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## SIGnature Libraries: A roadmap for the formation of special interest group libraries

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### Conflict of Interest

Drs. Kim, Chin, Fahey, Gelineau-Morel, Himmelmann, O'Malley, Oskoui, Shapiro, Shevell, Wilson, and Wiznitzer have no conflicts to report. Dr. Aravamuthan serves on the editorial board of *Pediatric Neurology* and *Neurology*; receives funding from the National Institute of Neurological Disorders and Stroke, Pediatric Epilepsy Research Foundation, and St. Louis Children's Hospital Foundation; serves as consultant for Neurocrine Biosciences; receives royalties from UpToDate; and has an immediate family member on the Speaker's Bureau for SK Life Science.

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## Abstract

**Objective:** "SIGNature Libraries" channel the dynamism of academic society-based special interest groups (SIG) to systematically identify and provide user-oriented access to essential literature for a subspecialty field in a manner that keeps pace with the field's continuing evolution. The libraries include literature beyond clinical trial data to encompass historical context, diagnostic conceptualization, and community organization materials to foster a holistic understanding of how neurologic conditions affect individuals, their community, and their lived experience.

**Methods:** Utilizing a modified-Delphi approach, Child Neurology Society's Cerebral Palsy (CP) SIG ( $n = 75$ ) administered two rounds of literature submissions and ratings. A final review by an 11-member international advisory group determined threshold ratings for resource inclusion and the library's final structure.

**Results:** Seventy-nine articles were submitted for the first Delphi round and 22 articles for the second Delphi round. Survey response rates among SIG members were 29/75 for the first round and 24/75 for the second round. The advisory board added additional articles in the final review process in view of the overall project goal. A total of 60 articles were included in the final library, and articles were divided into seven sections and stratified by rating scores. A process for ongoing revisions of the library was determined. The library will be published on the Child Neurology Society website and made publicly accessible.

**Conclusions:** The CP SIGNature Library offers learners an unprecedented resource that provides equitable access to latest consensus guidelines, existing seminal datasets, up-to-date review articles, and other patient care tools. A distinctive feature of the library is its intentional large scope and depth, presented in a stratified fashion relative to the consensus-determined importance of each article. Learners can efficiently navigate the library based on individual interests and goals, and the library can be used as core curriculum for CP education.

## Keywords

cerebral palsy; developmental; disability; education; library; systematic review

## Introduction

Evidence-based medicine integrates individual clinical expertise with best available external clinical evidence and effectively engages knowledge that is contextual, in flux, and always evolving.<sup>1,2</sup> The vast and growing volume of sources for information makes this task increasingly challenging, and filtered sources such as systematic reviews, practice parameters, and the Cochrane Library are becoming increasingly indispensable.<sup>3</sup>

While existing practice parameters and review articles provide a summary and application of the evidence base, their scope is generally limited to a specific aspect of a condition, whereas there remains an unmet need to summarize a broader scope of subspecialty knowledge for child neurologists (CN) and neurodevelopmentalists (NDD).<sup>4,5</sup> For instance, a practice parameter based on systematic review exists specifically for the pharmacologic treatment of spasticity in persons with cerebral palsy (CP); however, the limited scope of this systematic review does not adequately inform the appropriate care of persons with cerebral palsy and the complexities of their motor disability related to coexisting conditions such as negative motor signs, hyperkinetic movements, musculoskeletal abnormalities, pain, executive dysfunction, and systemic barriers.<sup>6–11</sup> Though various repositories of articles exist on platforms such as the Child Neurology Society (CNS) website, standardized primary literature libraries summarizing essential literature for different neurologic conditions do not exist.<sup>12</sup> Such libraries, generated and maintained via systematic methodology and presented in an equitable and accessible format, can be an invaluable educational resource for all levels of practice.

