



Hope Notes Springs Eternal

By Bill Matteson

Recognizing the need for a “patient friendly” newsletter, *Hope Notes* was created by Patient, Family and Community Education staff in 2001. The purpose was to present various types of information to patients and their caregivers, families and friends. Over the years, upcoming events were publicized, news of interest was presented and the availability of various support groups was identified. In addition, poems and stories of patients, caregivers and families were included that offered insight, compassion, and hope to any and all with health challenges.

Linda Baginski, one of the Patient, Family and Community Education staff, was the editor of *Hope Notes* throughout this period, and it would be inappropriate to continue without recognizing her tireless efforts and ongoing dedication and commitment to assisting the needs of patients and their families. As with all things, change is inevitable, and Linda has moved on to other challenges.

As we similarly move on with *High Hopes* and incorporating Linda’s ongoing philosophy of “how can I make this better?” we are re-engineering and renaming it

and implementing some changes that we hope will make *High Hopes* even more “patient friendly.”

Our overall goal is to make *High Hopes* YOUR publication. We want it to be “By Patients For Patients” and we want it to be entertaining as well as enlightening. As far as making it “your” publication (By Patients For Patients), how do we do this — how does the reader become the publisher?

The answer is simple — we need your input, and we need to facilitate how we get your input.

We plan to do this two ways.

First, we will have specific components that interest you, will spark your participation and will be based on your subsequent input. Among the initial additions will be:

- Dear Experienced Patient: Similar to Dear Abby, where you can ask patient-related questions and get answers from “experienced” patients.
- Patients As Experts: Patient articles recording knowledge, tricks and/or short cuts learned in various health situations such as recovery.
- Patient Art of the Quarter: Patient artwork and/or photography can be submitted for consideration.
- Did You Know?: Short tidbits of information about City of Hope.

Plus, a favorite category of *Hope Notes* has always been:

Expressions: Self-authored creative writing such as poems by patients, caregivers and/or family members, offering inspiration, documenting feelings, remembering loved ones and simply philosophizing.

Material for the above categories will have to come from your interest in them and subsequent participation — some in the form of questions, some in the form of answers and some simply in the form of submissions.

Second, to physically get your input, we will have a *High Hopes* contribution box located in the Sheri & Les Biller Patient and Family Resource Center to receive your questions, responses, suggestions, artwork and self-authored writings.

We also mentioned that we want *High Hopes* to be entertaining as well as enlightening. There will be one additional component — COMEDY!

Laughter, if not indeed the best medicine, is for sure an appropriate one. Having a health problem is serious enough without

“This newsletter is free - and worth it!”



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The Rose Garden at City of Hope

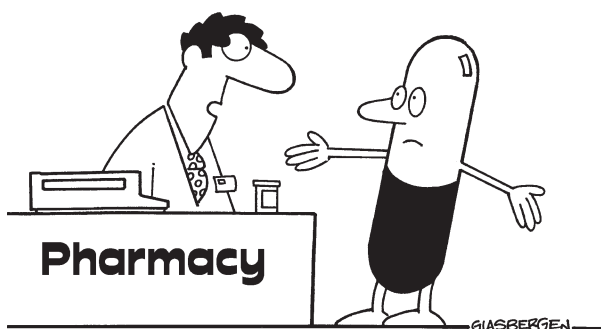


By Charles Fell, survivor

Each rose with each one's name
Seems to play, as in a game;
It is the soul of one, the heart of
another,
Basking in its bloom and in its Fame.
One shows
Mellow Yellow,
Another Bridal Pink,
Still another Royal Gold,
So many colors this must,
if truth be told,
Be near the Rainbows End; Eureka,
I have found it!
A veritable Joseph's
Coat of many colors.
This Easy Going, Carefree Delight,
Indeed, a Double Delight!
It is a kind of Lover's Lane,

A Paradise of Honey Perfume
And Fragrant Plum,
A Crowd Pleaser, with Red Ribbons above,
Where so many of the famous are
remembered,
Like Bob Hope, Henry Fonda,
Judy Garland,
Mr. Lincoln and Diana, Princess of Wales;
The roses speak, with a Touch of Class,
Of America and A Veteran's Honor.
And yes, they Whisper of A Starry Night,
A Secret Celebration,
With the Moon a Gypsy Dancer
And the stars a Candellabra of
Sun Sprinkles,
Each rose asking for Love and Peace,
But most of all the Timeless Plea:
Simply, Remember Me!

