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Guidance for the Clinician in Rendering Pediatric Care

CLINICAL REPORT

Providing a Primary Care Medical Home for Children and Youth With Cerebral Palsy

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KEY WORDS
cerebral palsy, medical home, care coordination, patient care/methods

ABBREVIATIONS
PCP—primary care provider
CP—cerebral palsy
GMFCS—Gross Motor Function Classification System

The guidance in this report does not indicate an exclusive course of treatment or serve as a standard of medical care. Variations, taking into account individual circumstances, may be appropriate.

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abstract

FREE

All primary care providers will care for children with cerebral palsy in their practice. In addition to well-child and acute illness care, the role of the medical home in the management of these children includes diagnosis, planning for interventions, authorizing treatments, and follow-up. Optimizing health and well-being for children with cerebral palsy and their families entails family-centered care provided in the medical home; comanagement is the most common model. This report reviews the aspects of care specific to cerebral palsy that a medical home should provide beyond the routine health care needed by all children. *Pediatrics* 2011;128:e1321–e1329

INTRODUCTION

Primary care providers (PCPs) will encounter children with cerebral palsy (CP) in their practice. With a prevalence of 3.6 per 1000, more than 100 000 children in the United States are affected.[1] CP, as recently redefined (see sidebar), is not a single condition with a clear etiology. It includes a continuum of disorders of movement, posture, and coordination caused by a wide variety of nonprogressive conditions that affect the developing brain. It affects body functions and structures, activities, participation, and quality of life.[2] CP ranges in severity from isolated, mild spasticity in the legs to 4-limb involvement (quadriplegia) associated with cognitive impairments, seizures, and complete functional dependency.

SCREENING, SURVEILLANCE, AND DIAGNOSIS

The PCP engages in an integrated process designed to promote early identification of children with CP and expedite referrals to appropriate community services. The first step is to establish a diagnosis of CP. The second step is to identify and access interventions that are most likely to optimize the health and well-being of the child and family. CP is suspected in children who have delayed or abnormal motor development, especially in those with a history of prenatal, perinatal, or postnatal brain insults. A definite cause cannot be identified for many children who have CP. Table 1 lists some perinatal factors that are associated with CP. The American Academy of Pediatrics has developed guidelines on developmental surveillance and screening in practice[4]; these procedures can help with the early identification of children who are at increased risk of having CP.

Delayed motor development, abnormalities of muscle tone, and atypical postures suggest a diagnosis of CP.[5] A careful neurologic examina-

REVISED DEFINITION OF CP[46]: CP describes a group of permanent disorders of the development of movement and posture that cause activity limitations that are attributed to nonprogressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of CP are often accompanied by disturbances of sensation, perception, cognition, communication, and behavior and by epilepsy and secondary musculoskeletal problems.

LOCALIZATION:

Diplegia: lower extremities are affected more than upper extremities.

Quadriplegia (tetraplegia): upper and lower extremities are affected to the same degree.

Hemiplegia: 1 side (often upper extremity) is more substantially involved than its opposite counterpart.

Children with CP typically receive care from multiple providers including orthopedists and neurologists, as well as physical, occupational, and speech-language therapists. They may receive services through Early Intervention and school-based programs. For some children with mild CP, the pediatrician is the primary manager; however, most children with CP receive collaborative and shared care (comanagement) among multiple specialists, coordinated through the medical home. For children with severe disabilities, specialists may serve as the primary manager.[3]

Parents, teachers, and therapists often approach pediatricians for medical and habilitative recommendations. Physicians who are knowledgeable about medical and functional issues, including community resources, can empower families by listening and responding to their concerns. Children with CP and their families benefit from family-centered, evidence-based, coordinated, and collaborative care that is based on shared decision-making in the context of the medical home.

