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The Cerebral Palsy Research Registry: Development and Progress Toward National Collaboration in the United States

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Abstract

Cerebral palsy is the most common neurodevelopmental motor disability in children. The condition requires medical, educational, social, and rehabilitative resources throughout the life span. Several countries have developed population-based registries that serve the purpose of prospective longitudinal collection of etiologic, demographic, and functional severity. The United States has not created a comprehensive program to develop such a registry. Barriers have been large population size, poor interinstitution collaboration, and decentralized medical and social systems. The Cerebral Palsy Research Registry was created to fill the gap between population and clinical-based cerebral palsy registries and promote research in the field. This is accomplished by connecting persons with cerebral palsy, as well as their families, to a network of regional researchers. This article describes the development of an expandable cerebral palsy research

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Ethics Approval

Institutional review boards from Northwestern University Feinberg School of Medicine and the University of Chicago, Division of the Biological Sciences, approved this study.

registry, its current status, and the potential it has to affect families and persons with cerebral palsy in the United States and abroad.

Keywords

cerebral palsy; registries; research

Each year in the United States, approximately 1 in 278 infants will be diagnosed with cerebral palsy, the leading neurodevelopmental motor disability in children. This cohort of more than 12 000 infants will contribute to the growing national population of an estimated 800 000 children and adults living with cerebral palsy.^{1,2}

Cerebral palsy describes a group of permanent disorders that affect the development of movement and posture, causing activity limitations that are attributed to nonprogressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication, and behavior; by epilepsy; and by secondary musculoskeletal problems.³ This consensus definition from the American Academy of Cerebral Palsy and Developmental Disabilities not only acknowledges the initial static or nonprogressive injury to the immature brain but also recognizes the resulting dynamic and evolving medical, developmental, and social issues that this disruption in normal brain development creates throughout the life span.

Cerebral Palsy Registries

Significant knowledge regarding the prevalence, cause, distribution, frequency, and severity of cerebral palsy has been elucidated by cerebral palsy registries throughout the world.^{4,5} Such registries also have been instrumental in assisting with successful interventions pertaining to the prevention of cerebral palsy and the improvement of function and quality of life for those who have this diagnosis.⁶⁻⁸ Pioneers in this field have been researchers in Europe and Australia, who began their population-based, epidemiological cerebral palsy registries more than 30 years ago.^{9,10} In 1999, to promote and expand upon past success and allow comparative studies with a larger number of registrants for future studies, 8 countries in Europe combined individual cerebral palsy registry databases to establish a network called the Surveillance of Cerebral Palsy in Europe.¹¹ In 2009, the Australian Cerebral Palsy Register was created to unite the data collected from all 7 cerebral palsy registries in Australia into one common database.¹²

Although various international cerebral palsy registries have been successful in promoting epidemiologic and scientific research for people with cerebral palsy, the United States lags behind. Possible reasons for this are population size, poor inter-institution collaboration, and the variety and number of health care delivery systems currently used. The United States' population of more than 308 million people is significantly larger than countries with established cerebral palsy registries: Australia (22.5 million), Canada (33.3 million), Sweden (9.3 million), and the United Kingdom (62 million).¹³⁻¹⁶ The public and private health care and school systems in the United States have segmented rules and regulations regarding the promotion and tracking of services for people with cerebral palsy. For example, a 15-year-old child with a diagnosis of cerebral palsy could realistically be enrolled in 7 different databases (hospital electronic medical record, neonatal intensive care follow-up clinic database, early intervention records, early childhood and school records, outpatient therapy sessions, primary physician records, specialty physician records, and program for children with special health care needs) and not have a systematic protocol for health providers to

know about or interact with each other. Many countries with population-based cerebral palsy registries have universal health care systems that make it easier to develop and maintain cerebral palsy registries.¹⁷⁻¹⁹ According to Norway's compulsory health insurance system, individuals are entitled to benefits for a disability that involves significant expenses, requires special attention or nursing, or reduces working capacity by at least 50%. These benefits are provided without regard to income or wealth and are considered to provide a fairly complete registry of disabled individuals in Norway.²⁰

Over the past 2 decades, 3 surveillance studies on children with cerebral palsy in the United States have been performed. In 1992, using a multiple-source case identification method, the Metropolitan Atlanta Developmental Disabilities Study by Yeargin-Allsopp et al²¹ assessed the prevalence of mental retardation, cerebral palsy, hearing impairment, and visual impairment among children who were 10 years of age between 1985 and 1987 in 5 Georgia counties. This study found a prevalence of cerebral palsy in this geographical area as 2 per 1000 children. A population-based cohort study in 1993 by Grether et al²² covered children born between 1983 and 1985 in 4 northern California counties to examine the impact of demographic shifts and changes in perinatal medicine on the distribution of cerebral palsy. In 2008, the surveillance study of 8-year-olds with cerebral palsy by Yeargin-Allsopp et al² addressed specific regions within 3 states and established the prevalence of cerebral palsy in the United States as 3.6 per 1000, comparable to cerebral palsy prevalence throughout the world.