Special interest groups (SIGs) are dynamic and diverse communities of practitioners who share subspecialty interest.<sup>13</sup> SIGs are uniquely positioned to guide CN/NDD via focused clinical expertise, interfacing with current cultural contexts related to specific clinical conditions, and involvement in clinical research that generates new knowledge. “SIGNature Libraries” aim to channel the dynamism of SIGs to identify the essential literature for a subspecialty field in a manner that keeps pace with the field’s evolution over time. These “living libraries” provide trainees and established practitioners with access to a subspecialty-specific evidence base that is current, broad in scope, and clinically relevant. An intentionally broad scope further distinguishes SIGNature Libraries from traditional systematic reviews. These libraries include literature beyond clinical trial data to encompass a neurologic condition’s historical context, diagnostic conceptualization, and community organization materials to foster a holistic understanding of how neurologic conditions affect human individuals, their community, and their lived experience.

Here we present the development process of the CNS CP SIGNature Library, a first-of-its-kind compendium of seminal articles relating to CP to guide general CN/NDD practice and education. Our intent is that this process serves as a starting point for living library development for other neurologic conditions.

## Methods

### Conception

The initial conception of a living library of seminal articles occurred at the inaugural Cerebral Palsy (CP) SIG meeting in 2019 at the 48th CNS Annual Meeting in Charlotte, NC. This arose from attendee consensus acknowledging the unmet need to establish a knowledge base for CN/NDD relating to the care of persons with CP, with particular focus on postgraduate trainees in CN/NDD residency programs as well as for the purposes of continuing medical education (CME). This prototype library was to be complete in scope while selective for the essential literature, readily accessible online, and amenable to ongoing maintenance to be kept up to date with evolutions in the field. Careful attention to methodology was emphasized to provide a potential roadmap for other groups to develop their own living libraries.

### Advisory board

The initial core advisory board was composed of CNS CP SIG leaders, including a designated project chair (YMK). This core group nominated additional field experts from across the United States and internationally to capture variations in practice and perspective, inclusive of CNS members as well as nonmembers. We also aimed to include junior faculty (less than five years from completing postgraduate training) to maintain proximity to the needs of trainees.

### Goals

A project charter was proposed by the project chair and approved by the advisory board following iterative discussion and revision (Figure 1). The aim of the charter was to create a “living library” of the seminal articles that inform the care of children with CP for CN/NDD. Specific goals included: (1) promote provider engagement with the primary literature and primary data sources; (2) promote equitable provider access to evidence-based and consensus clinical guidelines; (3) promote a holistic and multifaceted understanding of the topic for CN/NDD practice; and (4) promote access to high-quality resources for families.

### Article submissions, organization, and rating

Utilizing a modified-Delphi approach, we implemented two literature submission rounds and two rating rounds followed by a final review<sup>14</sup> (Figure 2). Two separate rounds of submission and rating were judged to be optimal. We anticipated that most articles in the final library would be from the first round but that a second round would still provide a substantial number of articles to be considered. A second round was also considered valuable for critically reviewing and identifying gaps in the library with broad SIG participation. A third round was considered unhelpful due to expected diminishing returns.

The advisory group first formed a short list of articles that served as exemplars of the quality and relevance expected for the SIGNature Library and provided a sense of general scope. Each entry included the article title, year published, DOI/URL link, free text description, and the reason for inclusion in the library (“what and why” as provided by the advisory board member), and a suggested category under which the article would fall. The names of authors

were deliberately excluded. This initial list of articles was presented in an online spreadsheet using Google Sheets to SIG members with solicitation for additional articles to be added to the spreadsheet for the first submission round (Figure 3). Articles were also accepted via direct email to the project chair.

For the first rating round, the advisory board organized all submitted articles into seven categories: Consensus Definitions and Guidelines, Assessment Tools, Primary Data, Systematic Reviews and Meta-Analyses, General and Topical Reviews, History and Perspectives, and Resources for Families. Submissions were then entered into a survey using REDCap. Each article was presented by title and year published with a hyperlink to the article, as well as a brief description of the article as a hover text. The articles were then rated by SIG members on an ordinal scale (5 ESSENTIAL = all CN/NDD should *master* content. 4 IMPORTANT = all CN/NDD should *read*. 3 RELEVANT = useful and *within general CN/NDD scope* of practice. 2 SUPPLEMENTAL = useful but *beyond general CN/NDD scope* of practice. 1 = NOT NEEDED) (Figure 4). These ratings were utilized in the final organization of the library to stratify articles according to their level of importance indicated by the rating. The collected scores of all raters were averaged for a final score for each article.

