



Cancer Resource Center of Mendocino County

NEWSLETTER Winter 1999

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Heart and Soul

Director's Notes
by Sara O'Donnell

Our mission statement mandates that we provide "information, support and advocacy to those with cancer and their families and friends," so we are constantly expanding and adding services and programs that will make the journey a little easier for the person with cancer and the caregiver alike. At CRCMC, we believe by providing educational and direct service programs we can offer hope to the people in our communities, however they are touched by cancer: Hope through education, which can lead to change, and hope through a reconnection to their own body/spirit wisdom. Therefore, this Newsletters is focused on the heart and soul of the CRCMC organization: the Center's volunteers and the services we offer.

Our services and support groups are expanding and changing. In addition to the Consultation Planning program, we now have three support groups on the coast and one in Ukiah. The cancer support group that meets on the first and third Thursdays of the month has been reconfigured to include men. Mary Bradish, past board president of CRCMC, has stepped down as group facilitator, a position she so generously held for over two years. Marilyn Hagar, registered expressive art therapist (R.E.A.T.) and long time CRCMC supporter, is now facilitating this group. In addition, Marilyn has joined forces with Joan Stanford, R.E.A.T. intern, to offer a new caregivers support group at the Center. The Advanced Cancer Support group will continue, facilitated by Kate Larson and the Ukiah Women's Cancer Support Group is thriving, led by WeCAN! advocates Nancy Johnson and Mimi Johnson. We plan to expand our services to inland Mendocino County this year as well.

Be sure to read the article highlighting a few of CRCMC's dedicated volunteers. My only regret is

Making A Difference

by Angela Knight



Delia and Ken Rightmier
Photo courtesy of the Rightmiers

Sometimes it's the little things that can make all the difference in the world.

For Delia Rightmier, it was the small sign that hangs outside the Mendocino Cancer Resource Center's office. She says she saw it while she was out walking one day and thought about volunteering, but first she had to "get up the nerve" to go in and ask if she could help. When she finally made it into the office, the first thing she said to the CRCMC office manager was something about not wanting to ask people for money, but she added, she would do just about anything else. And for the past two years she has. This former teacher and cancer survivor has done everything from driving people to Ukiah for radiation treatments on a regular basis to training to become a patient advocate for WeCAN! (Women's Cancer Advocacy Network).

Delia's family history of cancer, and her own bout with it, might explain some of the passion she feels for volunteering at the Center. A petite silver-haired woman with expressive brown eyes, Delia says she approached her treatment for breast cancer in the same way she trained to run 12 marathons, by focusing on the goal. In this case, the goal was getting better. Delia brings that same determination and spirit to her volunteering efforts, says Sara O'Donnell, CRCMC's executive director.

that we are not able to mention all of CRCMC's volunteers, both past and present. Our fundraising event, "From Paris to Provence," requires an enormous amount of time and energy and we need volunteers to make it run smoothly. If you would like to help, please take a moment to fill out the volunteer form enclosed with this Newsletters. If fundraising or processing raffle ticket orders doesn't appeal to you, there are many other jobs available.

Rabbi Margaret Holub's creative and touching article, "Is Cancer Funny?" connects humor with healing. Margaret is a member of CRCMC's Advisory Board and acts as a spiritual advisor to many. I can attest to the fact that, yes, there is a place for humor in the cancer world. Many times I have heard the blackest and funniest humor coming from support groups I have been in. It can be both healing and bonding.

In June, we will once again hold the community event, A Time For Remembrance. At that time we reflect on those we have lost to cancer and celebrate their lives through a reading of names, music and poetry. We are gathering names now until June. Please send or call in a name to us and we will hold them in our memory vessel, created by Marty Johnson, to be read at the ceremony.

I would like to take this opportunity to say a few words about Tony Rose, who left this earth on December 14, 1999. In the two years I knew Tony, I never saw him give up hope. He traveled the world, searching for a therapy that would work for him. He showed great tenacity and spirit in his quest. A little over a year ago, Tony sought treatment close to home. The treatment worked long enough for Tony to complete and enter his artwork in the Dancing With the Lotus art show. It also gave him time to finish his boat and launch it this summer at Big River in front of a rejoicing crowd of friends. Tony met death with his support system in place and his friends always at his side. Just as he had hoped.

We are here because we see a resounding need in our communities. Please let us know if there is a service or program you would like CRCMC to provide and we will work hard to do just that. Thanks to all of you who have given so generously of your time and money so our friends and neighbors can receive the information and support they desire and deserve.