tion might reveal alterations or asymmetries in muscle tone, strength, reflexes, posture, and coordination. For example, the occurrence of hand preference before 12 months of age is often suggestive of hemiplegia. An 8-month-old child who demonstrates palmar thumbs (adducted thumbs with clenched fists), scissoring of the legs, and hyperreflexia might have spastic CP. Many infants with CP have persistent infantile reflexes including the Moro reflex and asymmetrical tonic neck responses. Although neurologic findings in CP might change during infancy (eg, a floppy neonate who develops spasticity by 6 months of age), the brain lesion in CP is nonprogressive. Some infants who are born prematurely, especially those who weigh less than 2000 g, might have transient changes in muscle tone but not develop CP. Their findings include increased adductor tone in the lower extremities, truncal arching, and head lag. The symptoms usually resolve between 8 and 12 months of age.[6] Developmental surveillance (eg, serial examinations separated by 1 or 2 months) might be helpful to determine if the child is developing typically or has significant delays or other neurologic findings that suggest CP. Repeated evaluations also help foster the doctor/family relationship. The PCP can diagnose a child with CP in many instances. If questions remain, the child can be referred to a child neurologist or developmental pediatrician.

TABLE 1 Perinatal factors associated with the occurrence of CP

Chorioamnionitis (maternal infection)
Maternal disorders of clotting (eg, factor V Leiden deficiency)
Birth weight < 2000 g
Intracranial hemorrhage
Newborn encephalopathy (recurrent seizures, hypotonia, coma)
Periventricular leukomalacia
Hydrocephalus
Congenital malformations

Neurodegenerative disorders such as leukodystrophies, lysosomal storage diseases, ataxia telangiectasia, and mitochondrial disorders are uncommon conditions that might initially mimic CP; however, unlike CP, the manifestations of these conditions worsen over time. Glutaric aciduria and dopa-responsive dystonia (Segawa syndrome) are 2 rare progressive but treatable conditions that might be confused with CP. It is important to differentiate spastic diplegic CP from familial spastic paraplegia, which is a heritable condition in which lower-extremity spasticity and weakness worsen over time. Occasionally, a child who has transient toe-walking might be suspected of having spastic diplegia. Children who have progressive deterioration of cognitive or motor skills (ie, losing milestones) and those who have significant diurnal variation in symptoms should be referred to a child neurologist or neurodevelopmental specialist for further evaluation.[7]

Pediatric providers who identify abnormalities of development, tone, or posture in infants and toddlers should share their concerns with the child's family to facilitate patient/family self-management and access to resources. This requires spending sufficient time with family members to provide detailed feedback and to answer all questions. Referral to an Early Intervention or preschool program should be initiated even if a definitive diagnosis has not yet been established. These programs can perform formal developmental evaluations with standardized measures (such as the Bayley Scales of Infant Development and the Peabody

TABLE 2 Diagnostic Assessment and Classification of Children With CP

Category	Examples
I. Motor abnormalities	
A. Type of motor disorder	Spasticity; dyskinesia (dystonia and choreoathetosis); ataxia; hypotonia
B. Functional motor abilities	
a. Gross motor	Ambulation
b. Use of hands and arms	Self-help skills
c. Oromotor and speech	Communication; eating and drinking
C. Musculoskeletal changes	Contractures; hip dysplasia; torsional deformities, including scoliosis; joint instability; osteoporosis; pain
II. Associated impairments	
A. Central nervous system	Cognitive deficits; seizures; hearing impairments; vision impairments; attentional problems; behavioral problems; sleep disturbances
B. Gastrointestinal	Constipation; gastroesophageal reflux disease; malnutrition; drooling; incontinence; dysphagia; complications associated with enteral feedings
C. Respiratory	Aspiration, acute and chronic; pneumonitis and pneumonia; restrictive lung disease, secretion management
D. Genitourinary	Incontinence; voiding dysfunction; recurrent urinary tract infections
E. Dental	Poor hygiene; caries; periodontal disease
III. Distribution	
A. Anatomic	Limbs (hemiplegia, diplegia, quadriplegia); trunk; bulbar region
B. Radiologic	Periventricular leukomalacia; damage to basal ganglia or thalamus
IV. Causation and timing	Hyperbilirubinemia; in utero stroke (cortical cerebral infarction)
V. Severity	Degree of involvement (eg, weakness); number of associated impairments; GMFCS

Developmental Motor Scales), provide therapeutic and educational services, and assist families in connecting to parent support groups. Some communities have local volunteer organizations that can help families with peer support and linkage to helpful resources. Family Voices, a national organization, has established family-to-family health information centers in most states.[8]

The American Academy of Neurology has established practice parameters for the diagnostic evaluation of a child with suspected CP.[8] A brain MRI scan should be obtained in all children suspected of having CP if the etiology has not been established (eg, by perinatal imaging).[7] Those with hemiplegia and quadriplegia are most likely to have radiographic abnormalities.[9] When appropriate, formal gait analyses may be performed to inform decisions regarding therapeutic, medical, and surgical interventions to maximize mobility. Similarly, radiographic swallow studies may be used to evaluate dysphagia and determine strategies for optimizing nutrition and minimizing aspiration events. All children suspected of having CP should be promptly referred for formal hearing and vision evaluations. Formal developmental testing and electroencephalography might be helpful in the care of some children.