Population and surveillance studies are labor-intensive projects that require significant funding to develop and execute. Without a national cerebral palsy registry in the United States, individual institutions and clinicians have created their own clinical registries for research purposes, and parents have developed their own support and advocacy groups.^{20,21} Working in isolation during a climate of limited resources and funding for cerebral palsy is not cost-effective, productive, or practical²³⁻²⁵ (Table 1).

Given the decentralized nature of the US health care system and the prohibitive cost of developing a population-based cerebral palsy registry, a different approach for facilitating and promoting cerebral palsy research was created in the platform of a Cerebral Palsy Research Registry, a secure and expandable online database that can accommodate multiple research institutes. This practical and organized system works by continually expanding the database with contact information as well as medical, developmental, and participation variables on persons with cerebral palsy. The information can be used to assist researchers with study recruitment as well as develop preliminary research pilot studies.

The Cerebral Palsy Research Registry

Overview and Purpose

The Cerebral Palsy Research Registry was created as a collaborative effort among researchers and clinicians at Northwestern University Department of Physical Therapy and Human Movement Sciences, the Rehabilitation Institute of Chicago, and the University of Chicago Comer Children's Hospital to meet an underdeveloped yet vital component for cerebral palsy research in the United States—participant recruitment. This expandable multi-institution research registry has the ability to make a significant impact on exploring, encouraging, and executing cerebral palsy research by establishing relationships between health care, education, rehabilitation and community settings, researchers, and adults and children with cerebral palsy and their families. The Cerebral Palsy Research Registry is able to assist researchers with participant recruitment for studies in the areas of etiology, prevention, neuroprotection, bioengineering, and comprehensive interventions that optimize health and well-being.

Creating a Cerebral Palsy Research Registry

The Cerebral Palsy Research Registry began in 2006 with a donation from a private donor to create a cerebral palsy registry that would be more than a clinical registry. This challenge resulted in several planning sessions on what to name the registry, what definition of cerebral palsy was to be used, what ceiling age of “insult to the developing brain” was to be used, the purpose of the registry, how participants would be recruited, institution ethics board approvals, participant privacy rights and consenting, essential versus nonessential variables, database security, and ongoing funding. After 2½ years of discussion and piloting, the Cerebral Palsy Research Registry was established, embodying several characteristics that have been associated with successful epidemiological cerebral palsy registries worldwide, as noted by Cans et al²⁶: a clearly defined purpose, a multidisciplinary team approach for content and future direction, a clear definition of cerebral palsy with exclusion and inclusion criteria, a standard format for collection of variables, a large geographic distribution of participants, and the ability to expand and embrace new technology for secure data collection. The Cerebral Palsy Research Registry has limitations; data from questionnaires are provided by participants, their guardians, or their physician and are not compared with medical records, enrollment is restricted to passive and active recruitment, and participants are not drawn from population denominator data. These limitations prevent the Cerebral Palsy Research Registry from being an epidemiological, population-based registry; however, the registry serves as a tool to assist and promote cerebral palsy research across the life span.

Data Variables

Variables used to obtain information from participants and/or their families came from consolidating multiple national and international guidelines, outcome measures, and international cerebral palsy registries.²⁷⁻³² The World Health Organization's (WHO) International Classification of Function, Disability and Health Adult and Children and Youth Versions³³ (Figure 1) and the multicenter Cerebral Palsy Outcomes Project (supported by pilot funding from the American Academy of Cerebral Palsy and Developmental Medicine) were key references used to achieve a diverse medical, developmental, and social clinical snapshot of participants based on a framework of enablement. A balance between the length of the questionnaire and the comprehensiveness of information obtained was achieved through field testing various questions with parents of children with cerebral palsy.

Identifiable and de-identified data are collected. Identifiable information (17 variables) includes name, guardian's name, and contact information. This information is used to contact participants regarding research studies they may qualify to participate in, update personal records, and share general research and Cerebral Palsy Research Registry information through newsletters and e-mails.

De-identified information includes 45 variables that do not contain personal identifiers and are used when mining the database to determine an individual's appropriateness for a particular study and to create aggregate data that can be used for cohort population studies, such as comparing medical and developmental outcomes between subgroups (Table 2).