The final question in the first rating was a free-text box soliciting additional submissions. This functioned as the second submission round. Submissions were again solicited and accepted via email by the project chair. These additional submissions were entered into a new survey using REDCap, and the second rating round proceeded in the same manner as the first rating round. Articles from the first round were not re-rated (as in other iterations of a modified-Delphi approach) to support intent that each article was rated individually on its own merit and not in competition with other articles. We deliberately designed the library with no predetermined size restriction in favor of providing the library-user a maximally inclusive and comprehensive selection. This method proved advantageous and ultimately allowed for a unique presentation where articles were stratified by consensus-determined importance (see Results), empowering users to selectively access and navigate the library contents.

### Final review

The advisory board subsequently reviewed all article submission and rating round results. This group then determined inclusion rating score threshold and final library structure. Inclusion threshold and final library size were not predetermined. We prioritized maintaining an open and collaborative global assessment of the results in view of the project charter and its stated goals (Figure 1).

A draft of the library was then produced and distributed to the SIG at large for feedback. The advisory group then met for a final time to review and incorporate feedback and to consider final additions and deletions.

### Maintenance

At the final review, the advisory group deliberated a process of ongoing submissions and future revisions to the library.

## Results

The advisory board consisted of 11 members: eight from the United States, one from Canada, one from Europe, and one from Australia. Three were residency program directors or associate program directors. Five members were junior faculty (five or fewer years out of training). One was an NDD trainee. The CNS SIG email listserv included 75 members; nine members submitted articles for consideration for the first survey and 10 members for the second survey. Survey response rates among SIG members were 29/75 for the first round and 24/75 for the second round. Seventy-nine articles were submitted for the first survey and 22 articles for the second survey.

In the final review process, in consideration of the goals stated in the charter (e.g., promoting a holistic and multifaceted view of CP) as well as diversity, equity, and inclusion considerations, seven additional articles were reviewed and included by the advisory board. Some of these articles had been included in the rating rounds but had not been rated highly by the SIG. These additions included one historical overview, one article highlighting racial and socioeconomic disparities in CP, one article highlighting research priorities in CP, one article highlighting the International Classification of Function (ICF) framework, one article reviewing neuropsychological profiles and psychometric testing in CP, and two articles on physician-family communication and lived experience.

Rather than excluding articles that did not meet a high threshold score, we decided on a low threshold for inclusion in the final library and mirrored the rating scale used by creating a stratified presentation. A minimum threshold for inclusion was decided to be a 3.5 average score, leading to 53 total articles included from the surveys (a higher threshold of 4.0 average led to including only 16 of 101 articles, whereas a lower threshold of 3.0 average led to excluding only 16 of 101 articles). With the addition of the seven articles from the final review, the final library included 60 articles. Sixteen out of the 60 articles exceeded a 4.0 average score threshold. Two articles exceeded a 4.5 average score threshold. We adapted the survey rating scale and color-coded the articles according to their average score: articles scoring 4.5 and above were designated as “ESSENTIAL” and highlighted in green, articles scoring 4.0–4.5 were designated as “IMPORTANT” and highlighted in yellow, while all other articles (scoring 3.5–4.0) were designated as “RELEVANT” and not highlighted (Figure 5).

The library was organized into the same seven sections presented in the surveys. Each article was also presented in the same manner as the surveys: in chronological order, with the article’s title and year of publication, without the authors’ names, and with an associated hyperlink to the article’s DOI as well as a brief article description as a hover-text (Table 1).

The library was named a “SIGNature Library,” SIGNature being a triple entendre to indicate the distinctive nature of each subspecialty library, to reference SIG collaborations, and finally to reference “sig,” short for *signetur*, as in “instructions for the use of medicine.” The library is to be published on the CNS website and accessible to CNS members and nonmembers.



Each SIG can determine maintenance of their respective SIGNature Library. A project chair should be designated for each formal iteration of the library. Each SIG should determine the process and frequency for new article submissions (open submissions and/or solicited every two to five years), for rating new articles and previously included articles, and for publication of new editions of the library.