ASSESSMENT FOR INTERVENTION PLANNING

After a diagnosis of CP is suspected (or established), the PCP should evaluate the child's overall function to determine which interventions would be most beneficial. Family goals, structure, and resources should be considered when developing treatment plans that might include clinical consultations, community-based programs, and educational services. Traditionally, children with CP are classified on the basis of distribution of affected limbs and the predominant type of tone or movement abnormality (eg, "spastic diplegia"). However, a complete assessment, necessary for appropriate prognostication and treatment planning, must also include assessment of associated impairments and overall severity of CP (see Table 2). The PCP can make these determinations through the history and physical examination. In addition, the PCP can categorize children according to the Gross Motor Function Classification System (GMFCS), which provides a measure of the overall severity of the disability.[10]

An ongoing summary form or checklist of the primary and associated conditions should be maintained in each child's medical record to expedite accurate, serial assessments. Nickel and Desch[11] have published extensive guidelines for the care of children and adolescents with CP. In addition to the list of conditions based on a review of systems,[12] information on activities and participation should be included. Table 3 lists some suggested information that could be included on this form. It is important to note that tone or movement abnormalities are often mixed rather than pure. For instance, spasticity and dystonia frequently co-occur. In such instances, a child tends to have a greater severity of functional impairment and disability and is less likely to benefit from common interventions such as selective dorsal rhizotomy or systemic medication. Most children with spasticity also have impairments of strength and coordination. Thus, reducing spasticity might

TABLE 3 Form for Tracking Medical Conditions, Activities, and Participation in Children With CP

Area	Status	Providers
Cerebral Palsy		
Type		
GMFCS		
Review of systems		
General		
Growth		
Nutrition		
Pain		
Sleep		
Mouth		
Drooling		
Swallowing		
Teeth		
Respiratory		
Aspiration		
Infections		
Restrictive lung disease		
Gastrointestinal		
Constipation		
Reflux		
Urinary		
Toilet training		
Voiding dysfunction		
Urinary infections		
Gynecologic		
Puberty		
Musculoskeletal		
Joint contractures		
Dislocations		
Scoliosis		
Osteoporosis		
Orthotic devices		
Neurologic		
Seizures		
Muscle tone		
Strength/weakness		
Attention (attention-deficit/hyperactivity disorder)		
Sleep		
Skin		
Pressure sores		
Activities and participation		
Communication		
Abilities		
Assistive devices		
Therapy (eg, speech therapy)		
Mobility		
Abilities		
Assistive devices		
Therapy (eg, physical therapy)		
Cognitive and academic functioning		
Scores from cognitive testing		
Educational placement		

"unmask" underlying weakness or dystonia and further limit function. Likewise, a pattern of spasticity in the limbs and hypotonia in the trunk and midline (including poor head control) is common in children with quadriplegic CP. Many communities have medical teams for children with CP that include orthopedics, physical therapy, occupational therapy, orthotics, neurosurgery, social work, and developmental pediatrics or physiatry. Referral to those programs might greatly benefit children and adolescents with more complex or severe involvement. Other children might benefit from consultations with specialists in pulmonology, gastroenterology, or endocrinology.

