better response rates. Marti cautioned that “fludarabine is not an ideal drug however, as prolonged administration of the drug results in severe T-cell depletion and suppression.”

Many leukemia researchers think 506U may be the drug of choice for treating CLL in the next decade. In Phase I trials it has shown greater efficacy than any other drug commercially available. It will be entering phase II trials this summer and researchers hope that a good sense of its possibilities will emerge sometime in 1999.

Marti believes however that “the real hope for late stage CLL patients lies in multiple therapies that combine the best of the biological approaches with new and exciting molecular treatments which are still evolving.” Scientists are also looking at new ways to modulate cells to the sensitivity of chemotherapies.

— Mike Miller

Stat Bite
Age Distribution of Leukemias

Acute lymphocytic leukemia represents about 12% of all leukemias in the United States and is predominantly found in persons younger than 20. The majority of leukemias, including chronic lymphocytic leukemia and acute and chronic myeloid leukemias, are more commonly found in people aged 65 and older.

Patient Advocates Help Researchers Avoid “Bumps in the Road”

When it comes to patient advocates and medical researchers, some envision worlds colliding or impassable bridges. But a few trailblazers within the Specialized Program of Research Excellence (SPORE) are convincing skeptics that strong bonds can be forged between these diverse camps for a better research program.

Advocates have been a formal part of the breast cancer SPORE based at the University of California at San Francisco since its inception in 1992. Their example is spurring similar partnerships at other NCI-supported SPOREs and cooperative groups. The two main benefits of advocate participation mentioned by both sides are focus and a common language.

Easily Distracted

“It’s easy to become distracted when doing scientific research and follow things of scientific importance but not necessarily translational importance. Advocates bring a continual reminder that this is breast cancer we’re working on, not one’s research career. They provide a centering force all the time,” said Joe Gray, Ph.D., principal investigator for the San Francisco breast cancer SPORE.

Deborah Collyar described the challenge: “Researchers become experts in the letter Q and can tell you all about Q. But they forget that it’s only part of the alphabet.” Collyar is an advocate member of the UCSF SPORE and president of Patient Advocates in Research.

(PAIR), a northern California-based movement to involve advocates in cancer research. “As people living with the disease, we have to look at the big picture to put our lives back together. We help bring that larger picture into our research.”

The SPOREs receive NCI support to do research designed to move laboratory discoveries into patient and population research settings. Of the 14 SPOREs, six focus on breast cancer, three on prostate cancer, three on lung cancer, and two on gastrointestinal cancers. A concept for an ovarian cancer biologists, and surgeons. Each specialty has its own language. “Frequently, when someone discusses [his or her] research, if they fall into their jargon, not only do the advocates not understand, but neither do the other scientists,” said Marc Shuman, M.D., professor of medicine and associate director for research, education, and training at the UCSF Cancer Center. People now speak in a way that everyone can understand. As a consequence, there’s a lot more discussion. “I credit the SPORE advocates for accomplishing that,” added Shuman.

In the UCSF SPORE, the advocates participate in biweekly research discussions, an annual retreat, and informal multidisciplinary discussion sessions. The 100 or so advocates who are part of that SPORE help with trial design, enrollment, Institutional Review Board approvals, and raise money.

“We are partners. We have an active voice in all decisions,” Collyar said. “Some researchers quake when they hear that. But it works.” Gray vouched for the integral role that the advocates play. “They are a continual presence in everything. We benefit from and enjoy their participation.”

Shuman admitted to being a skeptic about the collaboration at first. “I didn’t think we’d be helpful in any way. I thought they’d be obstructive. Now I’m a convert.”

According to Collyar, clinical trials have traditionally been designed from the scientific viewpoint. “The people we want to attract into these trials are never considered until the trial is already planned and it’s time for accrual.” As a result, barriers to participation are built in. The advocates review eligibility criteria, informed consent documents, and ask about the necessity of frequent invasive tests. Collyar and her colleagues also convinced Kaiser Permanente, a major managed care provider in the Bay Area, to cover patient care costs for members enrolled in local SPORE studies.

