

Health Advocate News

*from The Center for Patient Partnerships
at the University of Wisconsin-Madison*

About the Center

The Center for Patient Partnerships trains graduate and professional students in patient-centered consumer health advocacy. Students from law, medicine, pharmacy, social work, public and population health, and public affairs work with clients facing serious chronic or life-threatening illness.

Consumer-centered advocacy empowers patients to make more informed medical decisions, negotiate insurance and financial issues, sort out employment concerns, and find support.

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Greetings from the Director

Fall is upon us – and with it that renewed sense of purpose, forever associated for me with a new pencil case.

This past spring and summer were a powerful time for us at the CPP. Because of the increasing number and acuity of our client cases, we have experienced the loss of no fewer than six people we knew well and cared about deeply. It has challenged us to think hard about how to support each other and our students.

For my part, I lost Cindy who was both a client and a friend. It has been quite a journey since she said goodbye on February 4th.

Cindy had asked me for several years to compete in the Danskin Triathlon with her. Last year, while in treatment for widespread breast cancer, she asked me again. I said “sure” and then, well, did I forget or get too busy? I don’t remember. All I know is that Cindy completed the swim and the run – in respectable times – seven months before she died.

Within a few days of her passing, it came to me clear as a bell: I had to do the Danskin this year – with and for Cindy.

She had asked me, she believed it was a powerful way to honor the gift of life, and she thought I should do it, for some reason.

She was right. It was more powerful than I could have imagined. Preparing for it meant I had to get in shape, of course, but by far the greatest challenge – and gift – came as I confronted my deep fear of trusting my body again. After a particularly good, tough workout, I remember saying “right about now is when I step into the shower and feel a lump.”

When our confidence in our physical safety is so deeply shaken, it is an enormous feat to get back in the saddle and trust again in our well being. Most survivors know these feelings. Pushing against them is among the hardest things I’ve ever done, and one of the most powerful.

The actual race was such a joyous celebration of being alive. And Cindy was everywhere. I joked while training



that my workout regimen was much harder than hers because she’d get to fly the whole thing. She’d shut me up by offering to trade places. But she didn’t fly; she swam, biked and ran with me.

And she smiled the whole way.

What a privilege it is to connect so deeply with our clients, to share real life with them and sometimes, when we’re very lucky, to be able to ease their burdens just a bit. Whatever twists and turns the road takes, it is our deepest gift to abide with them through the infinite richness of life and death.

We are grateful to you for making our work with clients and students possible. You are our advocates! – Meg

Center Launches New Consumer Health Advocacy Certificate

The Center is excited to announce a new 12-credit Certificate in Consumer Health Advocacy now available for UW graduate and professional students from the schools of medicine & public health, pharmacy, nursing, and law. We hope to have a “Capstone” certificate available for returning professionals by Spring ‘09.

The Certificate course of study combines applied health advocacy training, an introduction to health systems and health care delivery, and elective course work in one of three areas: law, regulations and ethics; health economics; or policy, management and public health. This certifi-

cate is designed to enhance home disciplinary studies of health care and other professionals by maximizing advocacy skills which complement professional expertise.

“This interdisciplinary certificate responds to the complexity of the health care experience for patients in the 21st century. It pulls together courses across campus from social work, business, economics, nursing, law, public affairs, medicine, and industrial engineering so that advocates are well rounded and prepared to advocate for patients.” says Center Associate Director Sarah Davis.

Today, as health systems

grow more and more complex, health consumers – individually and collectively – increasingly turn to adept advocates to help them navigate medical, legal, employment, financial and psychosocial issues, and improve the systems and instruments that support health care access and quality.

This Certificate will provide health professional and other graduate-level students with key knowledge of health consumer perspectives, advanced health advocacy competencies, and the tools to strategi-

cally advance health care reform efforts through inter-professional collaboration, policy initiatives, and systematic approach.

“This interdisciplinary certificate responds to the complexity of the health care experience for patients”

In addition to a base course on the health care system, students will earn six credits of clinical or service learning experience at

the Center or another patient advocate organization. Through that course work, students work directly with patients with life-threatening and serious chronic illnesses. Students also take one additional elective course from the numerous courses offered.

For more info, visit our website or call the Center.

Center Educational Update



Shown Above. Clinical students during the spring semester are shown gathered for weekly staffing meeting.

