Brian Howell, former editor of Madison Magazine, went to the doctor on three different occasions for rib pain that wasn’t going away. When the doctors finally did an X-ray, they found Howell had lung cancer. He passed away nine months later. He was only 53.

Howell’s story is sadly common. The symptoms for lung cancer—such as coughing, chest pain, shortness of breath—can be misleading and mistaken for other maladies like a cold, or in Howell’s case, unrelated bone pain.

Often, the cancer is found when a patient is being treated for a different condition, as was the case for Jody Schwerdtfeger’s mother.

“She was undergoing a pre-op screening for gallbladder surgery and had a chest X-ray,” explains Schwerdtfeger, a registered nurse and organ transplant coordinator for UW Health. “She had been experiencing rib pain, but none of the typical symptoms like a cough. She even had an X-ray six months before that was read as “normal.”

By the time lung cancer is diagnosed, it is often at a very advanced stage. For both Howell and Schwerdtfeger, their lung cancer had progressed to stage IV.

“One of the frustrations,” says Schwerdtfeger, “is that there’s no good screening for it. It’s often caught too late.”

That sentiment is echoed by Howell’s family. Says one of his daughters, Katie Shodola, “Early diagnosis would’ve made all the difference. He was passionate about improving early screening.”

Anne Traynor, MD, oncologist and director of the lung cancer program at the UW Carbone Cancer Center, explained that currently, there is no effective screening test for lung cancer. “Screening takes place on a population scale,” Traynor explains. “It has to be accurate and able to detect the disease while something can still be done to treat it.”

An effective screening test will help reduce the number of lung cancer deaths, says Traynor. Results from the first randomized clinical trial comparing chest X-rays against CT scans for early detection of lung cancer are due in 2010. The research offers tremendous hope for the nearly 50,000 people enrolled in this trial—more than 17,000 were from Wisconsin.

Each year an estimated 219,000 individuals in the U.S. are diagnosed with lung cancer, accounting for 15 percent of all new cancer cases, and despite the disease’s high mortality rate, lung cancer receives the least amount of federal research funding among the common cancers. Federal funding for breast cancer research is typically 16 times that for lung cancer.

Lack of funding is the greatest impediment to making any headway in diagnosing and treating this disease, according to Traynor.

Compounding the problem is the societal attitude toward lung cancer, even among the medical community.

“There’s a tremendous stigma with the disease,” says Traynor. “That it’s a smoker’s disease.”

Alan Craig, whose sister Paula was diagnosed with lung cancer at age 40, knows well how the stigma can affect those living with the disease. “When she was first diagnosed, she felt so ashamed,” he recalls. “She became a little reclusive even. It wasn’t until after she lost her hair for a second time due to treatments that she gradually became more accepting.”

One of the first questions people asked upon hearing the diagnosis was, “Did you smoke?” which is common for everyone who facing the disease.

“I think the only people who never asked whether Paula smoked were the physicians and nurses involved in her care,” continues Craig.

Allison Howell, Brian Howell’s other daughter, agrees. “The person behind the cancer gets lost because of the stigma. [Brian] really tried to raise awareness and eliminate the stigma.”

“He was adamant about getting the word out,” adds Shodola. “He wanted to give voice to the disease even as he struggled with it.”

Craig points out that when someone is diagnosed with heart disease, they’re not asked about their diet or exercise habits. Yet there is a perception that lung cancer patients brought the disease on themselves.

“My father wrote about the disease and writing about the advancements.”

For families like the Schwerdtfeegers, Howells and Craigs, they’ve dedicated their time and energy to raising money and awareness for the disease.

“My dad was a truly motivational person,” Allison Howell explains. “He was also in a very unique position being in the media profession. From the moment he was diagnosed he immediately began researching the disease and writing about advancements.”

continued inside
Q. My cancer treatment is done. Why do I feel anxious and depressed?

A. Many people have mixed feelings about completing cancer treatment. Hearing the cancer is in remission and treatment is done can be a time of relief or celebration. But it can also be a time of perceived anxiety or depression. While estimates of anxiety and depression vary depending on the specific type of cancer and the timing of studies, many survivors experience mild to moderate symptoms in the months to year after completing treatment.

A cancer diagnosis triggers an abrupt transition into a new world focused on cancer: there is a new language to be learned; a new identity as a “patient” evolves; schedules are structured around treatments and scans; clinical settings and procedures become familiar; staff and other patients become part of support networks. These people and activities are woven together to form a “safety net” during the treatment process.

When treatment is complete, a new transition happens just as abruptly. The safety net cheers “walk away – don’t look back – live your life!” But patients may hear this with a mixture of relief and worry. Removing the network may leave patients feeling unprotected and alone; they are trading known support for an unknown life in the future.

The question becomes: What do I do now? If we’re not fighting the cancer anymore, will it come back? Who am I now? When will I feel “normal”?

