



Summer '03

# Heart to Heart

Newsletter for Families & Friends of  
Jacob's Heart Children's Cancer Association

## Director's Note

Dear Families & Friends,

Summer at Jacob's Heart is full of events and adventures. Jacob's Heart kicked off the summer with a visit to the Monterey Bay Aquarium. We watched kids glide, float and swim in the aquarium's tide pool, kids who on land often struggle with walking. The *go for it* attitude reflected on the faces of these kids, so ready to plunge in to something new, was inspiring. The children are a testament to the bravery of their parents, who resisted the temptation to shelter their child and chose to offer them the gift of adventure.

The main event of the season is our Summer Celebration, which brings families together to enjoy the simplicity of a BBQ picnic & a swim. It's a time when kids can be kids and set aside the daily struggle of living lives affected by cancer.

The summer culminates in September when we commemorate Childhood Cancer Awareness Month through our Kidrageous Carnivals in Santa Cruz and Salinas. These fun days celebrate the lives of children battling cancer and honor those kids who have lost the struggle.

We are honored to be a part of the daily celebrations in the lives of our families. Jacob's Heart takes part in the joyous moments, the little victories along the way, and in the most difficult hours when we remember those beloved children who have died.

This summer, let's try to practice a little of the *go for it* attitude of these amazing kids in our own lives.

Warm regards,

Sally

## Teens Tell It like it Is

Our teen group meets monthly to discuss cancer issues that are specific to their age group. Talking with others who face the same challenges can relieve their isolation and provide a special kind of support.

One of the main challenges faced by teens with cancer is the loss of connection with their friends. Frequent hospitalization and debilitating side effects of treatment can prevent a teen from participating in school and social events. At a recent meeting, the teens put together this guide list for friends.

### **Do's And Don'ts For Friends of a Teenage Cancer Patient**

- Don't** give up on our relationship either during or after treatment.
- Don't** assume that once treatment is over, everything is okay and that it is all behind me, because it's definitely not.
- Don't** be afraid to ask about my health or treatments.
- Don't** be shy just because you don't know what to say about my cancer.
- Don't** think that cancer is contagious.
- Don't** be negative.
- Do** treat me as you used to. I am still the same person you've always known.
- Do** offer to come over and spend time with me at home or in the hospital. You could just sit and watch a movie even if you don't know what to say.
- Do** tell me if you are uncomfortable with seeing me in the hospital, or if you just don't like the hospital. It is very important that I don't feel you are avoiding me personally.
- Do** ask if I want to talk about my treatment. Sometimes I need to talk.
- Do** be patient with me. I am processing a lot of feelings.
- Do** think of me as "a person who has cancer," not a "cancer person".

## Teen Volunteers Needed

Relay for Life is the American Cancer Society's signature activity. It offers everyone in the community an opportunity to participate in the fight against cancer. It is more than a fundraiser. Relay for Life allows us to honor cancer survivors, remember those who have lost the battle, and educate the community on early detection and prevention of cancer.

During the Relay for Life teams of people camp out at schools around the country and take turns walking or running around the track. Each team is asked to have a representative on the track at all times during the event. The Relay is an overnight event, lasting up to 24 hours. The Santa Cruz Relay will take place on July 12-13 beginning at 10:00 am at Cabrillo College. Volunteers are needed to register participants, set up booths, provide information and decorate luminaria bags. If you are interested in volunteering during this event, please call Marlene Gilbert @ 831.477.0619.



We Care About Kids with Cancer

## Recent Events

### Jacob's Heart Open House & Spring Celebration

The wild wind and rain could not dampen the spirit of our Open House and Spring Celebration! The Spring Celebration, originally planned for the park behind our office, was brought indoors. A highlight of the day was the unveiling of the Olympic Torch used in the walk through Santa Cruz by the inspiring mother-daughter team of Stanzy and Kim Childs. Present were Kim, mother of Stanzy, Jean Davidson, wife of Jim Davidson who created the torch scone, and Mike McClellan who donated the funds to purchase the torch. We also held a speed egg hunt, a bunny beanbag toss, and a craft corner for creative kids. Thank you to the UCSC Praxis volunteers, sweet Georgia Brown for her wonderful face painting, Story Creek Critters for making us laugh, and to Gayle Mitchell for capturing the smiles on film.

### Annieglass Mother's Day Sale

The third annual Annieglass sale raised \$7,000 for Jacob's Heart Programs. We are grateful to Board Member and owner of Annieglass, Ann Morhauser, for her generosity. For those of you who have attended this event, you know what a wild day it is – a special thanks to the Annieglass Staff and the Jacob's Heart Volunteers for all of their energy and stamina!