PROGNOSIS

Parents often ask about the severity of their child's CP and prognosis for independent ambulation.[13] Children with good head control at 9 months of age who bear weight through their hands while prone at 18 months, sit by 24 months, and crawl by 30 months have a good prognosis for independent ambulation.[14,15] The GMFCS[10] provides a measure of overall severity of CP. Children who are the most severely affected (GMFCS level V) have the highest rates of mortality and morbidity, including respiratory tract infections. For example, children who cannot lift their head in prone, cannot roll over, or require feeding by gastrostomy tube by 5 years of age have significantly higher mortality rates than other children with CP.[16] Children with intractable seizures or with recurrent aspiration pneumonitis also have worse prognoses. Although the brain lesion associated with CP is nonprogressive, individual function might decline across the life span. Thus, an ambulatory child with CP might opt for wheelchair mobility during adolescence to conserve time and energy; if this decision enhances participation in activities (eg, being able to go to the mall with friends), it should not be viewed as a failure. Ambulation status, IQ, quality of speech, and hand function predicted employment status in 1 group of youth with CP.[17]

ONGOING CARE IN THE MEDICAL HOME

Optimizing Practices

High-quality health care for children with CP depends on collaborations

TABLE 4 Recommended Components of Medical Homes for Children With CP[11,12]

Medical Home Component	Examples
Information systems that provide better quality of care and increased office efficiency	Use specific care plans for children with CP (medical summary, emergency plan, and action plan) Use American Academy of Pediatrics/American College of Emergency Physicians emergency information form for children with special needs[43] Have a registry of patients with CP to help track their progress and initiate contact
Redesigned offices that optimize patient flow and use of space	Have buildings, examination rooms, and equipment (scales, examination tables) that are accessible to children with disabilities[23]
Quality and safety that incorporate patient feedback, outcomes analysis, and evidence-based best practices	Use regular mechanisms (eg, surveys to get feedback from patients and families) Consult with parent advisors through a family advisory committee or other mechanism Keep informed about best practices in CP and resources (including family-to-family information centers) available in the community
Practice management that includes disciplined financial management and advocacy	Try to negotiate care coordination fee from local payers Use billing to reflect time and complexity of condition (eg, using a −25 modifier) Advocate with families to payers for coverage of medically necessary services
Services that include disease prevention, wellness promotion, and chronic disease management processes	Promote optimal nutrition and regular exercise Have specific chronic condition management visits (complex visits that are separate from well-child care) Employ a care coordinator
A process that encourages a collaborative approach to the patient's care, optimized use of the clinical team, prearranged relationships with other specialists, and strong communication within the practice	Have explicit comanagement with specialists
Access to care that offers group visits, e-visits, and same-day visits or a multilingual approach to care, when needed	Provide multilingual care Provide accessible information to patients with visual impairments

among parents; health care providers, including dentists[18]; and community agencies (eg, educational services, recreation programs, parent groups) with ongoing monitoring of the child's health and function. Table 4 offers recommendations for improving practices and their implications for children with CP.[19–21] PCPs are often asked to order or sanction therapies (physical, occupational, or speech) or assistive devices (wheelchairs, bath seats, communication devices, others). The American Academy of Pediatrics provides guidelines for the prescription of therapies[22] and communication devices.[23] The PCP has the right to decline ordering equipment that is of questionable value; referral to a specialist for further review of the request might be helpful. Clinical settings should be physically accessible; the Center for Universal Design offers guidelines for improving accessibility.[24] PCPs should be knowledgeable about community resources for individuals with CP and their families and facilitate linkages to appropriate services. Appendix 1 lists a few Internet sites relating to CP. Office visits for children with CP should be extended to allow for more in-depth evaluations and discussions. Billing should reflect time spent in direct and indirect care (eg, care coordination). Appendix 2 provides some billing codes used when treating children with CP.

Specific Interventions and Treatments

PCPs are often asked to provide specific recommendations to families about specialty care. This requires knowledge of evidence-based care. Many treatments have become common practice, despite a lack of evidence regarding the dose and duration of intervention or expected outcomes. Such interventions include speech and language therapy to improve verbal communication,[24] physical therapy for passive stretching of spastic muscles,[26,27] and sensorimotor integration therapy to promote function.[28]

Strengthening and Tone Management

Although Early Intervention services have generally improved outcomes for children, the specific interventions that most benefit children with CP are uncertain. In addition, therapeutic interventions change over time. For example, increasing emphasis is being placed on muscle strengthening and achieving functional goals. These changes make comparisons among programs difficult. Table 5 lists common interventions categorized according to their current evidence base.