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"Well there's a side effect I haven't seen before."

To offer additional insight from your experience, e-mail to patientnewsletter@coh.org or drop your comment in the *High Hopes* contribution box located in the Sheri & Les Biller Patient and Family Resource Center. Appropriate contributions will be included in the next issue of *High Hopes*.

City of Hope's Rose Garden Facts

- 1. Full name of Rose Garden:**
Ruth & Allen Ziegler International Garden of Meditation
- 2. Number of rose plants in garden:**
1,655
- 3. Number of rose varieties in garden:**
77
- 4. Are new varieties added regularly?**
Yes.
- 5. Are replacements made as needed?**
Yes.
- 6. Approximate size (area) of garden:**
55,000 sq.ft. (1.25 acres)
- 7. Is the garden part of a park or public area?**
The grounds are open to public.
- 8. Do roses receive regular care?**
Yes.
- 9. Number of visitors annually (estimate)**
82,000
- 9. Are special public events held in the Rose Garden? If so, what?**
Yes. Anniversary celebrations (donors meet recipients), summer blood drive, Rose Tours and City of Hope Delegate Convention Dedication Ceremonies.

Brain cells come and brain cells go, but FAT cells live forever ...

Hope Notes Springs Eternal

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everything in a person's day also being serious. Besides miscellaneous humor scattered here and there throughout the issue, there will be at least one written or picture-oriented joke per issue, and many of the quotes at the bottom of each page will be humorous.

John Wooden, hall of fame basketball coach of the UCLA Bruins once said, "I don't like extreme jubilation after a win, I don't like extreme dejection after a loss — I like balance." That is what we would like the re-engineered *High Hopes* to be — balanced.

With your contributions, we can present compassion, education, sympathy, awareness, joy and laughter in a quarterly newsletter. The final product will not happen overnight; it will take a little time to develop the mechanics of cooperation and publication but, little by little, with your contributions *High Hopes* will get better and better.

We, as part of the City of Hope staff, look forward to working with you — the patients, caregivers and families — to produce this new generation newsletter. If you have any suggestions for new categories to include or how to make the newsletter better in any way, please contact Becky Andrews at 626-301-8221 or via e-mail at patientnewsletter@coh.org.

Where in the World are you?

Send us your adventures during or after treatment.



Photo courtesy of Amazon Heart Breast Cancer Organization

Linda Baginski in Sydney, Australia

Courageous Hope

By Judy Rinek

Before you come inside
See the garden at the entrance — roses
And at its center, the virgin,
Guadalupe.
Have you entered a holy place? you wonder.

As you know, roses have thorns.

Be prepared as I open the door ...
Standing there is a skeleton of a woman,
Stubbles poking through a protective veil.
Beside her is a child whose bald head
Is capped by the Dodgers — "ThinkCure"
Just those stories alone would make you cry:
Guadalupe, come in from your glorious shrine!
Can't you save any of us in this line?"

Dare you walk further? There are more ...
In waiting rooms, infusion rooms, surgery rooms, radiation rooms,
hospital rooms, clinics ...
This human anguish is all too much!
You want to run.
If you had known, you would not have come.

But thorns have roses.

If you stay, you will discover the kind of hope
That stares death in the eyes
And chooses life.



Questions and Answers from Experienced Patients

Question — Any thoughts on a healthy way to get some energy fast instead of the sugar high of a candy bar or a cup of coffee?

Answer — Conscious breathing. Often I sit or recline in a comfortable position, start breathing slowly so that the belly is inflated and breathe out slowly. As you breathe in, you may want to say "breathe in" or "I breathe in divine energy" or any mantra you make up. As you breathe out you may want to say "breathe out" or "I breathe out fatigue, tension or fear. Do this deep breathing for at least two minutes. I have found that it works on the go, as I am walking or driving as well. As a modification, the power of breath can be sent to a tense or hurting place in the body to comfort, release and heal it.

- Judy Rinek

Consider a Clinical Trial

by Judy Rinek

Imagine that weakened by illness and overwhelmed by a diagnosis of cancer, you are given a variety of treatment options by your doctor. All you want is to get well but you fear that you might not or that the treatment may be more challenging than the cancer itself. To add to your dilemma, your doctor has recommended a clinical trial.

