

Standards for Centers for Persons with Specified Inherited
Neurologic Diseases (Huntington's Disease, Friedreich's
Ataxia, Joseph's Disease)

Introduction

3.31.1

- A. With the passage of SB 1483 (1976) the Director of Health Services was given the responsibility to establish and administer a program for the medical care of persons with certain genetic diseases, i.e., hemophilia, cystic fibrosis and sickle cell disease, through physicians and centers qualified pursuant to the standards and/or regulations of the Department. On January 1, 1977 the Department established the Genetically Handicapped Persons Program (GHPP) to carry out these responsibilities. On September 28, 1979 legislation was approved (SB 929) to also include Huntington's Disease, Friedreich's Ataxia and Joseph's Disease.
- B. California Children Services was designated as the agency to administer this program, utilizing providers and centers which meet CCS standards and regulations with the addition of qualified providers and centers that deal mainly with the adult population.
- C. The law established an eleven member Genetically Handicapped Persons Program Advisory Committee to advise the Director of Health Services concerning this program.

Definition

3.31.2

- A. A center for persons with specified inherited neurologic diseases is a facility which provides comprehensive diagnostic evaluation, treatment (both inpatient and outpatient) and follow-up care, consultation to physicians and others caring for such persons, training of professional personnel, and which has at the center all the laboratory, radiologic and other technical equipment and facilities needed for such diagnostic evaluation and treatment.
- B. Centers wishing to participate in the CCS/GHPP should contact the California Children Services, State Department of Health Services, 714 P Street, Sacramento, CA 95814.
- C. Approval of centers meeting the following criteria, after a site visit by a CCS/GHPP team, is dependent upon geographic location and an established caseload adequate to maintain proficiency.

Organization, Facilities and Staff

3.31.3

A. Organization

1. Centers shall be located in hospitals approved for "Long Term" (Tertiary Hospital) care by the CCS program.

2. A center shall be organized and operated as a functional unit in an outpatient department with space specifically allocated for outpatient care and inpatient evaluation.
3. A center shall operate in conjunction with, and as a part of, a teaching hospital.
4. There shall be a basic health team (core team) consisting of a neurologist, a nurse specialist, a social worker (MSW), a licensed physical therapist, a psychiatrist or psychologist, and a geneticist or genetic counselor, (for persons under age 14 years, there must also be a pediatrician on the team). One member of the team shall be identified as the coordinator and shall be responsible for coordination of all phases of patient evaluation and care. Each member of the team shall have suitable experience with regard to inherited neurologic disorders.

B. Facilities

1. Adequate space shall be available for individual medical examinations, social work, physical therapy, mental health, genetic, nursing and other appropriate professional treatment and counseling, team conferences, parent/family conferences, and teaching conferences.
2. In-house capability shall be such as to provide at the center all tests and studies necessary for the differential diagnosis and treatment of genetically transmitted neurologic diseases.
3. Physical therapy, radiology, pathology, and laboratory departments or units suitably equipped, shall be located within the hospital and shall be staffed by qualified personnel and shall include equipment for CAT scans, EEGs and EMGs.

C. Staff

1. All persons providing services to patients shall satisfy the regulations or standards for panel participation as established by the State Department of Health Services, California Children Services.
2. The medical director shall be a CCS paneled, board certified neurologist, internist or pediatrician, with experience in the diagnosis and treatment of inherited neurologic diseases. If the director is not a CCS paneled pediatrician, when the care of children under 14 years of age is involved, this responsibility must be shared with a CCS paneled pediatrician.
3. A CCS paneled, board certified neurologist with experience in the differential diagnosis and treatment of inherited neurologic diseases shall be an active participating member of the basic team.
4. A nurse specialist with experience in neurologic diseases shall be a member of the basic team and shall carry out the components of professional nursing practice.

5. A CCS paneled social worker (MSW) shall be an active participating member of the basic team and shall provide necessary social work services.
6. A CCS paneled physical therapist shall be an active participating member of the basic team and shall provide necessary therapy services.
7. A geneticist or genetic counselor (MA in genetic counseling) shall be a member of the basic team to provide genetic counseling.
8. A consultant geneticist and consultant physicians in psychiatry and all other specialities knowledgeable in the treatment and management of inherited neurologic diseases shall be available to the basic team; these shall be listed in the center write-up and shall participate in the program.
9. Allied health personnel in the fields of speech, occupational therapy and nutrition shall also be available and utilized for consultation, counseling and/or treatment when indicated, and shall be listed in the center write-up.