We enter to fall semester with seven new students hailing from the disciplines of law, social work, and, yes, even French literature. Students bring with them a diversity of previous advocacy experience—ranging from work with the Wisconsin Coalition against Sexual Assault to Students for Organ Donations. Many students have already advocated for themselves or others- having had experience first-hand

health care navigation.

These students will begin the semester with two weeks of extensive orientation. “When they are assigned their clients, these new students will be able to hit the ground running,” says advocacy coordinator Aphra Mednick.

During orientation, we use case-based methods and explore core advocacy skills—from empathy to assessment. From empowerment to cultural competency. Each of our staff shares their unique expertise by introducing students to the key skills and knowledge essential to patient advocacy. Dr. Suzanne Lee introduces stu-

dents to medical decision-making and researching clinical trials. Magda Kmiecik, MSW introduces students to health literacy concerns. Pete Daly organizes current patients to share their stories with our new students. Aphra Mednick, LCSW, introduces the students to our triage process and the importance of case management.

In addition, five continuing students will return this fall. Says Jim Biese, Law ‘10: “I am really looking forward to continuing to advocate with my clients—through Social Security applications and medical bill sorting—we are really making some headway. I continue to be impressed by my clients’ self advocacy skills.”

Health Insurance Appeals: Perspectives from a Patient Advocate and a Center Client

Kari Ehrhardt, MSW '08

Student Patient Advocate '07-'08

After working relentlessly on three cases involving health insurance appeals over the past year, I've come to the following conclusion: Fighting with health insurance companies has to be one of the most unsavory tasks in the universe. As a patient and health consumer, I know firsthand that receiving a letter full of confusing terms that denies your benefits is frustrating, disappointing and intimidating.

Although it requires patience, attention to detail and tenacity, taking the time to dispute a denial can really pay off. You just might win, as I experienced in a recent victory with Barb, one of my clients at the Center. Furthermore, there is good reason to appeal. A recent case in California found that 30 percent of medical claims were improperly denied; a study done by the Kaiser Family Foundation found that approximately 40 percent of disputed claims were approved. Those are good odds.

Here are some tips:

1. Feel Free to Create Some "Phone Drama": When you contact your health insurance company regarding a denial, remember that the first point of contact, the customer service representatives, are there only to answer general questions. They are typically not empowered to fix problems or overturn decisions. So unless your claim was denied because of an easily-identified clerical error, you should escalate your claim to a case manager. If you are still remain unsatisfied, try to bump up to the next level of – a medical director, a vice president, or even a CEO. It may be impossi-

ble to actually reach these individuals, but be persistent and keep trying until you get the audience you need to hear your side of the story.

2. Logic, My Dear Watson:

Although you do not have to accept the reason behind the denial, you must, however, be able to understand it logically in order to provide evidence to the contrary in an appeal letter. The insurance plan document

more than likely contains some information that applies to your situation. You should try to refer to specific sections of your policy that apply to your particular circumstances and support your position. (If your policy has adverse language with respect to your circumstances, you may want to try to minimize or justify this in the letter).

3. Become Your Own Secretary:

Keep impeccable records. Document conversations with medical care providers and insurance company representatives, including the name and contact info of the people you speak with, the date of your conversation, and what you are told. All this may seem to be tedious, but the information will come in handy if your claim is denied and you need to file an appeal.

4. Your Doctor Is Your Best Ally:

Ask him or her to write a letter describing your condition, the treatment he recommended for you, why it is medically necessary, and what your prognosis will be with and without it. Ask him or her to include copies of

peer-reviewed research regarding your condition or your treatment.

5. Follow the Rules: File your appeal ASAP. Your insurance plan document should identify the timeframe allowed to file your appeal. Follow the complaint or appeal process described in the policy word for word.

6. When All Else Fails: Consider an external appeal. Most employer-sponsored group health insurance are subject to the federal Employee Retirement Income Security Act of 1976 (ERISA). Regulations pursuant to that law govern the time frames for health plans to decide whether or not to pay benefits under a claim, what information plans must disclose when they decide to deny benefits, and the process for handling appeals within a health plan (or internal appeals). These rules apply both to plans that are known as "insured" or "fully funded" (a health insurer bears the risk for claims) and plans that are known as "self-insured" or "self-funded" (the employer bears the risk for employee's claims). For plans that are insured or fully funded, state laws may apply in addition to ERISA giving consumers additional rights to appeal to an

"Not willing to give up, [my advocate] educated me on the external review process and assisted me in learning the rules unique to Oregon. It paid off."

independent entity outside of their health plan.

