
The most efficient means for dealing with the myriad problems of hemophilia is through a comprehensive hemophilia care center involving medical and paramedical personnel, as well as numerous non-medical supportive services. As in all consumer services, however, problems arise when the care center team and the individuals who comprise it are unaware of the true needs of the patients they serve. An active and vocal group of hemophilia families and friends can provide insights otherwise unattainable. Working in cooperation with the center, they can provide guidance and seek funding to reduce the cost paid by the patient.

We describe the role of consumer-patients in the initiation and development of New Jersey's first and only comprehensive care center for hemophilia. We also present a detailed examination of the kinds of assistance which have been provided and which is being provided in the growth and expansion of the center's team and its activities. A plan for a statewide treatment network centered around this treatment facility will be presented.

AN EVALUATION OF HOSPITAL FACILITIES FOR CANADIAN HEMOPHILICS. B. George and M.J. Imwood, Canadian Hemophilia Society, Hamilton, Ontario, Canada.

Wide differences exist in the standard of facilities currently available to Canadian hemophiliacs. In order to categorize these facilities a survey was conducted by members of the Canadian Hemophilia Society of 106 hospitals currently treating hemophiliacs in the 10 provinces of Canada. Two of the provinces (Quebec and British Columbia) had incomplete surveys performed. A scoring system was devised to grade the hospitals from level I to level V, with the following results. Eleven level I (comprehensive treatment centres as defined by the World Federation of Hemophilia) were identified in seven provinces. Seventeen level II (facilities considered acceptable for regularly attending hemophiliacs) were present in 8 provinces. Thirty five level IV hospitals (suitable for occasional and uncomplicated therapy) were situated in 8 provinces. Thirty five level IV facilities in 7 provinces and eight level V facilities in 4 provinces were considered to have inadequate facilities for routine or sporadic therapy. Only 63 of the 106 (level I, II and III) had suitable facilities for the reception of hemophiliacs. Of these 63 hospitals only 28 were providing materials and services for home infusion programs. In order that Canada can achieve a standard of facilities comparable to other countries actively involved in hemophilia care, hospitals in all provinces must be upgraded, along with an increased number and distribution of comprehensive treatment centres.