### Human Race

Perfect weather, beautiful surroundings and an energetic group of walkers were the hallmarks of our participation in the Human Race. We would like to give special recognition to Team Maddy, who walked in her memory celebrating the gift of her life. With everyone's help we placed 5th overall for most funds raised. Thank you to all who joined in the FUNraising.

### Monterey Bay Aquarium

On June 8th, more than 125 Jacob's Heart family members played in the underwater world at the Monterey Bay Aquarium. Once again, Kim Swan and the Education Department Staff and Volunteers organized a wonderful day of activities. They outdid themselves this year, providing an opportunity for kids to don a dry suit and swim with the fishes in the Great Tide Pool. Wow! Thank you for making us feel like princesses and princes of the sea!

## Upcoming Events

### Shortest Parade in the World

Join us for a walk in the Aptos 4th of July Parade—all are welcome! Dress festively and wear comfortable shoes. Call Elizabeth at 831.477.0690 x12 to sign-up.

### Family Summer Celebration

On July 20th, Jacob's Heart families from throughout our service area will gather to enjoy themselves at our annual summer celebration. Families, check your mailboxes in the coming weeks for your invitation.

### Taking to the Sea with Ride-A-Wave

Gear up for a day at the beach! August 3rd is our annual day of fun with the volunteers at Ride-A-Wave. You can look forward to surfing, kayaking, swimming and those early morning stretches! We'll mail further information in July. Rumor has it that this year, Jane "the Lane" McKenzie is hoping to get a couple of Jacob's Heart board members on board, a surfboard that is...

### 5th Annual Kidrageous Carnival

Look for the Kidrageous Carnival this year in Santa Cruz at San Lorenzo Park on the 21st of September and in Salinas at Toro Park on the 27th of September—celebrating the lives of children with cancer and Childhood Cancer Awareness month with games, food, entertainment and prizes!

### Ongoing Programs in Santa Cruz, Watsonville and Salinas

Our bereavement, teen, Art from the Heart and children's groups in Salinas, Watsonville and Santa Cruz have been scheduled through the end of the year. For times, dates, and locations please ring us at 831.477.0690. For information in Spanish, please ring Joana at 831.477.0728.



## Family Resources

**For further information or to obtain an application for any of the following programs, contact Elizabeth at Jacob's Heart: Phone 831.477.0690 x12 or email [elizabeth@jacobsheart.org](mailto:elizabeth@jacobsheart.org).**

### The Medicine Program

Provides prescription medicine free-of-charge for individuals in need.

To be approved for enrollment, some primary requirements are:

- NO insurance coverage for outpatient prescription drugs
- Does NOT qualify for a government program covering prescription meds, e.g. Medicaid
- Household income MUST fall within hardship range

If approved, your medication will be sent to your doctor and s/he will dispense it to you.

### Children's Leukemia Research Association, Inc.

Provides financial aid for leukemia patients currently in treatment and their families.

The Patient Aid Program will provide partial aid for leukemia treatment costs ONLY which include lab fees, radiation, chemotherapy, and prescription drugs. Families are encouraged to send a letter of diagnosis from physician with the completed application. Once approved by the Patient Aid Committee, aid will commence on the date of application and money allocated directly to the family for the approved claims only.

### Candlelighters Childhood Cancer Foundation (CCCF)

Two new FREE books for children with cancer are now available!!!

*The Amazing Hannah, Look at Everything I Can Do!* By Amy & David Klett (children 1-5yrs)

This is wonderful 28pg picture book with real-life photos so children are able to identify with Hannah's hospital stay, special friends, tests, treatment and germ care. (Also available in Spanish)

*Chemo, Crazyness & Comfort: My Book About Childhood Cancer* By Nancy Keene & Trevor Romain (children 6-12yrs) This 200pg resource with warm, funny illustrations and easy-to-read text help children and their parents make sense of cancer, it's treatment and feelings that arise during treatment.

Families can order the ONE book that best applies to their child's age by ordering directly from the CCCF website [www.candlelighters.org](http://www.candlelighters.org) or obtain and mail an order form available at Jacob's Heart.

## Staff Spotlight: Joana Dougherty deBelkadi

Singer. Aspiring novelist. Exotic bird owner. Meet Joana Dougherty deBelkadi, Bilingual Family Services Coordinator. In her role at Jacob's Heart, Joana extends programs and services to families whose primary language is Spanish. Forty-five, or about half, of JH families use bilingual services.

