

3.28 Standards for Centers for Persons with Chronic Pulmonary Disease, including Cystic Fibrosis

3.28.1 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, sickle cell disease, through physicians and centers that are qualified pursuant to the standards and/or regulations of the Department.
- B. The State Crippled Children Services program has been designated as the agency which shall administer this program, utilizing such vendors and centers that currently meet CCS standards and regulations, with an expansion to include those providers and centers that deal mainly with the adult population.

3.28.2 Definition

- A. A center for persons with chronic pulmonary disease shall provide 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 should contact the Crippled Children Services Section, State Department of Health.
- C. Centers meeting the criteria established in these standards will, upon a site visit by a CCS program team, be approved not only on the basis of meeting standards, but also on geographic location, and an established caseload adequate to maintain proficiency.

3.28.3 Organization, Facilities, and Staff

A. Organization

- 1. Centers shall be located in hospitals approved for "Long Term" (Tertiary Hospital) care by the CCS program.
- 2. A center shall operate as a functional unit in an outpatient department.
- 3. It is recommended that the centers operate in conjunction with a teaching hospital.
- 4. A basic health team (core team) consisting of a physician specialist in pulmonary disease, a qualified social worker, a nurse specialist, and a registered physical therapist, shall be responsible for coordination of all phases of patient evaluation, and care. (For persons under age 16, the physician shall be a pediatric pulmonary specialist.)

3.28.3 Continued

B. Facilities

1. Adequate space for individual medical examinations, social work, nursing, and other appropriate professional counseling, shall be available for 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 pulmonary disease.
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 pediatric pulmonary specialist (for centers limited to adults this may be a CCS panel internist pulmonary specialist).
3. A social worker (MSW) shall be an active participating member of the basic team and provide 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. A registered physical therapist shall be an active participating member of the basic team.
6. Consultant panel physicians in all specialties appropriate to the treatment of chronic pulmonary disease, shall be available to the core team, shall be listed in the center write-up, and shall participate in the program.

Allied health personnel in the fields of nutrition and occupational therapy, shall also be available for consultation, counseling, and/or treatment when indicated, and shall be listed in the center write-up.

28.4 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 health care services.

3.28.4 Continued

- B. The center must have an authorization from CCS prior to rendering any service for which a claim will be submitted to CCS.
- C. The comprehensive evaluation shall include:
 - 1. Medical, nursing, and social work assessments.
 - 2. Medical diagnosis and treatment plan, including a home treatment program, when appropriate.
 - 3. Nursing care, physical therapy, and social work treatment plans.
 - 4. Services, as needed by the consultant staff, which shall include genetic counseling.
 - 5. Consideration of concomitant needs of the patient-family and referral to appropriate agencies and/or consultants.
- D. Team Conferences
 - 1. 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 patient-family needs and should consider availability and adequacy 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 chronic pulmonary disease.
 - c. Re-evaluation: Held at intervals, not less than yearly, on all patients under supervision of the center, to review adequacy of services and to determine current needs.
 - 3. Organization and Scheduling
 - a. Conferences shall be held on a scheduled basis with a specific time set for individual case discussions. It is recognized that the type and content of these conferences may be combined and overlap.

3.28.4/D.3 Continued

- 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 preparation.
- 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.

E. Reports

1. The physician coordinator shall provide a composite report of the comprehensive planning 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.
4. Team members and other allied health workers shall submit individual reports when indicated by special patient-family needs and circumstances.

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 shall be established and maintained with persons providing services for the patient and family in the community.
4. Team members shall be available to 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.

3.28.5 Authorization and Payment for Services (See Section 7.12.1 for Authorizations and Section 5.12 for Fees)