helpful in getting us an appointment much sooner. When we went to that appointment we were very impressed that a biopsy was immediately done and viewed, giving us a likely diagnosis of lymphoma. Not only are we both MSKCC patients, we had the same surgeon. In May 2011 a node dissection was performed and we continued our care with a lymphoma specialist. Keith was further diagnosed with large B cell non-Hodgkin lymphoma. During the summer and fall of 2011 my husband received six rounds of chemotherapy and underwent four weeks of radiation at MSKCC Rockville Centre, at Mercy Medical Center.

Our daughters accompanied us on some of his treatments and both are interested in the healthcare field. Our oldest daughter, Monica, has applied for one of the programs offered for high school students in the summer of 2012.

Everyone we have encountered has been so wonderful to us. We are so thankful for the care we have received along with the support and prayers of our family and friends. We are so grateful to be able to come to a place like MSKCC and are relieved that my husband is now a survivor like myself.



*Congratulations,
Eileen Gould!*

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Bridges is available at
www.mskcc.org/bridges.

If you would like to connect with other survivors through the Resources for Life After Cancer Program, please see the online calendar at www.mskcc.org/livingbeyondcancer.

PATIENT – TO – PATIENT

We are grateful for the support of our patients and family members. If you are a former patient or family member who has completed treatment please consider becoming a Patient-to-Patient Volunteer.

For more information contact Marina Lenderman at 212-639-5329 or e-mail patient2patient@mskcc.org.

Visible Ink™ A one-on-one Writing Program for MSKCC patients

Interested patients will work individually with the guidance, encouragement, and support of a professional writer on a topic and project of their choice.

This program is **FREE**. All levels and writing interests welcome.

For more information or to arrange a writing session, please contact Judith Kelman at 212-535-3985 or kelmanj@mskcc.org.



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