



State of California—Health and Human Services Agency
Department of Health Care Services



EDMOND G. BROWN JR
Governor

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Addendum to: N.L. 01-0108

TO: All County California Children's Services (CCS) and Genetically Handicapped Persons Program (GHPP) Administrators, Medical Consultants, and Integrated Systems of Care Division (ISCD)

SUBJECT: CCS Standard 3.38: Neuromuscular Medicine Special Care Center (SCC)

I. PURPOSE

The purpose of this Numbered Letter is to inform county CCS programs and CCS Providers about a new section in the CCS Manual of Procedures Chapter 3.38 "CCS Neuromuscular Medicine SCC Standards" (Please see Enclosure).

This N.L. is to be used in conjunction with [Chapter 3.37 SCC Core Standards](#): "CCS SCCs General Information and Core Standards" for outpatient SCCs which is now available on the [CCS Provider Standards](#) webpage.

II. BACKGROUND

The ISCD CCS Program has oversight of SCCs located in California that provide comprehensive, coordinated, specialty health care to CCS clients with complex, physically handicapping medical conditions, and to GHPP clients with specific genetically eligible medical conditions. CCS-approved SCCs are located throughout the State and affiliated with CCS-approved hospitals.

The state CCS Program is in the process of reviewing and revising CCS Program specialty and subspecialty standards. As part of the revision process, the state CCS Program has identified a list of core requirements for all SCCs. [Chapter 3.37.1 SCC General Information and Core Standards](#) lists the common expectations and core requirements for all CCS outpatient SCCs.

In addition to the SCC General Information and Core Standards' requirements, CCS SCCs are also be required to comply with the specific [CCS Program SCC specialty and subspecialty standards](#) and any relevant [CCS Numbered Letters](#) that outline other SCC specialty and subspecialty requirements. At the time of this letter, CCS

Program specialty or subspecialty standards are currently undergoing revision. In the interim, CCS Providers should refer to current listed specialty and subspecialty standards and, if necessary, consult with the state CCS Program.

III. POLICY

- A. Effective the date of this letter, all CCS outpatient Neuromuscular SCCs are required to comply with the CCS Chapter 3.37 "[CCS Core Special Care Center \(SCC\) Core Standards](#)", AND
- B. The enclosed Neuromuscular Medicine SCC Standard.

As mentioned, at the time of this letter, CCS Program specialty or subspecialty standards are currently undergoing revision and will be made available to CCS Administrators and Providers when ready. CCS SCCs shall continue to refer to any listed [specialty or subspecialty standards](#) and any relevant [CCS Letters](#) on the CCS website.

If you have any questions regarding this N.L., please e-mail them to the CCS Facility Mailbox at CCSFacilityReview@dhcs.ca.gov.

Sincerely,

ORIGINAL SIGNED BY

Sarah Eberhardt-Rios, Division Chief
Integrated Systems of Care Division

Attachment: CCS Neuromuscular Medicine SCC Standard

3.38.1 Type of Special Care Center (SCC) General Information

In addition to the specialty and subspecialty requirements outlined in this standard, all California Children's Services outpatient SCCs are required to comply with CCS Chapter 3.37 "[CCS Provider Core Standards](#)."

- A. Definition: The Neuromuscular Medicine SCC (Center) provides comprehensive, multidisciplinary, multi-specialty care to CCS clients with neuromuscular conditions.
- B. Additional Core Team Members Roles and Responsibilities:
 - 1. Please refer to 3.37.1 "CCS Special Care Centers (SCC) General Information and Core Standards" (Core Standards) as all core standards must be satisfied in addition to the Neuromuscular SCC-specific requirements in this document.
 - 2. The Center must promote community awareness and early identification of children with neuromuscular conditions through programs designed to inform delivery room personnel, neonatal care personnel, and primary care providers in the community about these conditions.
 - 3. Neuromuscular medicine SCC team staffing.
 - a. Neuromuscular Medicine SCC Director shall have the following:
 - 1) Be a CCS paneled neuromuscular medicine specialist who is board certified in neurology or in physical medicine and rehabilitation with fellowship training in neuromuscular medicine or equivalent.
 - 2) Have responsibilities described in the CCS provider Core Standards and these supplemental standards to ensure that client and family and center needs are met through a multidisciplinary care approach.
 - 3) Assure that the center adheres to the consensus -based standards of care for neuromuscular medicine including but not limited to muscular dystrophy and spinal muscular atrophy (SMA).
 - 4) Assure that center staff have experience and training working with pediatric patients.
 - 5) Maintain communication with national neuromuscular medicine professional organizations, including but not limited to the Muscular Dystrophy Association and Cure SMA.
 - b. SCC Core Team staff including coordinator, nurse specialist, medical social worker, registered dietician, all described in the Core Standards.

