Bone Marrow Donor Campaign Expands Hospital's Outreach

BY RHODA WEISS

n April 5, Good Friday, 23-month-old Alana Dung of Honolulu was found to have acute myeloid type M-7 leukemia, an unusual and aggressive form of the disease. The disease is so rare that only three other residents of Hawaii are known to have had it. Alana's physicians said that, to save her life, they would have to give her a bone marrow transplant.

The search for a donor was directed by the Hawaii Bone Marrow Donor Registry (HBMDR) at St. Francis Medical Center in Honolulu. The HBMDR recruits bone marrow donors and educates the public about bone marrow donation and transplantation. The facility is part of an international bone marrow registry that helps match donors with recipients around the world. Since its founding in 1988, the HBMDR has received around 2,000 blood samples annually from residents of Hawaii. At the time Alana's illness was diagnosed, it had the names of some 15,000 potential donors.

In the four weeks following the HBMDR's call for a donor to help Alana, more than 30,000 Hawaiians volunteered blood samples. Because these were new potential donors, their names were a substantial addition to the HBMDR's list and, through it, to that of the international registry. "This drive has produced more than 200 potential matches for people needing marrow transplants, as well as a handful of perfect matches," said Young K. Paik, MD, director of St. Francis's laboratories and the HBMDR.

On May 29, Alana's family learned through the international registry that a matching donor had been found for her on Taiwan. The transplant surgery was performed in July. Hawaiians are now praying that the match turns out to be a perfect one.

HAWAIIANS ARE AT A DISADVANTAGE

The chances of finding a suitable donor for Alana were complicated by the fact that she has a multiethnic background. Unfortunately, noted Paik,



Ms. Weiss is a

Santa Monica,

CA-based

healthcare

consultant.

"the overwhelming majority of registered donors in the [international registry] are of Caucasian ancestry." This puts Hawaiians—three-fourths of whom are multiethnic like Alana—at a disadvantage.

The HBMDR is therefore important both as an actual donor registry and as an educational force, making the community more aware of bone marrow illnesses and therapies for them. By encouraging the participation in its program of many island residents—especially those of Asian, Filipino, native Hawaiian, and multiethnic ancestry—the HBMDR increases the chances that Hawaiians suffering from bone marrow disease will find a donor match. At present, as many as 70 percent of those Hawaiians who need transplants fail to get them because no donor can be found.

THE CAMPAIGN TO SAVE ALANA

Alana's family, once they had been informed of her diagnosis, appealed to the HBMDR and the region's news media to help find a bone marrow donor for her. Because of newspaper and television stories about Alana's plight, what had begun as a family effort soon grew into a campaign involving more than 500 volunteers.

The HBMDR Team Under Paik's leadership, the HBMDR organized a team to coordinate the recruitment of donors, the collection of blood samples from them, and the testing of those samples. St. Francis put its tissue-typing laboratory on a 24-hour schedule to do the testing. Even then, the lab received more samples than it could accommodate, and it had to send some to a laboratory at the University of California–Los Angeles.

Recruitment Site Volunteers Leaders of the campaign set up more than 30 donor recruitment sites—in, for example, churches, schools, parks, and shopping malls—throughout the islands. At these sites, volunteer phlebotomists, technicians, and nurses took blood samples from potential donors and sent them to the lab.

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Coming in the Next Issue of

Progress.

LONG-TERM CARE

Healthcare organizations are trying new approaches to help the elderly and their care givers. The November-December issue looks at a creative volunteer program that facilitates elderly independence, a nursing home's efforts to involve family members in care, and a retirement community's successful fitness program.

EUTHANASIA

Sidney Callahan makes a provocative case against self-determined dying in assisted suicide and euthanasia. Her insights come from a feminist perspective and have a message for all of society.

NEW COVENANT

In the context of the New
Covenant process for
facilitating networking
among Catholic organizations, Alan M. Zuckerman
addresses collaboration from
the perspective of the small
city, which typically has only
two or three hospitals,
one of which is Catholic.

BONE MARROW DONOR

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Data Processing Volunteers The owners of a Honolulu data processing firm donated the use of office space and computers for the campaign. Hundreds of volunteers worked rotating four-hour shifts, seven days a week, to process data concerning the thousands of blood samples and potential donors.

Other Volunteers Meanwhile, St. Francis's public relations staff turned out news releases and publicity fliers about the campaign. Musicians and other entertainers put on a free concert. Other volunteers made and distributed orange bows, which Hawaiians wore to show their support for Alana and the HBMRD's efforts in her behalf. By the end of the campaign, Angie Wyss, a St. Francis public relations representative, was saying, "I'd be surprised if there was a single person in Hawaii who didn't know about Alana's plight."

OTHER BENEFITS OF THE CAMPAIGN

Known as the "Transplant Center of the Pacific," St. Francis is the region's leader in organ transplantation. As a result of the search for a bone marrow donor for Alana, physicians located organ donors for other sick persons.

St. Francis is, moreover, the only Hawaiian medical center that has federal certification to collect bone marrow donations and to perform bone marrow transplants. The campaign to help Alana brought a great deal of attention to St. Francis's HBMDR and its efforts to help persons with bone marrow illnesses. "Before the campaign, fewer than a dozen preliminary matches were found each month on the registry," said Paik. "Since the campaign, the preliminary matches have increased tenfold."

VALUES MANAGEMENT

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organizations structure evaluation, the process will retain a subjective component. Similarly, issues will vary in their importance from one organization to another. Therefore the guide to assessing values integration was not intended as a series of checklists but rather as a flexible tool that can be applied as appropriate for each organization.

A SYSTEMWIDE BENCHMARK

A Guide to Assessing Values Integration: Key Indicators has helped SSMHCS obtain systemwide data that can serve as a benchmark for comparison and can identify areas of strength or needed growth within its entities. The system sent the instrument to each of its entities in March 1995, and then compiled summaries of the key indicator profiles for each entity, comparing their scores with the midrange scores for the system overall.

The system asked its members to set up a Values Assessment Task Force to look at the profiles, discuss areas needing improvement, contact other system members for collaboration and replication of best practices, develop a plan for improvement, and oversee the changes. The task force also filled out an Opportunity for Improvement worksheet, outlining the goal and plan for achieving it. These worksheets will be used by the Corporate Mission Values Department for ongoing support of the opportunities identified.

As the tremendous pace of change in healthcare continues, it is more important than ever that leaders in Catholic healthcare take time not only to evaluate their own mission and values integration, but also to assess that of potential partners. As leaders of organizations founded on Jesus' healing mission and on the Gospel values, it is crucial to ask whether "who we say we are" is in harmony with "what our actions and activities" say we value.

For more information or to obtain a copy of A Guide to Assessing Values Integration: Key Indicators, call Rita Raffaele at 314-994-7752.