

A Journey, Not a Destination

By Laird Jackson, M.D., Clinical Advisory Board Member and former CdLS Foundation Medical Director

In the beginning there were two West Coast mothers – Carol Welsh and Sue Anthony, who met in 1970 because their children shared the same rare condition, called CdLS. Frustrated by the appalling lack of available medical information about their children’s condition, they scraped up a supply of paper, an old duplicating setup with imprinting gel, master forms for typing and appealed to the March of Dimes for a mailing list of their clinical grantees. Working far into the waning Northwestern nights, they cranked out a newsletter, licked hundreds of stamps and sent the product forth in the mail. Thus began a journey that has just reached an important milestone.

That 1977 newsletter reached a clinician/researcher at Jefferson Medical College, Laird Jackson, and a subsequent issue had a medical question, which I answered initiating a correspondence. In 1980, Sue and the Matheson and Sharrard families arranged an eastern vacation to meet CdLS families at a Pennsylvania picnic. There, I met Sue and the other families, some of whom I knew from my work. There, I also met Julie Mairano and was asked, “Who are you and what do you want?” My answer (met with some skepticism) was simple – “I’m just someone who is interested in CdLS and want to help the children and families if I can.” I met a few families, took some notes and realized that this experience was unique so my wife, Marie Barr, and I began holding “clinic” at a picnic table outside to afford some privacy.

These gatherings moved to Maryland where families stayed overnight at the “Red Horse Motel.” In three years I had seen more children with CdLS than anyone and Marie had become a fast friend of the children and the families. Marie and I missed the 1984 picnic because of personal illness. The “picnics” transformed into “conventions” in 1985-86 in Indianapolis, sponsored by the American Legion. Families met at a hotel and the “clinic” and informational meetings were held at a school facility nearby. More families were recorded and the children’s medical information gathered. Close to 100 children had been seen.

In summer 1986, I traveled to a Los Angeles picnic arranged by Sue Salmons to film and examine children. Sue brought Dr. Dick Mungo to talk about dental problems and he became the beginning of a medical team. At the 1987 Philadelphia meeting, Marie arranged facilities at a medical school for pediatrics, genetics, orthopedics, ENT, neurology, radiology and ophthalmology to see children. The head of children’s service at the Wills Eye Hospital assigned a young resident in ophthalmology, Dr. Alex Levin to the task of seeing patients. The medical team was growing.

