

# Restore

Health and hope for patients and survivors SUMMER 2011



Be The Match brings donors and patients together to fight disease

## Matchmaker, Matchmaker

*City of Hope is one of the largest, hospital-based donor centers of blood and platelets in the U.S.*

**F**or thousands of City of Hope patients, a bone marrow transplant is the answer to beating the blood disorder threatening their lives. When no family members can provide matching marrow, finding a donor elsewhere can seem impossible. But the Be The Match registry, an international roster of bone marrow donors, helps make the impossible happen.

### Making a Match

When Kennedy Kraus was just 8 years old, she was diagnosed with severe aplastic anemia, which

is often fatal without a bone marrow transplant. Her doctors began searching the marrow registry and sent her to City of Hope, one of the largest, hospital-based donor centers of blood and platelets in the country. They didn't know that a donor match was waiting 9,000 miles away. Ten years earlier, Robert and Petra Benz of Germany volunteered for the bone marrow registry after hearing about a young man with leukemia who needed a matching donor. Neither was a match for him, but

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they remained on the registry. When Robert Benz received a call from the U.S. that someone needed his help, he donated without hesitation.

After the transplant, Kennedy recovered quickly. She and Benz were even able to meet in 2009 at City of Hope's annual Celebration of Life Bone Marrow Transplantation Reunion.

"To know someone's life was saved by my donation is the best feeling one can have," Benz said.

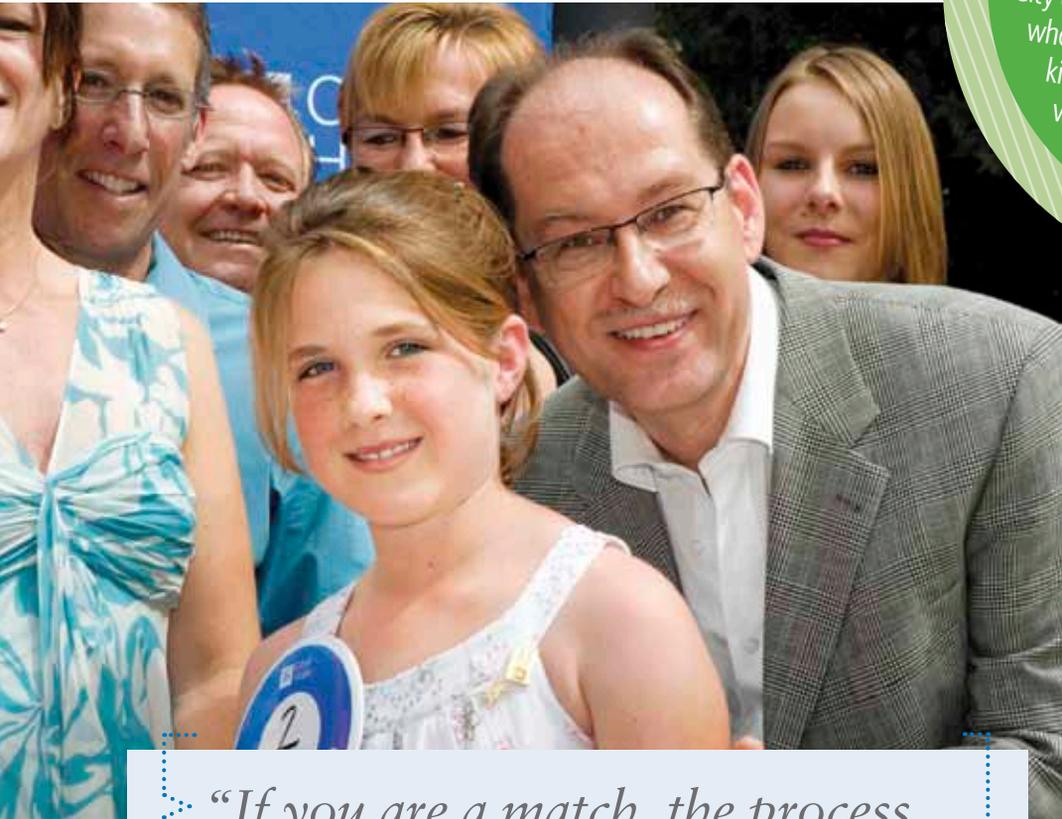


PHOTO OF KENNEDY KRAUS AND ROBERT BENZ BY THOMAS BROWN

*"If you are a match, the process to extract blood stem cells or bone marrow is quick and doesn't require any hospital time."*

### What to Expect

Once you've joined the Be The Match registry, you don't need to do anything else until you are contacted about a match.

