

CLINICAL DEMONSTRATION PROGRAM

III Home Treatment Programs

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HISTORY OF CARE FOR THE HEMOPHILIAC IN FRANCE: MOVEMENT FROM SPECIAL HOSPITAL TO HOME CARE. J.P. Allain. French Red Cross, La Queue-lez-Yvelines, France.

In the modern context of hemophilia care the boarding school for hemophiliacs has become a comprehensive center capable of recognizing and adapting to the needs of hemophiliacs through a diversified structure and a multidisciplinary approach. In and out patient care are provided. The duration of stay varies from days to years according to the common project of the child, his parents, and the institution. An educational program for both hemophiliacs and parents has been developed. Since 1972, 90 children ranging in age from 10 to 17 participated in the training for self-treatment. Eighty per cent succeeded and guidelines for optimal training were drawn considering age, psychological status and parents involvement. Since 1974 105 families participated in the program. Among 64 families whose children were not involved in self-treatment, 32 are treating their child, 11 were unsuccessful (5 with children under the age of 4, 6 for major psychological problems) and 21 had insufficient attendance. Twice a month, groups of 3-4 families meet successively for an hour with a nurse, a physiotherapist, a physician and an educator. The last two staff members moderate free discussions rather than teach. This training carried out over several months induced profound beneficial changes in the family's approach to hemophilia.

HOME CARE IN GERMANY: PHILOSOPHY OF TREATMENT, RESULTS OF INTENSIVE CARE. Brackmann, H. H., Hoffmann, P., Etzel, F., Egli, H., Hildenbrand. Inst. f. Exp. Hematology and Blood Transfusion, University of Bonn, 5300 Bonn-Venusberg, W. Germany.

In the FRG the work of several centers is concerned with introducing a program of self-treatment for hemophiliacs. The general goal of a self-treatment-program is: avoidance of a time lag due to long distances and the expansion of personal freedom and life style possibilities.

In respect to the dosage and treatment duration various opinions exist, some of them differing quite noticeably from ours. Our conception about the therapy, existing since the beginning of our program (June 1971), is based on an intensive cooperation with the department of orthopedics at the university. Through our teamwork the following results were achieved:

- the evaluation of 17.196 acute bleedings registered 93% joint and muscle bleedings
- 98% of the patients over 11 years of age with severe and semi-severe hemophilia A or B revealed at least one, in several cases more, arthropathic changes
- the pathophysiological process of a joint bleeding leads to an important electromyographic test as well as to new ideas about biomechanics.

Based on the general test results a specific dosage plan for each patient resulted, which, together with the orthopedic findings took into consideration the attained biological recovery. Since our goal is the strengthening and training of muscle in general, every patient receives a specially adopted training program, which largely excludes bleeding. Our results have led to a 90% improvement of the original orthopedic finding.