Many of us who are patients at City of Hope wish that this scenario was just a nightmare. Instead, it is all too real. In consultation with doctors and family, our decisions about treatment may be critical to our healing process. Because City of Hope has the goal of speeding promising treatments for cancer from the laboratory to the clinic, a patient may be invited to consider a clinical trial. What the researcher wants to know is, is it more effective than the “standard treatment”? Is it safe? What is the proper dosage? What we patients want to know is will it bring the good health that we seek? Unfortunately, participation in the clinical trial is the only way to answer these questions. It is a great leap of faith.

Upon my unexpected diagnosis of metastatic breast cancer, I was given

several choices:

1. No treatment, which meant go home and get my affairs in order
2. Trying various standard chemotherapies until they found one that worked
3. A phase I clinical trial (there are several phases for testing new treatments)

Considering the clinical trial, I was faced with reams of paperwork and medical jargon. Fortunately, I could draw upon my master’s in biology to comprehend what was before me. However, questions and concerns reared up like startled horses and I could feel my emotions bolting from even thinking about participating. I faced disclaimers such as “this may not work.” I wondered how one who ran at the sight of needles would ever learn to inject herself with neupogen daily. Even though I was reassured by doctors and nurses that there were ways of overcoming side effects of the weekly chemotherapy, my spirit was troubled. Barely coping, I prayed. Soon the following insight brought me to a peaceful decision. Over the years, cancer patients with nothing to lose and everything to gain volunteered for a clinical trials. Twenty years ago

there were few effective treatments available for metastatic breast cancer; now there are many. I have these courageous people to thank. Why not follow their example for the sake of the next generation? I said, “Yes,” to the clinical trial and was well taken care of by my doctor and protocol nurses. After almost three years of treatment, including two clinical trials, I had the joyful news that a PET/CT scan could find no evidence of active cancer in my body! While all who participate in a clinical trial do not always have such results, participants have the satisfaction that what is learned from their experience will provide even better treatments in the future. They have become bearers of hope.

Next time your doctor offers a clinical trial, you may want to seriously consider it. Trials at City of Hope can be found on the Web site: www.cityofhope.org. According to the “Power of Compassion” brochure: “City of Hope performs more than 300 clinical studies, involving 30 to 40 percent of eligible patients, which is much higher than the national average of less than 5 percent.”

Helpful Hints and Tips by Patients Who Have Been There

1. Always make a list of questions to ask your doctor. As they answer, check them off.
2. During treatment, stay away from people who are sick.
3. Always think positive.
4. For inpatient stays bring your favorite pillow from home with a fun, colorful pillowcase. The hospital pillowcases are so boring! Some folks have suggested bringing flannel pillowcases – cozy.

If it wasn't for doctors, nurses and hospitals, I wouldn't have any social life at all ... — Bill Matteson

This column begins a series of articles meant to provide insight into what to expect as a patient transitions into, through and out of serious illness. The author, Bill Matteson, is a bone marrow transplant survivor of six years. It will be his experience that he will write about, which may or may not, be similar to your experience. In an attempt to help others through their health challenges, he hopes to stimulate your thinking and he invites your comments, whether similar or different, regarding your own experiences.



Anna Yoast

Bill and Jeanne Matteson

Friends

by Bill Matteson

Now You See Them, Now You Don't (Or Do You?)

I'm going to cut right to the chase regarding friends. I have some good news and some bad news. The bad news is that, if you've been told you have a serious illness, you may lose some friends. The good news is that, if you do, you're going to make new ones that will more than make up for it.

Let's handle the bad news first. Some people just can't handle sickness; they avoid it, and there's a chance that if you have such a friend, little by little, they'll distance themselves from you. (A friend of mine who had a bone marrow transplant the same time I did lost her fiancé on the journey.)

In some cases, many of your friends are "business" friends. While you're working with them, you have a lot in common. Once you have something more than the common cold, something that takes you away from the workplace for an extended time, there is little left in common to talk about. They're not sick, and you're not at work. You may stay "friends," but they may not be visiting you in the hospital every week (maybe like you thought they would).

In some cases, you may find out that these friendships were in place because you were in a position to help them in some way. When that ability ends, so does the friendship. This is especially true if you're an older patient (all ages get sick, but older people are more likely to), and your illness is such that you probably won't return to work — that the combination of your age and illness prompts your retirement (this was my case).

