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CLL GLOBAL'S BEGINNINGS:

from concept to reality

CLL Global Research Foundation began as a concept from patients with chronic lymphocytic leukemia (CLL) and their families. Their generosity enabled the establishment of the Foundation, and the continued kindness of numerous people and organizations allows CLL Global to grow. How did CLL Global go from concept to reality?

The idea originated from Glenn Friedly, a businessman who retired early after being diagnosed with CLL at the age of 50. He was relatively young for having CLL, and his disease progressed rapidly. He took it upon himself to visit a number of oncologists. He went to Dana-Farber Cancer Institute in Boston, MA, Royal Marsden Hospital in London, a cancer center in Miami, FL and another one in Palm Beach, FL. He also went to MD Anderson Cancer Center in Houston, TX where he met Dr. Michael Keating.

At the time of his visit to MD Anderson, a clinical trial for FCR (a therapeutic combination of fludarabine, cyclophosphamide and rituximab) was under way and Glenn ultimately chose this treatment for his CLL. In his mind, FCR showed the most promise for remission even though it was a fairly new therapy. Dr. Keating's enthusiasm was also a big part of Glenn's decision. Dr. Keating was the most encouraging of the oncologists that he had seen for his CLL. With low platelets, no energy and little oxygen in his blood, this was possibly Glenn's only shot at survival.

When he came for follow-up appointments, Glenn and Dr. Keating frequently discussed the inadequate research being conducted for CLL and the need for additional support. Glenn recalls Dr. Keating discussing the difficulties in getting funding for CLL research.



Although CLL is the most common adult leukemia, the population of CLL patients requiring treatment is small compared to other cancers. Also, the average age of CLL patients is 70. Many of these patients may develop and succumb to other complications before their CLL progresses enough to become an issue or require treatment. The bottom line was that CLL did not represent a major market for the pharmaceutical industry. Subsequently, there was not much funding allocated to CLL research.

A number of foundations are established by people trying to focus more attention on an area that is not adequately funded. The recurring theme in each of these organizations is to take care of yourself and your family. Glenn came to the conclusion that the primary people interested in funding

research for CLL would be patients with CLL and their loved ones. Dr. Keating sees patients from near and far, all of whom have a vested interest in life. Glenn's proposition was simple. Establish an organization and have patients, their families and their friends put their own fate in their hands.

Glenn felt that Dr. Keating was capable of embarking on this proposition. "He had optimism and a passion for finding a cure and helping people," Glenn stated. As his leukemia moved into remission in the early 2000's, Glenn and Dr. Keating both became convinced of the power of a patient-driven organization dedicated to CLL research.

While Dr. Keating did not have the expertise to organize and run a non-profit organization, he did have a base of intelligent, experienced patients. As he discussed the concept with some of them, he soon realized that his patients were enthusiastically offering their suggestions and their help. Many of those patients turned to their network of professional colleagues who were also willing to help. Dr. Keating received assistance from attorneys, accountants and experienced non-profit professionals.

In the beginning, there was significant discussion regarding the organizational structure. A variety of meetings were held to discuss the concept and how to turn it into a reality. Multiple patients, relatives, friends, scientists, academics, philanthropists and business executives provided input. Jeff Taylor, the husband of one of Dr. Keating's patients and executive director of a non-profit healthcare research institute, kindly offered his expertise. He provided significant input regarding the formation of the organization.



The expanded network of colleagues and contacts led Dr. Keating to an attorney who graciously provided legal expertise to handle the incorporation of the organization as well as strategic thinking.

Because of his involvement in the CLL research community, Dr. Keating was well aware of investigators throughout the world that were conducting innovative research. Therefore, it was important to have the ability to fund research throughout the globe. Other imperatives were transparency and minimal dollars for fundraising. The consensus of Dr. Keating, Glenn Friedly and other visionaries was to operate with low overhead so that the bulk of funds would be allocated for research. CLL Global's administrative overhead remains extremely low, at five percent.

A rapid turn-around of scientific findings was also important in order to accelerate research. CLL Global has chosen not to fund exploratory basic research, but to focus on translational research that will be meaningful in the clinical setting. Grant recipients are expected to have results applicable in the clinic within two to three years of funding.

CLL Global has succeeded because of the generosity of so many individuals including the Board of Directors and the Scientific Advisory Board (SAB). The Board has always had a strong representation of patients and family members. After all, CLL Global was established for their benefit, and they have a particular interest in the operation and success of the Foundation. In addition, there has always been representation from the academic, scientific and business communities.

The SAB is comprised of noted CLL physicians and scientists. Each SAB member volunteers their time to review submitted grant applications and recommend how CLL Global's research dollars should be spent. The SAB Chair, Dr. Bill Plunkett has played an important role in shaping CLL Global. He is a long-time collaborator of Dr. Keating and has served as chairman of the SAB since the Foundation's inception. Dr. Plunkett has guided the organization in determining research priorities, ensuring that all applications are fairly reviewed and has spearheaded the efforts to ensure research dollars continue to be used effectively.

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Initially, all grants were awarded for individual projects. Up-and-coming investigators were invited to submit a letter of intent. This strategy proved successful in identifying promising technologies. The grants generated new insights and additional research questions to be explored. However, each project was independent and not inter-related. Therefore, CLL Global decided to incorporate a novel idea for CLL research. Rather than award only individual grants, CLL Global would promote integrated research.

The U.S./European Alliance for the Therapy of CLL, known as the Alliance, was established at the end of 2007. Successful CLL investigators, some of whom were previously funded through the individual grant program, were invited to take part in a break-through initiative promoting collaboration and openness. The Alliance is based on five themes important to CLL research; the themes, projects and researchers intentionally overlap. The atmosphere is one of great trust and enthusiasm.

An attractive aspect of CLL Global is that it is not locked into a standard format and can respond quickly as opportunities present themselves. Examples of this include two international initiatives, one in Australia and one in Israel, which were provided seed money to start CLL research programs.

CLL Global maintains a “dollars in, dollars out” approach. As funds are raised, the organization attempts to award money to investigators as quickly as possible. Although small in operation, the efficiency and growth of CLL Global makes it an outstanding model of a non-profit organization.

The future of CLL Global will depend on maintaining an active donor pool. More and more patients seem willing to donate as long as there is open communication regarding where their money is being spent and the success of the programs funded. The level of enthusiasm continues to expand. The talent of the researchers, the board, and those dedicated to CLL Global is outstanding. There is a realistic anticipation that curative strategies for CLL will be implemented in the clinic in the next 3-5 years. ::