The “return to normal” is anything but. Patients may have experienced physical, emotional, and spiritual changes and might not be the same people they were before their cancer experience. Other adjustments may include learning to live with uncertainty, resuming previous responsibilities, and being more focused on their health.

Many people hope the side effects of their treatment will ease when treatment stops, or shortly thereafter. The reality is that, many patients experience mild to moderate symptoms in the months to year after completing treatment.

The Many Faces of Lung Cancer continued from front cover

Add Joseph Howell, “Most of the time he was sick was spent researching everything he could about lung cancer, from shitake herbal tea to every different type of chem. He wanted to know everything there was to help beat his disease.”

A recreational golfer, Brian and his friends talked about organizing a golf outing to raise awareness and funds for lung cancer. After his death, his friends and family made the outing a reality with the Brian Howell Golf Outing. Since its grassroots beginnings, the golf outing combined with another to become the Drive for Hope Golf Outing. Through the efforts of families and friends whose loved ones have been touched by lung cancer, Drive for Hope has raised more than $243,000 in the last four years for lung cancer research at the UW Carbone Cancer Center.

Inspired by their dad, all three Howell children also participate in various run/walks as a way to raise awareness and funds.

“It is a constant struggle to get the awareness out there. That’s one reason why the events like the golf outings and run/walks are so important,” says Joseph.

Jody Schwerdtfeger was training for her first marathon when her mother passed away. She dedicated her run to her mom’s memory.

“One of the songs I play while I run is Melissa Etheridge’s ‘I Run for Life,’” she says.

Since her first marathon, she has gone on to run two half marathons and two full marathons, the most recently completed in Madison at the end of May. All the money she raises supports the Creating Hope campaign for lung cancer research at UW Carbone Cancer Center.

She jokes about her marathon experience, “For someone who never ran before, it’s pretty amazing.”

Schwerdtfeger estimates she’s raised approximately $25,000 for research through her runs.

“When I first began there wasn’t much out there, but it’s since grown with outings, run/walks and groups really dedicated to raising awareness and funds, like the Lung Cancer Task Force,” Schwerdtfeger says.

Craig, like Schwerdtfeger and the Howell family, is also a member of the Lung Cancer Task Force (see below). In addition to volunteering his time with the group, he’s also committed 10 percent of all the sales from his business to lung cancer research and disease prevention through education.

“I want to do what I can for research,” he says.

While there’s still much to learn about lung cancer, its biology and treatment, there’s also a tremendous amount of hope for patients and their families.

“Paula never gave up hoping, even until the very end,” concludes Craig. “This disease needs more reason for hope. I believe that will come with better funding and research.”

Experience the sometimes overwhelming experiences of being a cancer patient. The fundraising group helps coordinate events, such as the Drive for Hope golf outing or the Jodi Lou Lung Cancer Run/Walk.

“It’s a very exciting time to be involved in lung cancer research and care,” comments Traynor. “We’re moving into the Wisconsin Institutes for Medical Research this fall. The new facility offers us an exceptional opportunity to move laboratory advancements into the clinic more quickly.”

The Lung Cancer Task Force meets quarterly and is open to anyone interested in helping to make a difference for the disease.

“To raise funds and awareness of the disease, the Lung Cancer Task Force works on three fronts—legislative, patient advocacy and fundraising.”

“We can’t improve care until we better understand the disease, so research funding is key.”

— Anne Traynor, MD

“We’re trying to increase awareness, increase funding and to find hope,” Ramig explains.

The legislative group seeks to secure state funding to support research efforts, while the patient advocacy group helps patients and their families as they try to manage the sometimes overwhelming experiences of being a cancer patient. The fundraising group helps coordinate events, such as the Drive for Hope golf outing or the Jodi Lou Lung Cancer Run/Walk.

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To support lung cancer research and the efforts of the Lung Cancer Task Force, or to learn more, contact Steve Ramig, (608) 265-3527, or Steve.ramig@uwfoundation.wisc.edu.
Protecting Your Lips:
The Forgotten Cancer

Don't just give lip service to a severely peeling or flaking mouth. Oncologists say a few weeks of those symptoms could indicate lip cancer.

“Lip cancer is a disease we don’t talk about, yet it’s a real danger, especially for people who get lots of sun exposure,” says Paul Harari, MD, head and neck oncologist at the University of Wisconsin Carbone Cancer Center (UWCCC).

The National Cancer Institute (NCI) reports that there are 23,000 new oral-cancer cases each year and that 5,400 people die each year from oral cancer. Harari says lip cancer represents only a fraction of new oral cancer cases each year because the disease is not accurately reported. In addition, few people think about protecting their lips from sun.

According to Harari, people don’t realize that they should spread sunscreen on their lips as well as on their face and body when out in the sun. He recommends sunscreen with 30 SPF or more.

“The bottom lip is more likely than the upper lip to develop cancer because it gets more sun,” Harari says. “Cancer on the upper lip is rare and can be more lethal than cancer of the lower lip.”