You may find a few things interesting at this point. In my case, a few friends who I thought were "true" friends, disappeared, and a few friends who I thought were "casual" friends started coming to see me in the hospital, and became true friends.

We all have friendships we've developed over the years that are true friends, friends who, like family, will be there for you through thick and thin, through good times and bad times (yeah, I know — some "family" might fall into the casual category, if that). But your true friends will be there, and the ones who go away probably weren't worth it in the first place. You're better off without them.

Now, the good news — you're going to make new friends

who will be true friends, and will more than replace any who disappear.

Many staff members of the hospital will become friends. Many other patients who you meet will become friends (you have a lot in common), and if you attend any support groups, many of the members of that group (patients and/or caregivers) will become friends. (again, you have a lot in common) In my case, I attended the Writing for Wellness class offered at City of Hope. The class members almost immediately became a second family. I can't wait for the next class so I can see them again and, interestingly enough, bozo that I am, they appear glad to see me (at least I get hugs).

You'll also find new friends in unexpected places, like in your neighborhood. Somehow the word gets out that you've got a health challenge and, all of a sudden, sick people all around you make themselves known. My next door neighbor had a blood disease I didn't know about, the neighbor across the way had brain cancer, the fellow I took my ink cartridges to for refills was also being treated for brain cancer, a prior co-worker/casual friend let me know about a cancer he was being treated for and we started playing golf once a week, a retired nurse down the street wanted to know all about my situation and wanted a copy of a book I wrote detailing my procedure, etc. They came out of the woodwork ...

I found it interesting as I thought more about it. When we're healthy, we perceive everyone as healthy, but when we're sick, we find that many around us who appear to be leading normal lives are also ill. Sometimes they seek you out and let you know; sometimes you just recognize the signs (like puffiness or really bald baldness). I've come to think the difference here is eyebrows — if the bald person has eyebrows, he's bald; if a bald person doesn't have eyebrows, he's sick, and if you see a bald woman, she's sick or has questionable style preferences.

So, the bottom line is that (bad news?) you may lose some friends, but if you do, (good news!) you'll make it up in spades. Remember, the friends that you lose, you're probably better off without, and the new friends you make will be there with you through thick and thin.

Straight ahead ...

What's New

in the Sheri & Les Biller Patient and Family Resource Center

Music Therapy Program

Nourish your mind, body and soul with the healing power of music. Patients and caregivers can explore instruments, create music or just come and listen! This new music therapy program is offered on the 1st and 3rd Thursday of each month from 2 to 3:30 p.m. in the Biller Patient and Family Resource Center Activity Room.

For more information or to register, call 626-256-HOPE ext. 3CARE.

Patient and Family Orientation Class

Whether you are a new patient at City of Hope or a patient who is familiar with the system, new information is always helpful as you navigate through your appointments. The Biller Patient and Family Resource Center is now offering an orientation class to patients and their families. During this one hour class, participants will learn about the wide array of support and practical resources currently available for City of Hope patients. Orientation classes are offered weekly and are held in the Biller Patient and Family Resource Center Activity Room. Preregistration is required.

- Mondays, noon to 1 p.m.
- Wednesdays, 9 to 10 a.m.

For more information or to register for a class, call 626-301-8913.

Yoga Classes – Six Week Series

New to City of Hope for patients and caregivers is Restorative, Gentle Mind, Body and Meditation Yoga. This six week series began on Monday, June 15, from 2 to 3 p.m. Classes are held in the Biller Resource Center Activity Room.

Preregistration is required as space is limited. For more information or to register call 626-256-HOPE ext. 3CARE

Hands-on-Harps Upcoming Performances

Back by popular demand! Patients, caregivers and staff are welcome to join this unique **free** music series where outstanding professional musicians will perform Celtic, folk and world music on harps and acoustic instruments.

- Tuesday, July 7 and August 4, 6:30 to 8 p.m. Dr. Alfredo Rolando Ortiz, premier harpist of South American music Performances are held in the City of Hope Helford Clinical Research Hospital Main Lobby. For more information, call 626-256-HOPE, ext. 3CARE.



“It relieves watery eyes, runny nose, aching head, and scratchy throat. Side effects include runny eyes, watery nose, aching throat, and scratchy head.”

Next Issue: October 2009

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