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Changes

CRMC offers new Caregiver Support Group

CRCMC is starting a new support group for caregivers which will be co-facilitated by Marilyn Hagar, M.A., R.E.A.T. (registered expressive arts therapist) and Joan Stanford, M.A. and R.E.A.T. intern. Marilyn and Joan intend to use writing, non-threatening art activities and group sharing processes. The group is open to friends and family members whose lives have been touched by cancer.

For the past year, Marilyn and Joan have been leading seasonal women's cancer groups through

For Ken Rightmier, Delia's husband, his initial volunteer effort at CRCMC was due to his need to become involved in the community and keep busy. That involvement has grown from the occasional little project, to acting as a back-up driver for Delia, and completely rewiring the CRCMC office. "Whenever I call him," says Eva Brown, CRCMC's office manager, "Ken just puts on his overalls and comes on down." His latest endeavor, in between working on their two-story home and volunteering at the Botanical Gardens, involves building a much-needed set of bookshelves for the office.

Ken, who recently relocated to Mendocino with Delia from Plumas County, says he understands the need for a strong support network because of his experience dealing with his wife's cancer diagnosis and treatment. We "supported each other" during that time, he says, but access to a local cancer facility and a support group might have helped.

Joyce Gilbertson, recently elected to the CRCMC board of directors, says when she first moved to the coast two years ago, she assumed the community was too small for a cancer resource group. She explains her first inkling CRCMC existed came when she attended a lecture by Sandra Steingraber, which was sponsored by CRCMC. She recalls being introduced to an impressive woman with a mischievous smile. "There's something about Sara," Joyce laughs.

The Center and Joyce are a perfect match according to Sara. Joyce, a former oncology nurse who worked primarily in acute-care hospitals, has chosen not only to volunteer in the office one day a week, but also serves as a much-needed referral source. In her spare time, she is working on creating complete, concise and up-to-date cancer information binders for the CRCMC library.

Joyce was diagnosed with breast cancer four years ago. She says after the diagnosis she received five requests for volunteer help from breast cancer action groups; she couldn't imagine how all those groups got her name. Before she moved from the Bay Area, she became involved with the Community Breast Health Project in Palo Alto, she says, because it was a way to work on her own healing and use her nursing skills.

Like Ken and Delia, Joyce says she views her volunteer work at CRCMC as a way to get involved in the community. But she says she gets more out of volunteering than she gives. "It's a privilege to have this opportunity," she says.

Chuck Hinsch says he regards the recent opportunity to help his friend Tony Rose through the dying process as one of "the most beautiful experiences I've ever had." But it wasn't an experience that was reserved for Chuck alone. Many members of the coastal community came together to assist Tony in the last few weeks before he died. The involvement started as a trickle, Chuck explains, with only a couple of people bringing Tony food and checking on him during the day. However, before he died on December 14th, over 40 people, coordinated by Liz Helenchild and Chuck, had cooked for, comforted, nursed, laughed and cried with Tony in his small house in Mendocino. Some people brought soup. Some shared a meal with Tony. Some spent the night next to his bed.

CRCMC. Marilyn has a Masters degree in psychology from Sonoma State University, with an emphasis in expressive arts therapy. She has a private practice in Mendocino and leads groups and workshops for both children and adults. Joan received her Masters in psychology from Sonoma State University in August 1999. She is currently an intern for registration as an expressive arts therapist. Please contact CRCMC for times and location at 707.937.3833.

Thursday Support Group Open to Women and Men

The cancer support group that meets the first and third Thursday of each month at the CRCMC office is now being facilitated by Marilyn Hagar. This group was originally a women's cancer support group, but due to the pressing need to offer support to men who have been diagnosed with cancer, the decision was made to change the format.

Meetings are held at the CRCMC office located at 45040 Calpella Street in Mendocino. The group meets from noon to 1:30 p.m.. Transportation is available by contacting the Center at 937.3833.

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It's Your Choice

by Sara O'Donnell
CRMC's Executive Director

In today's world, when a person hears a diagnosis of cancer from a medical provider, often he or she is sent home with a bewildering array of treatment options to ponder. No longer does the physician make the decision, disregarding input from the patient. This is a good thing, but it also throws the patient into unknown territory. Medical language is foreign to most, and the treatment direction may be unclear to many.

Last year, CRCMC received over 200 requests from first-time callers. Those requests varied according to each person's need. A newly diagnosed woman with breast cancer may have many questions, that when answered, will lead her to an informed decision: Surgical options; mastectomy, lumpectomy, reconstruction? Radiation? Chemotherapy? Acupuncture and herbs? A newly diagnosed man with prostate cancer may face similar decisions: Surgery? Watchful waiting? External-beam radiation? Radiation-seed implants? Chemotherapy? Nutrition and Supplements? These are not small decisions to make.