Procedures and Services

3.31.4

- A. There shall be a written plan covering referrals to the center, including the intake procedure, initial family contact and appointments, contact with the referring or family physician and follow-up procedures for continuity of comprehensive health care services. Where indicated, there shall also be a written plan for outreach and coordination of care and services in the patient's own local community, including respite care.
- B. The center must have an authorization from CCS/GHPP prior to rendering any service for which a claim will be submitted to CCS/GHPP, including initial diagnostic services.
- C. The comprehensive evaluation shall include:
 1. Medical, nursing, social work and physical therapy evaluations.
 2. Medical diagnosis and treatment and management plan, including home treatment program, when appropriate.
 3. Nursing care and social work treatment plans.Services provided by the consultant and team staff such as genetic, psychiatric and psychological services.
5. Consideration of concurrent needs of the patient-family and referral to appropriate agencies and/or consultants.

D. Team Conferences

Major decisions concerning acceptance, delivery and coordination of services and continuity of care shall be made at team conferences.

2. Types and content of team conferences (it is recognized that types may be combined and content may overlap):
 - a. Intake: Held for acceptance of cases for care; team members assume responsibilities to carry out specific services for cases accepted and set their priorities for action accordingly.
 - b. Comprehensive Planning: Held shortly after the comprehensive evaluation has been completed in order to set coordinated treatment goals and to plan for delivery and coordination of services in providing continuity of care. Planning should focus on meeting patient-family needs and consider adequacy and utilization of community resources for on-going care, wishes and recommendations of the referring physician and should lead to the delivery of comprehensive services for the individual afflicted with the specific inherited neurologic disease.
 - c. Re-evaluation: Held by the core team at periodic intervals on all patients under supervision of the center to review adequacy of service and to determine current needs.
3. Organization, Scheduling and Referral to CCS/GHPP:
 - a. Conferences shall be held on a scheduled basis with a specific time set for individual case discussions.
 - b. Cases should be scheduled in advance of the conference date and the conference list prepared for circulation.
 - c. Appropriate agency personnel and others from the community should be notified in adequate time for individual case preparation and participation in the conference. The referring physician shall be notified and given an opportunity to participate.
 - d. Each member of the conference should contribute and make recommendations as necessary.
 - e. Adequate time should be allowed for case discussion and dictation upon conclusion of the presentation.

A mechanism for date filing and a conference rescheduling system shall be established and maintained.

E. Reports

1. The director shall provide a composite report of the comprehensive planning conference to the authorizing CCS/GHPP agency which shall include summaries and recommendations of all team members and other consultants involved with the case.

2. Periodic reports shall be submitted as indicated for patients under on-going care.
3. Physician consultants, other than core team members, shall submit individual reports with the claims for service.
4. Team members and other allied health workers shall submit initial individual reports. Reports shall also be submitted when special patient-family needs and circumstances arise.

F Continuity of Care

1. There shall be collaborative planning for the delivery, coordination and continuity of health care services.
2. The patient and family should participate in decision making regarding plans for the provision of the individual health care affecting them.
3. Communication, coordination and feedback shall be established and maintained with persons providing services for the patient and family within the community.
4. Team members shall provide consultation to community personnel regarding patient needs.
5. Consideration should be given to a review of the status of patients after transition to other health care has been completed.

Authorization Policies and Procedures

3.31.5

See CCS Manual Section 7.17.1 for authorization policies and procedures

Payment Policies and Procedures

3.31.6

- A. See CCS Manual Section 5.12 for payment policies and procedures.
- B. The center must be willing to abide by the CCS/GHPP policies and procedures related to claims and payment.

Referral to CCS/GHPP

3.31.7

The center must be willing to make information available to all patients and families concerning potential eligibility for CCS/GHPP and provide appropriate assistance to all those who wish to apply for the benefits of the program.