Catching On

“The San Francisco group served as a model for some of the other SPOREs,” said Andrew Chiarodo, Ph.D., who retired in August as chief of NCI’s Organ Systems Branch, which oversees the SPORE program. “The other SPOREs are beginning to see that the advocates can play an important role in their activities,” he added.

To date, advocacy involvement is really confined to the breast cancer SPOREs. The breast cancer SPORE based at the University of Texas Health Sciences Center at San Antonio counts on advocates to educate the community about clinical trials and the SPORE’s activities. Advocates also came to the SPORE’s aid to push the state legislature for discrimination protections for people who undergo genetic testing, according to Dale Eastman, who initiated the relationship between the SPORE and local advocates and is president and founder of the Alamo Breast Cancer Foundation. Thirty San Antonio volunteers have been trained by Collyar’s advocacy group — PAIR — and will soon be assigned to relevant SPORE projects.

For the Department of Defense breast cancer research grant at Georgetown University in Washington, D.C., patient advocate Margaret Borwhat serves as a conduit to a larger group of patients who review materials and surveys to improve their readability and sensitivity. She was recently asked to do the same for Georgetown’s SPORE. That group is also looking at ways that patients who have gone through clinical trials can guide those considering or just beginning the process,” Borwhat said.

The North Carolina breast cancer SPORE also has active advocate involvement. Collyar said she hopes to see efforts expand to the SPOREs that focus on other cancers as well.

Advocates’ roles have been expanding within the National Cancer Institute in recent years. Along with membership...
on the National Cancer Advisory Board, consumer representatives are members of NCI's Board of Scientific Advisors, which reviews extramural research, and are soon to be appointed to the subcommittee of the Board of Scientific Counselors that advises on intramural clinical and epidemiologic research; and they participate in the Progress Review Groups, which advise the NCI director on breast, lung, and prostate cancers. NCI plans to enlist consumers for reviews of the cancer center planning grants and the clinical cooperative group cooperative agreements. The NCI Director's Consumer Liaison Group brings patient and consumer input to the institute on important issues and was recently chartered by Congress as a top level advisory group within the government.

Along with NCI, some of the cooperative groups, such as Cancer and Leukemia Group B and the Southwest Oncology Group, have included advocates in their activities.

**Training Is Essential**

Hands-on involvement in research planning calls for heavy duty training and continuous science education. Many of the advocates have been through Project LEAD, a science training program for advocates run by the National

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**Wisconsin’s Cancer Centers Announce Intent to Merge in 2001**

Wisconsin’s two federally funded cancer centers, the McArdle Laboratory for Cancer Research and the University of Wisconsin Comprehensive Cancer Center, have announced they will merge. Joined under one banner, the two organizations will share administration, support, and research goals. The official merger will occur in 2001, when the two centers’ grant cycles from the National Cancer Institute coincide.

The University of Wisconsin campus in Madison is the only academic campus in the United States that hosts two NCI-funded cancer centers. Established in 1940 by Harold Rusch, M.D., the McArdle Laboratory was the first academic center in the country devoted to basic cancer research and has been funded as an NCI cancer center for nearly 35 years. In 1973, Rusch founded the UWCCC to focus on clinical research.

John Niederhuber, M.D., assumed his position as UWCCC director last year and was the impetus behind the merger. McArdle Laboratory Director Norman Drinkwater, Ph.D., agrees that the consolidation will facilitate joint research efforts between the two centers.

"Consolidation will help bring together the more clinical focus in the Comprehensive Cancer Center with the research focus in the McArdle lab," Drinkwater told local news reporters when the merger was announced. "We’ve always worked together, but the fact that we’ll be under the same umbrella will create more opportunities for interaction."

No name has been selected yet for the new joint venture, but several names are reportedly being considered, said Dian Land, a spokesperson for the UW medical school.

— Jennifer Smith

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**Awards, Appointments, Announcements**

The Board of Managers of the Wistar Institute, Philadelphia, announced that it established a named professorship honoring Hilary Koprowski, Ph.D., who served as Wistar's director from 1957 to 1991 and is now professor laureate there and Wistar Professor of Research Medicine at the University of Pennsylvania, also in Philadelphia.

The Hilary Koprowski Endowed Professorship, Wistar’s first, is funded by the Wistar Science Trust Fund. Se-