The American Academy of Neurology has published guidelines on the pharmacologic treatment of spasticity in children and adolescents with CP.[29] Treatments recommended include injections of botulinum toxin into spastic muscles, as well as intrathecal baclofen. These interventions are usually not performed directly by PCPs. Systemic medications, including diazepam, baclofen,

TABLE 5 Therapies for Children With CP

Indication	Intervention	Comment
Therapies for which some evidence exists to support their effectiveness		
General	Muscle strengthening	Growing evidence supports its use
	Equine-assisted therapy (hippotherapy)	Increases social participation as well as strength and coordination
Ambulation	AFOs	Choice of specific type of AFO is often a judgment call
	Gait trainers, assistive devices; wheeled mobility	
Drooling	Glycopyrrolate, scopolamine patch, botulinum toxin injections, removal of salivary glands	Short-term improvement has been documented; less is known about long-term effects
Hemiplegia	Constraint-induced movement therapy	Optimal duration and intensity of therapy are uncertain, but several study reports have documented its effectiveness
Joint contractures, dislocations, deformations	Orthoses (like AFOs)	Surgery is more effective if linked with functional abilities (eg, gait)
	Orthopedic surgery	
Malnutrition	Gastrostomy feeding tube	Decision to use is often difficult for families; long-term benefits have not been well studied
Spasticity	Botulinum toxin (type A) injections	Most studies have been of gastrocnemius or biceps muscles
	Dorsal rhizotomy	Generally used for children who are ambulatory; long-term benefits are uncertain
Spasticity/dystonia	Intrathecal baclofen	One of the few interventions that is effective for both dystonia and spasticity
Therapies for which some evidence exists to refute their effectiveness		
General	Hyperbaric oxygen	Because CP is so heterogeneous, it is unlikely that all children would improve with a single therapy; benefits have not been proven
	Patterning	Interventions such as the Doman-Delacato method have been discredited[44]
Promising therapies for which data are insufficient		
General	Stem cell injection	
	Acupuncture	
Dyskinesia	Deep brain stimulation	
Mobility	Treadmill training	
	Neuromuscular electrical stimulation	
	Training in virtual environments	

AFO indicates ankle-foot orthosis.

tizanidine, and dantrolene have been used to diminish spasticity in children with CP, although they might cause weakness or excessive sedation. Moreover, few studies have documented functional gains in children who have been treated with systemic medications. Similarly, trihexyphenidyl (Artane) has been used in children with dystonia, but there is no convincing evidence of its effectiveness.[30] Interventions to reduce spasticity and promote function in children with CP are usually recommended in a sequence from least to most invasive (eg, ankle foot orthoses before intrathecal baclofen).

Nutrition and Growth

A key goal of the medical home for children with CP is to optimize nutritional status and physiologic growth. Children with severe CP often struggle with oral and/or pharyngeal dysphagia, which leads to inadequate intake of calories and nutrients. In addition, gastroesophageal reflux disease (GERD) and gastrointestinal dysmotility are common in children with CP. Aspiration events might occur primarily during feeding or secondarily from gastric refluxate. Appropriate positioning during feeding (head in midline, physiologic chin tuck) might reduce the risk of aspiration, and dietary modifications (thickened feedings, specialized formula, dietary supplements) might promote growth. Management of chronic constipation with regularly implemented bowel programs might reduce symptoms of feeding intolerance, GERD, and generalized discomfort that tend to exacerbate spasticity and disorders of sleep. However, these interventions alone might not be enough. Growth charts for children who have CP are available[31]; however, they only describe how certain samples of children with CP have grown and are not standards for how all children with CP should

grow. When feedings are prolonged, growth is inadequate, or aspiration risk is high, gastrostomy or jejunostomy tubes might be indicated.[32,33] It is important not to overfeed the child enterally. Children with significant GERD might benefit from an antireflux procedure, such as fundoplication at the time of the gastrostomy, although selection criteria are lacking.[34]

Other Comorbid Conditions

In general, the severity of a child's motor impairments and functional limitations correlate with the prevalence of comorbid conditions. Seizures are common among children with CP and are typically managed in consultation with pediatric neurologists. Because children with CP frequently have visual impairments, at least 1 ophthalmology evaluation is recommended. Visual field cuts might be subtle and, when present, can hinder stair negotiation, self-care activities, and academic performance. Cortical visual impairments and refractive errors might further compromise function. Similarly, all children with CP should undergo audiologic testing.