## Discussion

The principal goal of this project was to foster a holistic understanding of a human condition as well as the practice of evidence-based medicine, which is defined as “the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients.”<sup>1</sup> The CP SIGNature Library offers the CN/NDD learner an unprecedented resource that provides access to latest consensus guidelines, existing seminal datasets, up-to-date review articles, and other patient care tools. Furthermore, this library intentionally highlights the nature and limitations of the current science and evidence base while providing complementary insights regarding experiential and humanistic aspects.

This first iteration of the SIGNature Library is limited by relatively few contributors (for submissions as well as ratings). The library thus depended largely on expert opinions rather than a broad consensus. However, the project was intended to provide expert guidance on navigating the literature as a service to the learner and practitioner. It will be vital to include trainees and generalists, as well as perspectives from other specialists (e.g., physical therapists, orthopedic surgeons, etc.) and members of the CP community, in future iterations of the library to ensure that the current needs of learners and the CP community are continually being met.

A distinctive feature of the SIGNature Library is its large scope and depth, presented in a stratified fashion relative to the consensus-determined importance of each article. Learners can efficiently navigate the library based on individual interests and goals, and the library can be used as core curriculum for CP education (e.g., over a one-month rotation for trainees). Integrating SIGNature Libraries into training curricula and programs may provide efficient pathways toward understanding CP-related literature at levels ranging from basic competence to mastery. Likewise, SIGNature Libraries can be utilized for CME purposes for CN/NDD and other specialists, such as adult neurologists who may have limited clinical exposure to childhood-onset conditions.

Continued SIG engagement to maintain and further develop each SIGNature Library will be vital to its relevance as a dynamic education tool. A formal committee dedicated to developing SIGNature Libraries within CNS is planned to incentivize and to galvanize participation across all CNS SIGs.

## Acknowledgments

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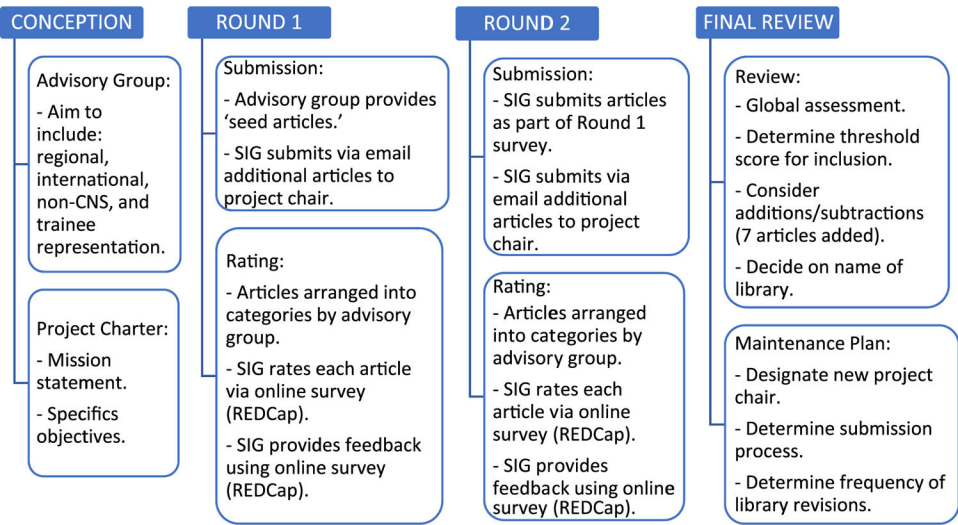


We aim to create a 'living library' of the seminal articles that inform the care of children with cerebral palsy for Child Neurologists (CNS) and Neurodevelopmentalists (NDD).

Goals:

1. Promote provider engagement with the primary literature and primary data sources.
2. Promote equitable provider access to evidence-based and consensus clinical guidelines.
3. Promote a holistic and multi-faceted understanding of the topic for CN/NDD practice.
4. Promote access to high-quality resources for families.