The final decision is the patient's, and that can be a lonely and frightening road to walk alone. That is where the trained staff and volunteers at CRCMC come in. We understand the importance of making an informed decision; many of us have stood at the crossroads and needed assistance in finding our own direction. Through our personal experiences and training, we are able to provide this assistance in several ways: Our lending library is brimming with up-to-date information; our public access Internet service is open Tuesdays & Wednesdays 9 a.m. to 4 p.m., or by appointment; we have a peer referral

Some gave him morphine shots. It was an outpouring of love and commitment from the community that Chuck will never forget, he says.

CRCMC relies on the help of the community to accomplish the work it needs to do. Sara says she has called on Toni Lemos many times over the years to work on CRCMC's bulk mailings. Jill Stroup, after putting in a long week at the Cafe Beaujolais in Mendocino as a chef, has willingly come in and processed countless raffle orders for the last 3 years. There are many other volunteers who are willing to clean someone's house, drive people to the doctor, distribute Newsletters or do whatever needs to be done.

Sometimes it is just takes a couple of people who are willing to commit to perform one seemingly small task or volunteering a few hours a week that can and does make all the difference to someone who has cancer, an organization like CRCMC, and ultimately, to the community we live in.

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Is Cancer Funny?

by Rabbi Margaret Holub

Many months ago when I was first asked to write this article I made a dumb joke to the person who asked me: "I don't know what to write about. Maybe I should write about cancer jokes." And she said, poker faced, "That sounds great." Being a bit of a connoisseur of silliness of every kind, I'm aware there are jokes and schtick about every human difficulty imaginable. So I was wondering if there are any "How many cancer patients does it take to change a light bulb?" jokes, not to mention jokes and stories that might actually be funny. I was thinking not only about light bulb jokes but also about the more private kind of joking around, things that people with cancer might laugh at with their friends and families and caregivers. I haven't heard any, and that itself is interesting to me. Actually I admire very much the will to survive that is often expressed in jokes, both the recountable kind and the idiosyncratic stories where "you just had to be there." I imagine there must be a treasure trove of cancer humor, because, for many people I know who are dealing with cancer, that spirit of resistance is so vivid. It just has to bubble up in the silly and irreverent now and then.

Comes time to actually write, and I'm thinking about this more and more. Mostly I'm thinking, "Why did I ever sign up for something so ridiculous?" So I decide to do a little research. I call my friend Shelly, who is an oncology nurse at a big hospital in New York, and a person with a great laugh and a nice sense of the dark side besides. After explaining my basic question I ask Shelly: "Do you ever hear your patients making jokes about their situation?" There's silence on the other end of the phone. Finally she says, "Nope." Now I'm silent. So she says, "Let me think a little further. Um... nope." She goes on to tell me that there are laughter therapies. "You mean like you make an appointment and the laughter therapist comes into the room right after the occupational therapist?" "Well, not really," she says, and tells me that at Sloan Kettering, where

network, matching people with similar diagnoses and treatment plans. We are here to listen. We do not give medical advice. We do not encourage a particular course of treatment; that is for you and your medical provider to decide. What we want to provide you with is a light for your treatment path.

This past year many have chosen to participate in our Consultation Planning program, which gives participants a tool to facilitate patient-physician communication. Currently we have five trained consultation planners in Mendocino County who are ready to assist participants with mapping out their questions and concerns in flow-chart form. (Ayn Ruymen, CRCMC's new office manager, is a trained consultation planner). One participant, after her planning session, said, "I had a sense of clarity about the direction I was willing to go with treatment that I didn't have before."

Patient navigation services, like Consultation Planning and the Peer referral network, provided by trained advocates, are at the center of the services we provide. The feedback we have received from both medical providers and patients has shown that an advocate is beneficial for all parties. Dr. Kathleen Persky, a surgeon in Ukiah, says she values the "insightful and caring approach" of CRCMC, as well as its advocates. "CRCMC is taking care of the very important physical and psychological needs of our cancer patients at the time of diagnosis and afterwards," Persky says. She continues to send people to the Center from all over Lake and Mendocino counties.

Nancy Johnson has provided the bulk of the advocacy services to our inland residents for the last five years, as a volunteer. She has worked hard during her off-hours to assist women in navigating the medical system and is a valuable asset to the women she serves as well as to the medical offices she visits. She is one of CRCMC's advisory board members and will soon be the Women's Cancer Advocacy Network (WeCAN!) coordinator. The transition from volunteer to paid staff member can't happen soon enough. Currently, we are writing grants to insure that inland Mendocino County will have a full-time patient advocate in place this year.