You may be able to request an independent external review from your state's health ombudsman or insurance regulatory agency. Visit www.kff.org/consumerguide/7350.cfm to find details about your state's external review process. If you are covered by a self-insured/self-funded plan, which is not

subject to state regulations, you may be able to appeal at the federal level by contacting the Department of Labor's Employee Benefits Security Administration. To find the DOL EBSA office nearest you, visit:

http://www.dol.gov/ebsa/aboutebsa/org_chart.html#section13.

Handling Health Insurance Appeals: A Client's Perspective

Barb T., Center Client

In the spring of 2007, when I was overwhelmed with health insurance problems, I read an article in the Wall Street Journal which mentioned the Center's work helping those with chronic or life-threatening illness deal with health insurance issues at no cost to the client/patient.

After reading the article, I contacted the Center, and they agreed to worked with me. My advocate Kari was able to show my health insurance company they had inappropriately denied my appeals. Once convinced that Kari was right, my insurance company allowed me another in-house appeal. They ruled against me. Not willing to give up, Kari then educated me on the external review process and assisted me in learning the rules unique to Oregon. It paid off. I was just informed that when my case was sent for an external review, the reviewer overturned my insurance company's decision. The money I spent on an expensive, but necessary medication will now be reimbursed to me by my health insurance company.

Sun and Skin Damage: Tips from a Melanoma Guy

Peter Daly, Patient Advocate

Summer isn't the only time skin needs protection from the effects of the sun. Skin should be protected year round to give you the best chance of healthy skin throughout the years. We all know years of sun can lead to wrinkles, dryness, age spots and even cancer.

Here's how to protect yourself and young ones from the sun's harmful rays:

- Enjoy outdoor activities before 10am in the morning and after 4pm in the afternoon and evening. These are the best parts of the day for most sports and recreation. The air is cooler and the sun's low angle enhances everything it touches.
- If you need to be out mid-day, shade yourself with light feeling fabrics and a wide brim hat. Being shaded and sporty is cool, being exposed is not. Cover any of your exposed skin with a moisturizer that includes a sunscreen with a SPF (sun protection factor)

rating of 16 or above. (Sunscreen offers flexibility to being out in the sun but doesn't replace timing and covering.)

What if you notice skin damage? Here's what to do:

Sunburn - Relieve the pain, take note, and learn from the experience. We all only have so many "tickets" to any kind of sunburn before serious skin damage sets in. The burn has several messages – it's uncomfortable, we're vulnerable to the sun, we need to follow the pointers above, and our chances are running out. Damage from the sun can be life threatening.

Skin lesion – Unusual lumps, bumps, funny looking spots, and non-healing scabs need medical attention when you can see them developing and they're not going away. These are not usually directly associated with an immediate sunburn and don't always occur in skin exposed areas but can be the result of sun damage and skin cancer. Get to a doctor within two weeks, and if in any doubt about possible cancer, ask for a sampling to be sent to a lab.

Here's how to make sun safety part of your seasonal style:

Choose your times for outdoor activities wisely and appreciate the joys of summer without the sun risks.

- Find clothing you love to wear that gives you shade, comfort, style and protection. Put it out and wear it!
 - Use a lotion or sunscreen with a SPF of 15 or higher everyday. Put your favorite by the bathroom sink, in your bag and on your person, and use it all the time.
 - Avoid laying in "tanning" beds and sitting in front of sunlamps (in any season). Get out and move, it's beautiful out!
- If trouble arises on your skin, take action:**
- Ask a loved one to help you monitor its developments.
 - Seek medical attention within weeks, not months.
 - Get a sampling or biopsy sent to a lab if suspicious.
 - Don't wait, postpone or delay – skin cancer usually isn't painful.

- Expect to "fight" to get in and get the care you need.

While experts agree trouble spots on the skin - worrisome skin lesions - require attention within two weeks, getting near term medical attention can be difficult. Appointments extending this two week guideline run the risks of serious trouble developing and patients giving up on seeking care. In Wisconsin we found the average wait time for an appointment to be over 4 weeks and sometimes much longer. The graph on the following page shows the range of wait times for a skin lesion appointment at clinics across Wisconsin.

These wait times have to change if we are going to have effective skin cancer screening in Wisconsin. In the meantime, expect to "fight" to get in, demand thorough screening, and seek lab verified results.