c. Physical therapist shall:

- 1) Meet the requirements for CCS paneling.
- 2) Assess and work with client and family to increase overall mobility in the areas of muscle strength, range of motion, and joint contractures.
- 3) Conduct neuromotor function testing at baseline and periodic assessment as required for certain medications.
- 4) May recommend exercises or assistive devices to maintain optimal posture.

d. Occupational Therapist shall:

- 1) Meet the requirements listed in the CCS Program Participation Requirements.
- 2) Assess functional movement patterns and needs related to assistive devices.
- 3) Work with client and family to increase independence in specific tasks like dressing bathing or handling utensils.
- 4) May recommend adaptive equipment or home modifications when appropriate.

e. A Feeding Specialist shall:

- 1) Be certified by the American Board of Swallowing and Swallowing Disorders or be certified in Feeding, Eating and Swallowing by the American Occupational Therapy Association.
- 2) Conduct feeding assessments on clients with new or changing feeding problems.
- 3) May be the occupational therapist or speech pathologist affiliated with the neuromuscular medicine SCC team.

f. Speech/Language Pathologist (optional) who, as appropriate shall:

- 1) Assess and develop treatment recommendations for speech, hearing, and language aspects of care.
- 2) Teach adaptive language skills to patient and family, and coordinate with other agencies and service providers.

- g. Respiratory Care Practitioner (or access to Respiratory Care Practitioner and Pulmonary Medicine SCC) shall:

- 1) Meet the requirements for CCS paneling,

AND

- 2) Perform the following as appropriate:
- 3) Assessment of cough effectiveness.
- 4) Periodic spirometry and/or capnography.
- 5) Periodic evaluation for sleep-disordered breathing.
- 6) Instruction to families on strategies to improve airway clearance.

- h. Genetic Specialist shall:

- 1) Be board-certified geneticist or genetic counselor.
- 2) Order appropriate genetic testing to identify the genetic cause of the disease.
- 3) Discuss genetic testing results with client and family.
- 4) Provide guidance to client and family on genetic risks.
- 5) **Note**, this function may be done by the neuromuscular medicine specialist in some cases.

- i. Orthotist who meets the requirements for CCS paneling (or access to Orthopedics or Rehabilitation SCC).

C. Specialty and Subspecialty Consultants

Pediatric and general Specialty and Subspecialty Consultants will include, when clinically appropriate:

1. Pulmonary Medicine
2. Orthopedic Surgery
3. Gastroenterology
4. Physical Medicine and Rehabilitation

5. Cardiology

6. Genetics

D. Patient Care

Described in the CCS SCC provider Core Standards.

E. Additional Policies and Procedures

1. The center shall have staff and adequate space to address each client's needs, including but not limited to:
 - a. Airway clearance, cough, secretion management, and ventilator support.
 - b. Nutrition.
 - c. Assessment and intervention by physical therapy, occupational therapy and speech therapy.
 - d. Supportive (palliative) care.
2. If there is insufficient space or staffing for the above, the center shall have policy addressing provision of the services in a manner and timeframe that addresses and meets the client and family's needs.

F. Quality Assurance and Quality Improvement

1. Center shall submit quality reports or data dashboards at the time of an on - site or desk review.