While involved in monthly support groups, art classes and events like the Kidrageous Carnival, Joana also performs community outreach at schools and community groups such as the Kiwanis, Soroptimist and Rotary Clubs.

Joana connects families with resources "that come our way." She points to a washing machine going to one family, while another received a donated car. Another donation of a sofa will soon reach another family in need.

### A "Natural Affinity" for Spanish

Joana discovered her passion for the Spanish language while in high school, changing her life direction. Before then, Joana admits she had nearly stopped going to her classes. Encouraged by a "natural affinity" for Spanish, Joana followed it through to a graduate degree from the University of California, Santa Barbara. Soon, she was teaching Spanish and English to high school, community college and adult ed students in the Bay Area as well as in both Spain and Mexico.

She moved to Santa Cruz with her husband two years ago to "live in the woods" and be closer to the beach. Joana joined Jacob's Heart the following year. "I feel so lucky to be living here," she says.

### Amazed and Humbled

Joana actively involves herself with each of the families, making hospital and home visits. "It's incredibly inspiring to learn about the ways in which parents learn to daily manage the stress of having a seriously ill child, and moreover, it's wonderful to simply get to know these families better. For the most part, 'my' families are very hard working people with whom I have developed true friendships that I treasure. To think that they find me to be of help, and consider me to be a friend is a great compliment."

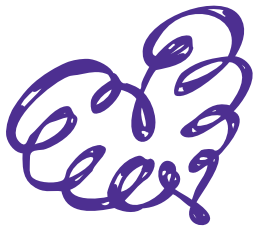
Continually amazed and humbled by the people she meets through Jacob's Heart, Joana is hard pressed when asked if any particular moment stands out for her. There have been so many memorable moments; each case is so poignant.

Joana believes most of the families would be surprised to learn of the "personal closeness and affection that I feel for them. Each family has carved a meaningful space in my heart and I think about them every day. I admire and love 'my' families' perseverance, their love for one another, their great attitudes, and grace. I can always learn a lot from them and am thankful to be included in their lives."

*"My experience with Jacob's Heart is wonderful although by nature bit-tersweet. It does not cease to amaze me how...children deal with their illnesses, and the strength I see in them is humbling. Each one of theirs is a moving story—from those who steadfastly come, face-masked and teetering on their unstable feet (due to chemotherapy effects) to join an art group; to those who feel confident enough with me to remove their hats and expose their hairless heads; to those who light up when I come to visit."*



## Vivacious Volunteers - Thank You for All You Do!



**Joy Offenberg** and **Arielle Goldstein** dreamed-up and facilitated "Expressions in Clay", Jacob's Heart's first after-school workshop. There was such a huge interest that Joy and Arielle offered two 4-week sessions and are planning a third this summer for teens! Arielle's initiative and big heart were the moving force of this workshop while her mother, Joy, as artist and teacher made the workshop possible by generously donating the materials, firing costs, and her time & expertise. Every child created an artpiece, each amazing and beautiful. Thank you Joy and Arielle for their smiles and feelings of accomplishment!

Working on their Bronze Award for 2003, **Girl Scout Troop 1169** volunteered to help create a Dr. Seuss mural in the play room. Not only did they brighten the walls of Jacob's Heart, but also filled the stomachs of Jacob's Heart families. These 9-11yr old girls prepared, cooked, and served a spaghetti dinner for our Children's Group in May and our Bereavement Group in June. They also made placemats for everyone and a special chocolate, peanutty dessert. Thank you Girl Scout Troop 1169 for being creative, warmhearted, and giving!



**Akara Draper** is one amazing volunteer with one amazing heart! Her latest project has been to lend a caring hand to one of our mothers during her son's treatments at Lucille Packard Children's Hospital at Stanford by providing in hospital childcare for her other children. The job requires extreme flexibility, careful planning, and lots of energy considering three children under 6 need to be kept busy while their mother tends to their brother's treatment. Thank you Akara for being an important link in this family's struggle with cancer! (To read more about the family Akara is helping go to [www.montereyherald.com](http://www.montereyherald.com) and search the newspaper's June 10, 2003 archives.)

**Volunteers make our job possible.**

**For volunteer opportunities, email [volunteer@jacobsheart.org](mailto:volunteer@jacobsheart.org) or ring 831.477.0690.**



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**Our mission... to improve the quality of life for children with cancer and to decrease the burdens faced by their families**

Jacob's Heart provides services that include counseling and support groups, library and resource referrals, community education, arts programs, celebrations, direct financial assistance, and meal, telephone & grocery vouchers.