Pete Daly is a 5 yr advanced melanoma survivor and a patient advocate at the Center. He's a husband of a strawberry blond and a father of two teenagers who (mostly) abide by his advice. Summer is Pete's favorite season when he trains and competes in Ironman triathlons.

Average Wait Times for Melanoma Screenings in WI: An Informal Survey

Gabe Krambs,

Student Patient Advocate and UW Law School Student Class of 2009

SUMMARY

Eleven clinics with dermatology services were selected from around Wisconsin. The clinics were telephoned and presented with possible first signs of melanoma that were still ambiguous without biopsy. The average wait-time for an appointment was 5 ½ weeks, with one clinic at 12 weeks, and two clinics at 8 weeks.

METHOD

Thirteen stand-alone clinics with dermatology services were initially selected, each contracted to one of thirteen different HMOs in Wisconsin. These clinics were not chosen with any scientific randomness, though I did try to get a good mix with respect to both city size and geographic location.

I called and told each clinic that I had been "watching a 1/4-inch bump or scab on my arm for the past few weeks that [wasn't] going away, although it [didn't] seem to be getting any worse." I then asked them when I could get someone to take a look at it.

Two of the clinics were in the process of discontinuing their dermatology services and were not taking any new patients. These clinics were excluded from the results.

QUESTIONS

- How long is too long to wait to be screened with possible signs of melanoma?
- Is the 6-12 week wait-time given by over half of the clinics too long?
- And if patients are waiting too long, what can we do to get them screened faster?

RESULTS

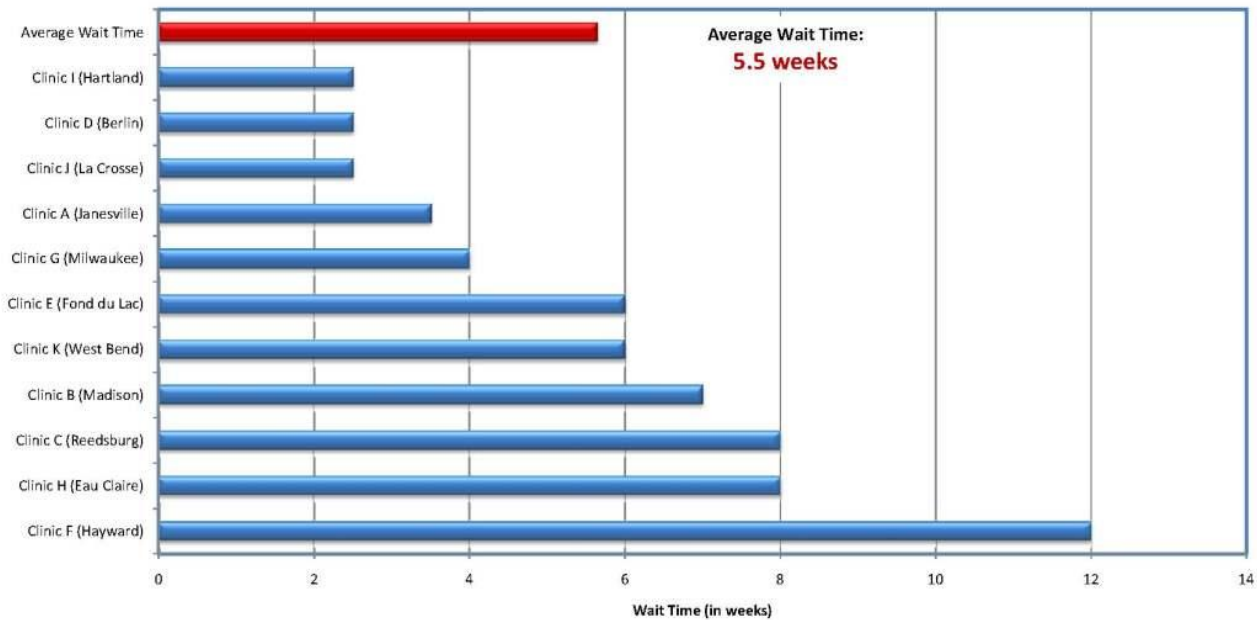
See the graph on the next page.

CONCLUSION

It's up to the melanoma experts, the dermatologists and oncologists themselves, to decide whether these wait-times for appointments are acceptable. If they aren't, possible solutions might include having more health professionals (besides physicians) trained for melanoma screening and biopsies, either in full-service clinics like those surveyed here, or in no-wait routine-service clinics in retail centers (e.g. RediClinic).

