

health nurse may need to supervise compliance with the regimen. Rarely, orthopedic intervention (such as casting, application of traction, or aspiration of blood) may be necessary to preserve joint function. Diet is also an important consideration because excessive body weight can increase the strain on affected joints, especially the knees, and predispose the child to hemarthrosis. Consequently, calories need to be supplied in accordance with energy requirements.

### **Support the Family and Prepare for Home Care**

Genetic counseling is essential as soon as possible after diagnosis. Unlike many other disorders in which both parents carry the trait, the feeling of responsibility for this condition usually rests with the mother. Unless she has an opportunity to discuss her feelings, the couple's relationship can suffer. Technology is now available to identify classic hemophilia carriers using DNA testing and may reduce the anxiety regarding childbearing in women who may be at risk of carrying the defective gene. Factor concentrates have greatly changed the outlook for these children by minimizing bleeding and allowing the child to live a normal, unrestricted life. Children are taught to take responsibility for their disease at an early age. They learn their limitations, preventive measures, and self-administration of the prophylactic AHF.

The needs of families who have children with hemophilia are best met through a comprehensive team approach of physicians (pediatrician, hematologist, orthopedist), nurse practitioner, nurse, social worker, and physical and psychological therapist. Parent-group discussions are beneficial in meeting the needs that are often best met by similarly affected families. For example, with the improved prognosis for these children, parents and adolescents with hemophilia face vocational and financial problems in addition to concern over future childbearing. This can be disastrous in terms of the cost of treatment, which can exceed \$100,000 a year. Financial support is particularly important. The National Hemophilia Foundation\* and the Canadian Hemophilia Society<sup>†</sup> provide numerous services and publications for both health providers and families.

Children who have become infected with human immunodeficiency virus (HIV) through transfusions and factor