**Figure 1.**  
Project charter.



**Figure 2.**  
Steps in creating the prototype SIGnature Library.

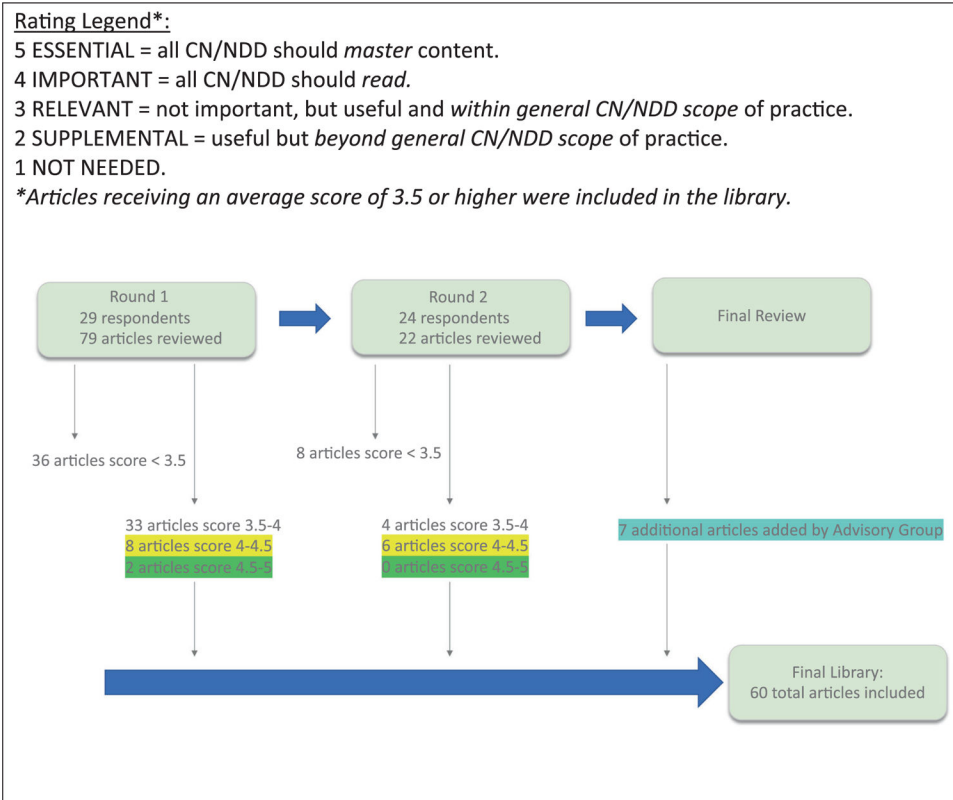
Title	Year Published	Section	What and Why	URL
A report: the definition and classification of cerebral palsy.	2006	Definition / Diagnosis / Classification	Most current international 'consensus' definition of CP.	<a href="http://www.ncbi.nlm.nih.gov/pubmed/17370477">http://www.ncbi.nlm.nih.gov/pubmed/17370477</a>
Surveillance of cerebral palsy in Europe: a collaboration of cerebral palsy surveys and registers.	2000	Definition / Diagnosis / Classification	Original SCPE publication with classification and diagnosis flowsheets (may already be covered in reference manual, but I like how this paper is organized)	<a href="https://www.ncbi.nlm.nih.gov/pubmed/11132255">https://www.ncbi.nlm.nih.gov/pubmed/11132255</a>
Surveillance of Cerebral Palsy in Europe (SCPE): - Reference and Training Manual		Definition / Diagnosis / Classification	The European standard for diagnosis and classification. Flow-chart format is useful and easy to follow.	<a href="https://eu-rd-platform.jrc.ec.europa.eu/scpe">https://eu-rd-platform.jrc.ec.europa.eu/scpe</a>
What constitutes cerebral palsy in the twenty-first century?	2013	Definition / Classification	Summary and update of diagnostic criteria across registries	<a href="https://www.ncbi.nlm.nih.gov/pubmed/24111874">https://www.ncbi.nlm.nih.gov/pubmed/24111874</a>

**Figure 3.**

A sample of the spreadsheet used for article submissions.