Average Wait Times for Melanoma Screenings in WI: An Informal Survey, cont.

How long do I have to wait to be screened for melanoma in Wisconsin?



Third Year of Funding From Komen For the Cure Supports Survivorship Workshops

Michelle Neustedter,
Komen Advocate

In its' third year of funding from the Madison affiliate of Susan G. Komen for the Cure, the Center for Patient Partnerships (CPP) will be collaborating with CPP- trained Komen Advocates and taking survivorship planning "on the road" hosting workshops for breast cancer survivors in Dane County. I am grateful to the Center for creating a valuable tool that encourages a holistic approach to living with cancer. I look forward to working with The Center staff and other CPP trained Komen advocates to bring survivorship planning to Madison area breast cancer survivors.

I became a cancer survivor four years ago, but had not

heard of a survivorship plan until The Center for Patient Partnerships introduced survivorship planning to Madison area breast cancer survivors at the *Sharing The Knowledge* Conference spon-

"A survivorship plan builds strength"

sored by The Breast Cancer Recovery Foundation in November 2007. The level of excitement and interest from the audience was overwhelming, including my own.

When I first read the outline of the CPP survivorship plan which included medical planning, but encompassed so much more, I thought; "Here is a healthy way for me to organize my thoughts and choices about cancer which brought about so much more than just a medical change to my

life". When I sat down to do my survivorship plan I realized I had already completed many parts of the plan. Other topics in the outline included important issues I had thought about but not expanded on. These topics appeared more approachable as words on paper and I could begin to consider how and when to address them. This is how a survivorship plan builds strength. It is defined by the survivor to best suit the needs of the survivor and unlike cancer, subject to change at anytime as directed by the survivor.

If a survivorship plan is introduced early within a cancer diagnosis, the plan has potential to keep connections between parts of life that often get disconnected effectively after hearing the words "you

have cancer".

If survivorship planning is introduced at the completion of medical treatment, the plan may ease the transition of "what comes next?" and reduce the wonder if it's possible to be free again. If medical treatment is life long, a survivorship plan may bring emotional or mental empowerment when physical control is reduced.

Cancer is a heavy burden on the body, mind and spirit but survivorship planning permits self-exploration, research, support, emotional release and can start a survivor on a healing path.





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Interested in patient advocacy services?

The Center serves patients or caregivers facing serious chronic or life-threatening diagnoses at no cost.
 Advocacy Phone: 608-890-0321
 Advocacy Email: cppadvocacy@law.wisc.edu

Visit our website:
www.patientpartnerships.org

The Center for Patient Partnerships is a center of the University of Wisconsin’s Schools of Law, Medicine and Public Health, Nursing and Pharmacy.

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Support the mission:

80% of our funding comes from individual donors like you. In order to maintain independence, we do not take money from entities that profit from health care. Help us keep our services free. Donating is easy through our website.

In the News

Scholarship Funding

For a second year, UW alums **Bob and Marlene Hartzman** provided funds to support stipends for students enrolled in the summer clinical program. These funds make it possible for students, who otherwise would not be able to enroll, to participate in an intensive summer advocacy experience at the Center.

The **Evjue Foundation** has also awarded the Center \$10,000 to fund student scholarships. “These gifts from the Hartzmans and Evjue make it possible for us

to have a robust summer program and recruit a diverse student body” says Director, Meg Gaines.

WI Women’s Health Foundation Grant

The Center was awarded \$1000 by the Wisconsin Women’s Health Foundation to fund Spanish-language advocacy brochures. “In order to provide culturally appropriate service to the Latino community, we need to offer advocacy materials in Spanish and have these materials available at community clinics and neighbor-

hood centers familiar to the community.” says patient advocate Magda Kmiecik who also serves as the Center’s liaison to the Latino Health Council.

If the Shoe Fits Event

Join us at this year’s fundraiser extravaganza, the annual “If the Shoe Fits” auction. Held Thursday, November 6th, 5:30-8:30 at the Nakoma Country Club. This is a unique opportunity to have fun and support the Center’s advocacy work. For tickets call 265-6267. View the shoes after October 6th at cppiftheshoefits.org



And coming soon—a new **Website**, including links in Spanish, and this Spring an on-line **Consumer Guide**.