

29 Standards for Centers for Persons with Sickle Cell Disease

3.29.1 Introduction

- A. With the passage of SB 1483 (1976) the Director of Health 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 that are qualified pursuant to the standards and/or regulations of the Department. On January 1, 1977 the Department established the Genetically Handicapped Person's Program (GHPP) to carry out these responsibilities.
- B. The State Crippled Children Services program was designated as the agency which shall administer this program, utilizing such 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. Upon advice of the Genetically Handicapped Person's Program Advisory Committee "sickle cell disease" was defined as covering all hemoglobinopathies producing anemia including Thalassemia.

3.29.2 Definition

- A. A center for persons with sickle cell disease 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, and training of professional personnel.
- B. Centers wishing to participate in the CCS program and/or the GHPP should contact the Crippled Children Services Section, State Department of Health.
- C. Approval of centers meeting the criteria established in these standards, after a site visit by a CCS/GHPP team, is dependent also on criteria relative to geographic location and an established caseload adequate to maintain proficiency.

3.29.3 Organization, Facilities, and Staff

A. Organization

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

A center shall be organized and operated as a functional unit in an outpatient department.

- 3. It is recommended that the centers operate in conjunction with a teaching hospital.
- 4. There shall be a basic health team (core team) consisting of a physician specialist in hematology, a qualified social worker (MSW), and a nurse

3.29.3/A.4 Continued

specialist. 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. (For persons under age 16, there must be a board certified pediatrician on the team.)

B. Facilities

1. Adequate space shall be available for individual medical examinations social work, nursing and other appropriate professional counseling, team conferences, parent conferences, and teaching conferences.
2. In-house laboratory capability shall be such as to provide all tests and studies necessary for the diagnosis and treatment of hemoglobinopathies.
3. A physical therapy department or unit shall be located within the hospital and shall be staffed by qualified personnel.

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, Crippled Children Services Section.
2. The medical director, or coordinator, shall be a CCS panel hematologist. If the director is an internist hematologist this responsibility must be shared with a CCS panel pediatrician for the care of children under 16 years of age.
3. A medical social worker (MSW) shall be an active participating member of the basic team and shall provide necessary social work services.
4. A nurse specialist shall be a member of the basic team and shall carry out the components of professional nursing practice.
5. Consultant panel physicians in all specialities appropriate to the treatment of sickle cell disease shall be available to the core team; these shall be listed in the center write-up, and shall participate in the program.
6. Allied health personnel in the fields of nutrition, physical and occupational therapy shall also be utilized for consultation, counseling, and/or treatment when indicated, and shall be listed in the center write-up.

3.29.4 Procedures and Services

- A. There shall be a written plan covering referral to the center, 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.

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- B. The center must have an authorization from CCS/GHPP prior to rendering any service for which a claim will be submitted to CCS or the GHPP.
- C. The comprehensive evaluation shall include:
 - 1. Medical, nursing and social work assessment.
 - 2. Medical diagnosis and treatment plan, including a home treatment program, when appropriate.
 - 3. Nursing care and social work treatment plan.
 - 4. Services as needed by the consultant staff which shall include genetic counseling, if appropriate.
 - 5. Consideration of concomitant needs of the patient-family and referral to appropriate agencies and/or consultants.
- D. Team Conferences
 - 1. Major decisions concerning acceptance, delivery of services, and continuity of care shall be made at a team conference.
 - 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.
 - b. Comprehensive Planning: Held shortly after the comprehensive evaluation has been completed in order to set coordinated treatment goals, plan for delivery of services and continuity of care. Planning should focus on meeting patient-family needs and should consider adequacy and utilization of community resources for on-going care, wishes of the referring physician and should lead to the delivery of comprehensive services for the individual with sickle cell disease.
 - c. Re-evaluation: Held at intervals on all patients under supervision of the center to review adequacy of services and to determine current needs by the core team.
 - 3. Organization and Scheduling
 - 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 a conference list prepared for circulation.
 - c. Appropriate agency personnel and others from the community should participate in the conference and should be notified in adequate time for individual case preparation.

3.29.4/D.3 Continued

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

E. Reports

1. The coordinator shall provide a composite report of the comprehensive planning conference to the authorizing CCS/GHPP agency which shall include summaries and recommendations of the 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 medical reports with 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 and continuity of health care services.
2. The patient and family should participate in decision making regarding plans for the provision of their own health care.
3. Communication and feedback shall be established and maintained with persons providing services for the patient and family in 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.

3.29.5 Authorization Policies and Procedures (See CCS Manual Section 7.17.1)

3.29.6 Payment Policies and Procedures (See CCS Manual Section 5.12)

- A. The center must be willing to abide by the CCS/GHPP policies and procedures related to claims and payment.

17 Sickle Cell Disease Centers

7.17.1 General Provisions

A. Medical Eligibility

Persons with sickle cell disease (this includes all hemoglobinopathies producing anemia including thalassemia) shall be referred to these centers for comprehensive diagnostic evaluation, treatment (inpatient and outpatient) and follow-up.

B. Referral Procedures

1. As soon as the patient is identified as having sickle cell disease he/she shall be referred to a CCS approved Sickle Cell Disease Center
2. The center shall have a written plan covering intake procedures, such as referral, initial family contact and appointments.
3. The center must have an authorization from CCS prior to rendering any service for which a claim will be submitted to CCS.

C. Follow-up

1. Services as needed by the consultant staff (limited to those who are on the CCS panel).
2. The center shall, in cooperation with the CCS authorizing agency, establish follow-up services in the local community if appropriate. Consultation must be readily available to the local physician and allied health personnel.
3. Ongoing follow-up care may be provided by the center staff if so requested by the referring physician and/or the CCS Program.
4. Services as needed by the consultant staff which shall include genetic counseling, if appropriate.
5. Consideration of the concomitant needs of the patient-family and referral to appropriate agencies and/or consultants.

D. Reports

The team coordinator shall provide a composite report of the comprehensive planning conference and of the disposition conference to the authorizing CCS agency which shall include summaries and recommendations of the 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 medical reports with claims for service.

17.1/D Continue

4. Team members and other allied health workers shall submit individual reports when indicated by special patient-family needs and circumstances.

E. Authorizations for Diagnostic Evaluation, Treatment and Consultation

1. Authorization for diagnostic evaluation shall be issued to the coordinator and will cover:
 - a. Coordinator's services.
 - b. Consultative examination by any of the specialists listed as members or consultants to the individual center staff.
 - c. Necessary laboratory and/or radiology services ordered by the coordinator or other panel specialist consultants.
2. Consultant specialists not listed in the individual center sections as member of the center staff will need to be issued prior individual authorizations. Such authorizations shall be requested in advance by the coordinator.
3. Authorization for diagnostic and/or treatment services shall also be issued to the center and will cover:
 - a. Administrative, clerical and secretarial services.
 - b. Use of necessary clinical space and equipment.
 - c. Services of the nurse specialist, and the social worker.
4. Authorization for treatment shall be issued to the coordinator or to a Crippled Children Services panel physician designated by the coordinator.
5. Any inpatient care must be requested in advance by the coordinator or by the designated treating physician and authorized in the normal manner.

F Authorization to the local physician.

Treatment authorization may be issued to the local physician for ongoing care as recommended by the Center or for interim care if the child remains under continued supervision by the center.

G. Payment

See Manual Section 5.12.

7.17.1/D Continued

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