We at CRCMC believe it is important for you to be an active participant in your healthcare choices; whether it is deciphering the incredible array of treatment options, or learning how to ask the questions. We want to offer you, your friends and loved ones, the possibility of a partnership with CRCMC to help facilitate your decision-making process.

We are here to light your way, with information and services. And, always, to listen.

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she used to work, the halls were full of clowns. Usually the clowns were there for pediatric patients, but sometimes they'd come and see adults as well. A phenomenon that sounds rather un-funny, and in fact distinctly scary, to me.

It occurs to me that this is the computer age and I should do some research online. So I go to the Hotbot and type in "cancer+jokes." I have to admit, even as I'm typing, I'm hoping no one can see what I'm doing. It just feels profane to put the two words together. Apparently the search engine thinks so too, because I get joke sites and cancer sites but nothing that brings them together, but in the service of knowledge I forge ahead. Yahoo finally offers up a charming cancer humor page (with an apt disclaimer about how this might not be helpful if you've just learned you have cancer). I can't give you the jokes here -- they're copyrighted -- but CRCMC maintains a computer and you can go in and type in www.canceronline.org.

My husband Mickey is about the funniest person I know. When I first met him ten years ago, he was two years this side of having vocal cord cancer. In the first year of whatever it was we were doing that they used to call courtship, he developed another nodule. It was a terribly scary time, and frankly, I don't remember any laughter in those months at all. So the other day I was asking him whether he remembered anything funny about his cancer experience. He began to retell a story I've heard a number of times, from his first bout, his first day of radiation therapy: He goes to the radiation oncologist's office and sits in the waiting room. Finally someone opens the door and says, "Follow me, Ralph." (Mickey's name, as it happens, is "Mickey," but the radiation doctor's name is Ralph.) The nurse or receptionist or whatever he is sits Mickey down and begins to take a history. In the middle of the interview, with all its intimate questions, another worker comes into the room and says to the guy that's talking to Mickey, "You want to finish up or go to lunch?" And the first guy hands the second the clipboard, says, "Here, you do it," and walks out. The punch line of the story is that some minutes later, when Mickey is laying on a table, a metal prong with a piece of wax or something on the end is lowered into his mouth, pinning him to the table in terror. A day or two after he has angrily fired this doctor and is recounting this whole horror story to the new one, the new doctor exclaims, "Oh, my god, Dr. Jones still uses a bite block?"

This story, like the cancer clowns, I actually find more scary than funny, but Mickey thinks it has some laughs in it. So, I asked him, how soon after it happened did you start seeing this experience as funny? As I suspected, not until he was well away from the clutches of Dr. Jones and feeling like he was going to survive the radiation, not to mention the cancer.

As it happens, the day Mickey and I were talking about cancer and humor, we had each recently spent a night with a man we know who is dying right now of cancer. Both of us have been moved by our time with this person, someone we like very much, though we don't know him well. Particularly as he moves closer and closer to his final passage, time in his company becomes more and more awesome. Thinking about him keeps us awake at night, and we open our eyes in the morning and mention his name. As friends and friends of friends and Home

Health nurses move in and out of this man's home, caring for him, I've heard and spoken every kind of beautiful, loving, reassuring phrase. There has been little laughter that I can recall.

Which leads me to a theory, if you like, a bit of a conclusion from a tiny bit of very unscientific research. Jokes and schtick emerge not only from the will to survive but also from a kind of ironic distance from the center of events. What makes something funny is often looking from the outside at a situation and seeing it differently than do the people in the middle of everything. It's dual perspective, a word or an action taken out of its obvious context, is what makes it funny. Hence the Cancer Online folks advice to wait until you have some distance from the first shock of a cancer diagnosis before tuning in to their jokeline.

Cancer has a way of reaching out and including everyone. There is something so fundamental, so literally cellular, about the disease process of cancer that it is unusually hard to find ironic distance from it. It's hard to have a dual perspective. For one thing, you never really know that you don't have cancer. It could be in any of us at any moment, even if we won't find out for years. Even aside from this literal aspect, there is something about the unfolding of cancer within a person's body that is so awesome, as well as upsetting and dangerous, that it has a way of connecting soul to soul and making distance difficult.

I guess I've learned from this excursion into cancer humor something about another kind of beauty that emerges from this illness, a connective quality, an awe-inspiring aspect. Maybe it doesn't lead to a lot of joking around. But I still wonder. Maybe when I see you at the post office you'll come up and whisper to me, "Hey, I've got a really terrible one. You've just gotta hear it..."

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