Children with more severe CP often develop osteoporosis over time, especially if they take anticonvulsant medications. Adequate intake of vitamin D and calcium might not completely stave off osteoporosis but can minimize early bone loss. Although it has been suggested that passive weight-bearing in standing frames might increase bone density in children with CP, there is a lack of evidence to support or refute such interventions.[35]

Children with CP, even the milder forms, are more likely than children without CP to have comorbid conditions such as learning disabilities, attention-deficit/hyperactivity disorder, and pervasive developmental disorders.[36] These conditions are managed in the same way that they are in children without CP. Some children with CP have intellectual and developmental disabilities (mental retardation) and might need advocacy from their medical homes for appropriate educational interventions. Impairments of communication might be addressed with augmentative communication devices such as an electronic voice-output communication aid.[23]

FAMILY SUPPORT

Because the child with CP is part of a larger family system, assessment of the family's functioning can help guide interventions and planning. This assessment should include evaluations of family stress, social capital, resources, priorities, and adjustment of parents and siblings to having a child with a disability in the family. By listening carefully to parental concerns, pediatricians can better address family concerns and children's needs. The current US health care system depends on parents to be willing and able to provide long-term care for their children with CP while also balancing competing family needs. However, parents of children with CP generally are in worse physical and emotional health than are parents of typically developing children.[37] For example, in 1 study, more than 70% of mothers of children with physical disabilities reported low back pain.[38] When the health of parents or caregivers is compromised, outcomes for their children with CP might suffer. Pediatricians should provide family-centered care for children with CP and their families, because such care reduces stress and enhances parental well-being.[39] Children with CP and their families might also benefit from referrals to community resources including parent support and advocacy groups, respite programs, and community programs for recreational and adaptive sports. Input from community experts regarding home modifications to reduce architectural barriers (ramps, lifts, roll-in showers) is often indicated but financially challenging. Families might need support in anticipating treatment decisions when their child's CP and secondary conditions are expected to be life-limiting. Such decisions might include writing orders to allow natural death or to provide supportive interventions such as tracheostomy tubes. The principles of palliative care can be helpful in those instances.

TRANSITION AND TRANSFER OF CARE

Adolescents with CP transition from pediatric to adult health care systems, from school to work, and from home to the community. Transitions are affected by physical or cognitive impairments as well as by community and attitudinal barriers such as limited recreational and employment opportunities and lack of peer acceptance.[40] Health-related transition culminates with the transfer of care to adult health care providers. For the person with CP, this transition is influenced by the severity of the disability, family and social supports, community resources, and the availability of interested and capable adult health care providers. To be effective, transition planning should begin when the adolescent is no older than 12 years.[41,42] Likewise, discussions regarding sexuality, including sexual vulnerability, should begin well before the person is an adolescent.[43] Issues of guardianship and informed consent should be addressed when youth with lifelong functional dependencies approach 18 years of age.[44]

APPENDIX 1: RESOURCES

American Academy for Cerebral Palsy and Developmental Medicine (AACPDM): www.aacpdm.org.

American Academy of Pediatrics, National Center for Medical Home Implementation: www.medicalhomeinfo.org.

CanChild Centre for Childhood Disability Research, McMaster University: www.canchild.ca.

Center for Medical Home Improvement: www.medicalhomeimprovement.org.

National Institute of Neurological Disorders and Stroke CP information page: www.ninds.nih.gov/disorders/cerebral_palsy/cerebral_palsy.htm.

Hemi-Kids (online support for children with hemiplegia or hemiplegic cerebral palsy): www.hemikids.org.

Pathways Awareness: www.pathwaysawareness.org.

The ARC: www.thearc.org.

United Cerebral Palsy (UCP): www.ucp.org.

APPENDIX 2: *INTERNATIONAL CLASSIFICATION OF DISEASES, NINTH REVISION, CLINICAL MODIFICATION* (ICD-9-CM) CODES FOR CP

343.0 Diplegia.

343.1 Congenital hemiplegia.

343.2 Quadriplegia.

343.3 Monoplegia.

343.4 Infantile hemiplegia (postnatal) NOS (not otherwise specified).

333.71 Athetoid (dystonic) CP.

334.1 Hereditary spastic paraplegia.

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