History	
79) <a href="#">From congenial paralysis to post-early brain injury developmental condition: Where does cerebral palsy actually stand? (2019)</a>	<input type="radio"/> 1 NOT NEEDED <input type="radio"/> 2 SUPPLEMENTAL <input type="radio"/> 3 RELEVANT <input type="radio"/> 4 IMPORTANT <input type="radio"/> 5 ESSENTIAL reset
80) <a href="#">William Osler, Sigmund Freud and the evolution of ideas concerning cerebral palsy (1993)</a>	<input type="radio"/> 1 NOT NEEDED <input type="radio"/> 2 SUPPLEMENTAL <input type="radio"/> 3 RELEVANT <input type="radio"/> 4 IMPORTANT <input type="radio"/> 5 ESSENTIAL reset
Resources for Families	
81) <a href="#">Cerebral Palsy Resource</a>	<input type="radio"/> 1 NOT NEEDED <input type="radio"/> 2 SUPPLEMENTAL <input type="radio"/> 3 RELEVANT <input type="radio"/> 4 IMPORTANT <input type="radio"/> 5 ESSENTIAL reset
82) <a href="#">CP NOW Foundation ('Cerebral Palsy Toolkit' and 'Wellbeing for Parents and Caregivers')</a>	<input type="radio"/> 1 NOT NEEDED <input type="radio"/> 2 SUPPLEMENTAL <input type="radio"/> 3 RELEVANT <input type="radio"/> 4 IMPORTANT <input type="radio"/> 5 ESSENTIAL reset
83) <a href="#">Cerebral Palsy Foundation (also see 'CP Channel' app)</a>	<input type="radio"/> 1 NOT NEEDED <input type="radio"/> 2 SUPPLEMENTAL <input type="radio"/> 3 RELEVANT <input type="radio"/> 4 IMPORTANT <input type="radio"/> 5 ESSENTIAL reset

**Figure 4.**  
Sample of online article rating survey using the REDCap online application.



**Figure 5.**

Results summary. Rating legend\*: 5 ESSENTIAL = all CN/NDD should *master* content. 4 IMPORTANT = all CN/NDD should *read*. 3 RELEVANT = not important, but useful and *within general CN/NDD scope* of practice. 2. SUPPLEMENTAL = useful but *beyond general CN/NDD scope* of practice. 1 NOT NEEDED. \*Articles receiving an average score of 3.5 or higher were included in the library.

Author Manuscript

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Author Manuscript

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The CP SIGNature Library.

Table 1.

Articles with score average 3.5 – 4.0, RELEVANT.

Articles with score average above 4.0 – 4.5, IMPORTANT.

Articles with score average 4.5 – 5.0, ESSENTIAL.

Articles added by Advisory Group at Final Review.

Consensus Definitions and Guidelines

1. Classification and definition of disorders causing hypertonia in childhood (2003)
2. Practice parameter: diagnostic assessment of the child with cerebral palsy: report of the Quality Standards Subcommittee of the American Academy of Neurology and the Practice Committee of the Child Neurology Society (2004)
3. Definition and classification of hyperkinetic movements in childhood (2006)
4. Definition and classification of negative motor signs in childhood (2006)
5. A report: the definition and classification of cerebral palsy (2006)
6. The updated European Consensus 2009 on the use of Botulinum toxin for children with cerebral palsy
7. Practice Parameter: Pharmacologic treatment of spasticity in children and adolescents with cerebral palsy (an evidence-based review) Report of the Quality Standards Subcommittee of the American Academy of Neurology and the Practice Committee of the Child Neurology Society (2010)
8. Motor Delays: Early Identification and Evaluation (2013)
9. Status dystonicus: a practical guide (2013)
10. What constitutes cerebral palsy in the twenty-first century? (2013)
11. Early, Accurate Diagnosis and Early Intervention in Cerebral Palsy: Advances in Diagnosis and Treatment (2017)
12. International expert recommendations of clinical features to prompt referral for diagnostic assessment of cerebral palsy (2019)
13. Genetic or Other Causation Should Not Change the Clinical Diagnosis of Cerebral Palsy (2019)
14. The Role of Neuroimaging and Genetic Analysis in the Diagnosis of Children With Cerebral Palsy (2020)
15. Early Intervention for Children Aged 0 to 2 Years With or at High Risk of Cerebral Palsy International Clinical Practice Guideline Based on Systematic Reviews (2021)
16. AACPDM Care Pathways