If you are a match with a patient, the process to extract the necessary blood stem cells or bone marrow is quick and doesn't require any hospital time. Also, donors are able to return to their daily activities almost immediately. There are two ways to donate:

- **Blood stem cells:** About 80 percent of those called to donate will be asked to give blood stem cells. To prepare, you will receive four or five injections of a drug that will increase your blood stem cell production. The cells will then be extracted from a vein in your arm, similar to giving blood.
- **Bone marrow:** The remaining 20 percent of donors give bone marrow. To do this, you are put under general anesthesia. A needle is inserted into the back of the pelvic bone where the cells are then extracted. Afterward, you may feel a little sore for a few days, but over-the-counter pain medication will help. — *Colleen Ringer*



### BE SOMEONE'S MATCH

Joining the Be The Match registry is simple, and is a great way for friends, family members and caregivers of City of Hope patients to give back to others who need help. Request a free donation kit by calling **626-301-8483** or by visiting [www.marrows.org/join](http://www.marrows.org/join).

## Becoming a Donor Is Easy

Be The Match connects donors with kids and adults who need bone marrow transplants and blood stem cell transplants, says Jill Kendall-Erb, program director for Be The Match at City of Hope.

Today, more than 8 million people are on the Be The Match registry, but it could use many more. "There's a great need for people who are of an ethnic or racial minority," Kendall-Erb says, because minority and mixed-race patients have more difficulty finding a matching donor.

Signing up to be a donor is simple. First you must be between 18 and 60 years old, in good health and reside in the U.S. or Puerto Rico. Then, complete an online form to order a registration kit. When your kit arrives, follow the instructions to swab the inside of your mouth and return the kit.

# Chew on This

The enamel covering our teeth may be the hardest substance in the human body, but it can wear out — especially among those who have survived cancer

## Are You at Risk?

Everyone should see a dentist regularly, but childhood cancer survivors need to be especially vigilant with their dental care.

Risk factors for dental problems include:

- Treatment with chemotherapy before permanent teeth were formed, especially if treatment happened before age 5
- Radiation that included the mouth or salivary glands
- Treatment with azathioprine, sometimes given to patients receiving a hematopoietic cell transplant (HCT)
- Chronic graft-versus-host disease associated with HCT

## Dental Issues to Watch For

Dental problems that may result from chemotherapy or HCT and radiation during childhood include:

- Increased risk for cavities
- Shortening or thinning of teeth roots
- Absence of teeth or roots
- Difficulty with tooth enamel development resulting in discolored patches, grooves, pits or easy staining of teeth. These problems may be repaired by bonding.

*If you had a bone marrow or stem cell transplant using a donor, it is important to let your dentist know so he or she can check for signs of graft-versus-host disease.*

## The Littlest Chompers

If a child received radiation to the mouth or salivary glands, watch out for these potential issues:

- Small teeth, which might need caps or crowns to improve the function and look
- Early loss of teeth
- Baby teeth not falling out
- Delayed development or eruption of teeth
- Increased tooth sensitivity to hot and cold
- Xerostomia, or dry mouth, due to decreased saliva production, which increases risk of cavities. Drinking more fluids, using artificial saliva and limiting candy or sweets can help.
- Alteration in taste
- Trismus, the limited ability to fully open the mouth. Talk to your dentist or an occupational therapist to learn stretching exercises.
- Temporomandibular joint dysfunction, which causes pain in front of the ears
- Bite problem such as overbite or underbite

- Abnormal growth of bones in the face and neck
- Periodontal (gum) disease that can cause gums to shrink away from the teeth and lead to infection in the bone that supports the roots. This condition, known as periodontitis, may be prevented by proper brushing and flossing of the teeth and gums at least once a day.
- Problems with the jawbone healing after dental surgery or tooth extraction should be discussed by a dentist with a radiation oncologist prior to any dental surgery.

*No matter your current health, make sure your dentist has your health history and the treatment you received on file. See your dentist at least every six months, with an oral cancer screening performed each time. Notify your dentist immediately if you develop any signs of infection such as redness, tenderness, excessive bleeding of the gums, painful teeth or increased areas of sensitivity.*

SOURCE: CHILDREN'S ONCOLOGY GROUP



# 6/11-9/11

Unless noted, all classes and support groups meet at the Sheri & Les Biller Patient and Family Resource Center, City of Hope, 1500 E. Duarte Rd., Duarte, Calif. To sign up, call **626-256-4673, ext. 3CARE (32273)**, or visit [www.cityofhope.org](http://www.cityofhope.org). Class schedules are subject to change. Please call to confirm.

