

A BRIEF HISTORY OF HEMOPHILIA CENTER AT ORTHOPAEDIC HOSPITAL, LOS ANGELES; 2004

A group of patients with hemophilia had been under the care of the pediatricians Shelby Dietrich MD and Shirley Whiteman MD at California Hospital starting in the late 1950's. Plasma, which first became available in the 1950's, was used for treatment. That hospital soon found it could not sustain the program financially. Few patients had insurance that covered blood products.

Orthopaedic Hospital agreed to take on the group of patients, some two-thirds of whom were children. In 1962, with a "demonstration grant" from the federal government, Dr. Dietrich set up a multi-specialty team for comprehensive care of hemophilia, an innovative notion at the time, at the hospital. The team included the above pediatricians, an internist Dr. Andon Andonian, a part-time orthopedic surgeon Dr. Max Negri, a physiotherapist Ms. Donna Boone, a nurse, a social worker, a vocational counselor and a secretary.

Patients with hemophilia needed a great deal of medical care at the time, because the available treatment was sub-optimal. Bleeding into joints is common in hemophilia and the resulting arthritis required the attention of physiotherapists and an orthopedic surgeon. Frequently-recurring bleeding episodes, in the absence of adequate health insurance, put social and emotional strains on patients and their families, demanding the attention of social workers. Young men whose schooling had been curtailed had a hard time finding employment. All team members needed information from each other, and needed each other's encouragement when faced with the problems of over a hundred seriously-affected patients. At weekly team conferences, they exchanged information and made plans for individual patients.

In 1962, the only available treatment was whole plasma, and that was given to every patient regardless of type of hemophilia. When it became apparent that concentrates would become available at the end of the 1960's, but would be specific for different types of hemophilia, a hematologist, Dr. Carol Kasper, was recruited to set up a coagulation laboratory to make specific diagnoses and to supervise treatment of difficult hematologic situations. In 1968, with concentrate, which is more effective than plasma, the first elective reconstructive operation was performed, a hip cup-arthroplasty (replacement of the hip socket), by Dr. J. Vernon Luck. With concentrate, patients were trained to infuse themselves intravenously, which led to self-treatment at home, just as diabetics use insulin themselves at home.

All components of the hemophilia program including the examining and treating rooms, the coagulation laboratory, and doctors offices moved into adjacent quarters when the Lowman Outpatient Building was finished in 1968.

The success of the team approach, with the center's strong emphasis on physical rehabilitation with physiotherapy, became widely known very rapidly. Many patients from other parts of the country came to Orthopaedic Hospital for consultation and treatment. Dr. Dietrich was an advisor to the World Federation of Hemophilia, formed in 1963. In 1970 that organization named the center at Orthopaedic Hospital as one of its first four "International Hemophilia Training Centers" where health-care personnel from developing countries could be taught how to manage hemophilia. In 1971, the first such Fellows were trained, a team of three doctors from San Jose, Costa Rica, where they returned and established an excellent center. In subsequent years, many foreign Fellows were trained. Domestic hematology Fellows from USC were trained in hemophilia management at the Center from 1974 to 1998; hematology Fellows from UCLA have been trained from 1999 to the present time.

Funding for care of patients improved in 1968 when Dr. Dietrich was able to convince the state's California Children's Program to cover boys with hemophilia, so that their expensive blood products could be covered. A few years later, Dr. Kasper and the director of the Hemophilia Foundation of Southern California, with the help of then-State Senator George Moscone, were able to establish the state's Genetically Handicapped Persons Program to

cover medical care for adults with hemophilia who worked but did not have health insurance, or had inadequate health insurance. Private insurance began to cover blood products in the 1970's.

Mr. Louis Friedland, then president of the National Hemophilia Foundation and a Vice-President of Universal Studios, impressed with the care given to his son at Orthopaedic Hospital, convinced a United States senator to sponsor a bill to encourage formation of comprehensive care centers across the country. It was passed in 1976. The amount of money allocated to each center by the Maternal and Child Health Bureau was limited, typically enough for a nurse for a small center or two or three mid-level employees for a large one, but that much help was critical. The USA now has a network of over 140 centers. Strong programs, such as the one at Orthopaedic Hospital, were assigned the task of developing programs where none existed and where there was no local initiative to form one. Orthopaedic Hospital was paired with Hawaii; medical personnel from the Hospital worked with health-care personnel in Hawaii for nearly 20 years until, at last, a center came into existence in Honolulu.

With the advent of more plentiful clotting factor concentrate and the means to pay for it, many long-standing orthopedic problems could be improved with rehabilitative surgery. In 1974, Dr. James V. Luck Jr, joined the team and became a devoted, geographic-full-time orthopedic surgeon for the program. Close to a thousand elective surgical operations have been performed on persons with hemophilia since 1968. Patients continue to come from across the country for orthopedic surgery.

At the beginning of the 1980's, the Center had some 500 patients, with an ever-growing proportion of adults (thanks to the improved survival with plasma and then concentrate.) In 1982, AIDS first struck patients with hemophilia. The virus had been transmitted through blood products. By 1985, a test for HIV was available and plasma products were safe again, but the damage had been done. Some 200 of its patients, mostly adults, died of AIDS before good drugs to control the infection were developed.

At the same time, in the 1980's, major changes took place in health insurance (with HMOs and PPOs) and with the way concentrates were delivered and reimbursed. Revenues for hemophilia care fell throughout the decade, creating further stress on the program.

Dr. Kasper, who had become a Professor of Medicine at USC, served as director of the Center from 1988-1999 and as medical director of the World Federation of Hemophilia from 1994 to 2000. The Center was "twinned" with developing hemophilia centers in Bogota, Colombia and in Vellore, India, providing those centers with further training and encouragement. Increased international experience broadened the team's understanding of hemophilia care and appreciation of its own advantages.

In the new millennium, under the directorship of Dr. Laurence Logan, the Center serves some 300 patients with hemophilia with scheduled and unscheduled outpatient clinics for hematological and orthopedic care, physiotherapy, social work services, and a specialized coagulation laboratory for diagnosis of bleeding disorders and their follow-up care. Clinics, doctors' offices and the laboratory are clustered on the 4th floor of the Lowman Outpatient Center. An urgent care center is located on the ground floor and provides quick treatment to patients when the outpatient clinics are not open. Dr. Luck trained a young orthopedic surgeon, Dr. Mauricio Silva, who assists him and will eventually succeed him. Dr. Logan trained a young hematologist, Dr. Doris Quon, who joined the program as of July 1, 2003.