Assessment Tools

17. Development and reliability of a system to classify gross motor function in children with cerebral palsy (1997)
18. The Manual Ability Classification System (MACS) for children with cerebral palsy: scale development and evidence of validity and reliability (2006)
19. GMFCS-Expanded and Revised (2007)
20. Development of the Hypertonia Assessment Tool: a discriminative tool for hypertonia in children (2010)
21. Developing and validating the Communication Function Classification System for individuals with cerebral palsy (2011)
22. SCPE Working Group. MRI classification system (MRICS) for children with cerebral palsy: development, reliability, and recommendations (2016)



23. Use of the Hammersmith Infant Neurological Examination in infants with cerebral palsy: a critical review of the literature (2016)
  24. Overview of Four Functional Classification Systems Commonly Used in Cerebral Palsy (2017)
  25. Surveillance of Cerebral Palsy in Europe (SCPE)
  26. (also see 'SCPE Reference and Training Manual')
- Primary Data**
27. Prognosis for gross motor function in cerebral palsy (2002)
  28. Prognosis for ambulation in cerebral palsy: a population-based study (2004)
  29. Psychiatric disorders among children with cerebral palsy at school starting age (2012)
  30. Birth Prevalence of Cerebral Palsy: A Population-Based Study (2016)
  31. Comparing parent and provider priorities in discussions of early detection and intervention for infants with and at risk of cerebral palsy (2019)
  32. Neuroimaging Patterns and Function in Cerebral Palsy-Application of an MRI Classification (2020)
  33. Molecular Diagnostic Yield of Exome Sequencing in Patients With Cerebral Palsy (2021)
  34. Autism and attention-deficit/hyperactivity disorder in children with cerebral palsy: high prevalence rates in a population-based study (2021)
  35. "It Should Have Been Given Sooner, and We Should Not Have to Fight for It": A Mixed-Methods Study of the Experience of Diagnosis and Early Management of Cerebral Palsy (2021)

#### Systematic Reviews and Meta-Analyses

36. The epidemiology of cerebral palsy: incidence, impairments and risk factors (2006)
37. A systematic review of interventions for children with cerebral palsy: state of the evidence (2013)
38. Effectiveness of motor interventions in infants with cerebral palsy: a systematic review (2016)
39. Efficacy of ankle foot orthoses types on walking in children with cerebral palsy: A systematic review (2017)
40. Prevention of hip displacement in children with cerebral palsy: a systematic review (2017)
41. <https://doi.org/10.1002/14618B8.CD011660.pub2>
42. Pharmacological and neurosurgical interventions for managing dystonia in cerebral palsy: a systematic review (2018)
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49. The 'F-words' in childhood disability: I swear this is how we should think! (2012)
50. Clinical presentation and management of dyskinetic cerebral palsy (2017)
51. The genetic basis of cerebral palsy (2017)

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52. NINDS/NICHHD Strategic Plan for Cerebral Palsy Research (2017)

53. Pathophysiology of chronic pain in cerebral palsy: implications for pharmacological treatment and research (2018)

54. Intrathecal baclofen in dyskinetic cerebral palsy: effects on function and activity (2018)

55. Genetic mimics of cerebral palsy (2019)

56. Treatable Movement Disorders of Infancy and Early Childhood (2020)

57. Cognitive and academic profiles in children with cerebral palsy: A narrative review (2020)

**History and Perspectives**

58. From congenital paralysis to post-early brain injury developmental condition: Where does cerebral palsy actually stand? (2019)

**Resources for Families**

59. Cerebral Palsy Resource

60. CP Research Network (‘Cerebral Palsy Toolkit’ and ‘Wellbeing for Parents and Caregivers’)

61. Cerebral Palsy Foundation

62. (also see ‘CP Channel’ app)

*Note:* Each entry is a hyperlink: click to access article via PubMed, hover for a brief description.