People living in warm climates are at greater risk of getting lip cancer, technologically identified as skin cancer. Harari says smokers, people who chew tobacco and spend a lot of time in the sun have an even higher risk.

Harari recommends that anyone with symptoms lasting more than three or four weeks should see a doctor. He says when a lip malignancy is caught early, the cure rate is 90 percent or more. He believes early detection has improved over the last few years.

“For the past 10 years or so, dentists have been doing routine oral-cancer screenings for their patients. That has accounted for an improvement in early detection,” Harari explains. He estimates that every year, UW oncologists see a dozen patients who have been referred from dentists following an oral screening.

Symptoms of lip cancer include:

• an irritated area that can look and feel like chapped lips or a cold sore
• crusty patches on the lips
• bleeding
• lip pain

For patient services at the UWCCC, please contact Cancer Connect, (800) 622-8922 or (608) 262-5223 or e-mail cancerconnect@uwcarbone.wisc.edu.
Bevacizumab being evaluated for brain tumors

This study will enroll patients with a Glioblastoma Multiforme tumor (GBM). GBM is the most aggressive and malignant form of glioma, a type of primary brain tumor. This trial will combine the standard care therapy for newly diagnosed GBM patients (radiation and temozolomide chemotherapy) with the addition of a newer agent called Bevacizumab (Avastin). Bevacizumab was recently approved by the FDA for use in recurrent or progressive GBM patients.

Half of the patients enrolled on this trial will receive radiation, temodar chemotherapy and Bevacizumab and half will receive the standard of care therapy radiation + temodar.

Bevacizumab is an anti-body that is designed to inhibit the vascular endothelial growth factor protein (VEGF), which plays an important role in the development and maintenance of blood vessels that feed tumors. Many GBM tumors express high levels of VEGF and it is hoped that if we can suppress the amount of VEGF present, we can better control the disease. (Study No. RTO05820)

High Intensity Focused Ultrasound for Prostate Cancer

High intensity focused ultrasound (HIFU) is a therapy for prostate cancer that uses ultrasonic energy to destroy tumor cells without harming the surrounding tissue. The HIFU Sonablate device does not use ionizing radiation, but focuses ultrasonic energy, or sound waves, on a specific location to rapidly heat and destroy the tissue. HIFU prostate cancer therapy is a non-surgical, minimally invasive outpatient procedure that has many advantages including a quick recovery and minimal blood loss.

David Jarrard, MD, is currently conducting a clinical trial using the HIFU device for localized, non-metastatic, recurrent prostate cancer. Men between the ages of 40 and 85 whose prostate cancer has returned after treatment with external beam radiation therapy two or more years ago may be eligible for this study. Jarrard is also conducting a second study for men who have newly diagnosed localized, non-metastatic prostate cancer. It will compare the safety and effectiveness of the HIFU device with the standard of care brachytherapy (implanted radiation seeds). (Study No. CO08810, Study No. CO08859)

Double Umbilical Cord Blood Transplantation for Blood Cancers

Many patients with blood cancers that cannot be cured with standard therapies can be cured with blood stem cell transplantation using a tissue matched donor. Unfortunately, many patients who need this therapy do not have a matched adult sibling or volunteer to serve as a donor. Finding a donor is particularly a problem with patients from minority groups and those with mixed-heritage.

Umbilical cord blood (UCB) contains stem cells sufficient to grow a new bone marrow and immune system, but there are too few cells in a single UCB product for an adult. In collaboration with several other cancer centers, the UWCCC has opened two studies using products from two umbilical cords as a source of stem cells to perform donor stem cell transplantation for adults.

Patients who require donor stem cell transplantation to treat acute leukemia and aggressive lymphomas, but who do not have an adult donor, are eligible for one of the two clinical trials. One trial, open to younger patients, uses aggressive chemotherapy and radiation followed by infusion of two UCB units. The second trial open to older patients, uses a milder form of chemotherapy prior to transplantation. (Study No. HO08402, Study No. BMTCTN0604)

For more information about these and other clinical trials at the UW Carbone Cancer Center, visit CancerConnect, (800) 622-8922 or (608) 262-5223 in the Madison area.

A complete listing of clinical trials at the UWCCC is also available on our website, www.cancer.wisc.edu
The second annual Jodi Lou Run-Walk, held Saturday, June 6, 2009, raised more than $23,000 for lung cancer research and patient services at the UW Carbone Cancer Center. More than 325 people participated in the event, which remembers Jodi Lou Rickert, who died from lung cancer in 2008.

The tenth annual Hope Walk raised more than $85,000 for Our Hope of Burlington. Proceeds benefit four local health care providers who are committed to helping people in the Burlington area with life-limiting illnesses, including the UW Carbone Cancer Center. More than 500 people spent a rainy night at “Hope Walks Down on the Farm” around the Burlington High School track on June 19-20 for a total of 16 hours. Thank you to Our Hope of Burlington and all your support!