## SPECIAL PROGRAMS

### Art Therapy

Tuesdays: 1:30-3 p.m.

For patients and caregivers. Preregistration required. Express yourself through drawing, collage and other crafts. Art therapy can relieve stress and increase physical and emotional well-being.

### Music Therapy

1<sup>st</sup> and 3<sup>rd</sup> Thursdays of the month: 2:30-4 p.m.

For patients and caregivers. Preregistration is encouraged. Nourish your mind, body and soul with the healing power of music.

### Yoga Restaurador (Yoga in Spanish)

Wednesdays: 3-4 p.m.

### Gentle Restorative Yoga (Evening)

Wednesdays: 7-8 p.m.

For patients and caregivers. Preregistration is required. Course includes yoga postures, development of home practice and relaxation techniques.

### Nutrición Para una Vida Saludable

El segundo jueves de cada mes, entre las 2:30 y 4 p.m.

Clase gratis y abierta al público. ¡Aprenda sobre la relación entre la nutrición y su salud y como hacer cambios para comer saludablemente cada día!

Se servirán refrescos; sorteo de premios. En español. Límite de 15 participantes, así que se requiere reservaciones.

### Patient & Family Orientation

Daily: 11 a.m.-noon and 1-2 p.m.

Learn how to get the most out of your appointments, who to call when you need help, how to navigate City of Hope and where to find resources that can make life easier for patients and families.

### Empowering Your Cancer Journey: Communication, Problem-solving & Coping

For patients and caregivers. Call for dates and times. Classes will empower patients and families to take an active role in their health care and maximize their quality of life. Contact Lina Mayorga, [lmayorga@coh.org](mailto:lmayorga@coh.org), or Blanca Rivas, [brivas@coh.org](mailto:brivas@coh.org).

## SUPPORT GROUPS

### Lung Cancer Education

1<sup>st</sup> Wednesday of the month:

6-7:30 p.m.

Preregistration is preferred.

### Hope Network Peer Support Program

Hope Network is recruiting patients to provide peer support and understanding to City of Hope patients and caregivers who share the same experiences. Call the Biller Patient and Family Resource Center, or email [hopenetwork@coh.org](mailto:hopenetwork@coh.org).

### Leukemia, Lymphoma & Multiple Myeloma Support Group

1<sup>st</sup> Thursday of the month:

6-7:30 p.m.

Conference Room Y-9  
Preregistration is required.

### Breast Cancer Support Group

2<sup>nd</sup> Tuesday of the month:

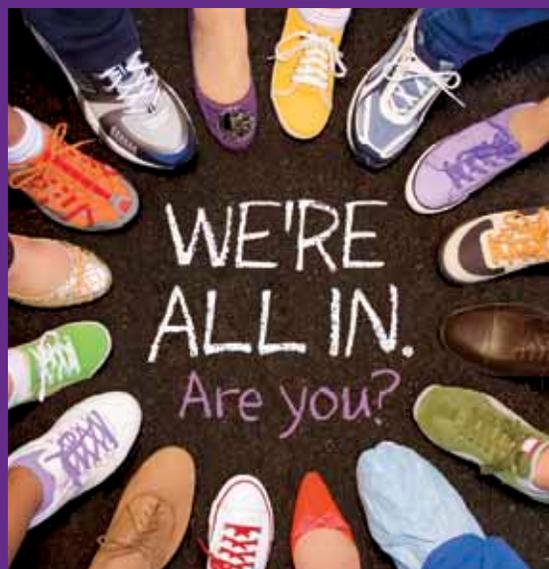
6-7:30 p.m.

Preregistration is required.

### Women's Meeting for Gynecological Support Group

2<sup>nd</sup> Tuesday of the month: 4-5 p.m.

Contact Lennie Salmon at 626-471-9200 or email [lsalmon@coh.org](mailto:lsalmon@coh.org).



City of Hope.

## WALK OF HOPE

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CHICAGO Sept. 18

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PHOENIX Oct. 2

SEATTLE Oct. 2

LOS ANGELES Nov. 6

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Register now at [www.walk4hope.org](http://www.walk4hope.org)

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