Database Development

In January 2006, the Cerebral Palsy Research Registry team received its first institutional review board approval and began the process of consenting and enrolling participants. Data from the questionnaire were entered into a single, secured computer, and the hardcopies of the consents and questionnaires were stored in a locked cabinet at Northwestern University Department of Physical Therapy and Human Movement Sciences.

By 2008, the single computer model was no longer effective and a secure online database was created and launched. The capability to insert site-specific consents and single- or multiple-variable searches of the database was incorporated in anticipation of multi-institution collaboration. The Cerebral Palsy Research Registry Web site, <https://www.cpregistry.org>, was developed, allowing for remote access by the registry coordinator to enroll new participants and search the database while off-site (Figure 2).

Web site access of the database is protected with a Secure Sockets Layer (SSL) certificate, and all users are required to log on to the site using a password in order to enter or view information. The registry coordinator is able to view or change any record in the database, whereas participants only have access to their own personal record. In the case of a parent or guardian enrolling multiple family members as participants, the option for a family identification password to be connected to more than 1 record was created.

The original database that contained all participant information was constructed as a MySQL (Sun Microsystems, Santa Clara, California) database and was housed on a secured server at Northwestern University. The database software was chosen because it was open source and therefore affordable, yet well supported, secure, and reliable. The software was able to sustain growth, both in numbers of participants and in variables collected and saved.

In 2009, the Cerebral Palsy Research Registry Web site was upgraded to support direct online registration by individual participants. Choice of institution affiliation was given, informed consent was signed electronically, and completed questionnaires were stored online. This achievement allowed adults with cerebral palsy and guardians of children with cerebral palsy to enroll from home, increased passive recruitment capabilities via the Internet, and required less storage of private health information as hardcopy. With the addition of online registration, the geographic region of participants enrolled in the Cerebral Palsy Research Registry expanded from 3 states to 20.

Cerebral Palsy Research Registry Enrollment

Enrollment in the Cerebral Palsy Research Registry requires a signed informed consent, assent if possible, and completion of a questionnaire. Tonal abnormalities are obtained from health care providers. From 2006 to 2008, recruitment for the Cerebral Palsy Research Registry was limited to passive recruitment efforts: small advertisements on pediatric research and support group Web sites and brochures in clinician offices and waiting rooms. Many eligible families showed interest, but efforts only resulted in 35 participants enrolling.

In June 2008, a registry coordinator was hired to increase the enrollment and profile of the Cerebral Palsy Research Registry and determine its feasibility. Consensus on project title and mission, definition of cerebral palsy, variables to be included in the questionnaire, and recruitment strategies were reviewed and agreed upon. The primary mode of recruitment was for the registry coordinator to begin direct recruitment (6 hours/week) from 2 cerebral palsy clinics located in a large metropolitan city. This approach was piloted in a quaternary academic rehabilitation hospital as well as a community hospital committed to serving children who are predominantly of minority status and living in distressed neighborhoods.

Face-to-face personal interaction with families in the hospital clinics resulted in the largest impact on increasing the number of participants. In addition to this active recruitment, the registry coordinator made presentations at scientific, hospital, and therapy provider meetings and parent groups at schools and met with local support groups to explain the Cerebral Palsy Research Registry's mission; brochures were left in clinic waiting rooms and with physicians. Enrollment doubled, from 35 to 66 participants, in 6 months.

In 2009, Spanish versions of consents, assents, and questionnaires were completed and online registration was initiated. Active and passive recruitment efforts continued and enrollment increased to 244 participants by the end of the calendar year.

Cerebral Palsy Research Registry Participant Profile

With the implementation of systematic active recruitment, Cerebral Palsy Research Registry enrollment increased from 35 to 397 participants (from June 2008 to December 2010). Participant enrollment and subsequently the database demographics are dependent on the clinic settings and locations, linguistic ability of the recruiter, clinic attendance, and motivation of the person with cerebral palsy or the guardian to be part of a research registry. Despite these obstacles, a diverse cerebral palsy participant cohort in terms of gender, race, age, and limb distribution who have a range of medical, social, and developmental associated impairments has been captured (Table 3).

The Cerebral Palsy Research Registry's current population is biased from the standpoint that the majority of participants enrolled have been in a tertiary setting and are typically more medically and developmentally involved, as reflected in the Gross Motor Functional Classification System distribution. Recruitment efforts have expanded to include more community-based programs, identify adults with cerebral palsy, increase hours per week for recruitment, increase awareness of online registration, and facilitate participating institution relationships. Cerebral Palsy Research Registry enrollment is not restricted, and the goal is continual expansion to include as many children and adults at all levels of the Gross Motor Functional Classification System so that recruitment cohorts can be selected for studies.

Assistance With Research Studies

Researchers wanting to use the Cerebral Palsy Research Registry as a recruitment source for their study can request a pre-institutional review board or pre-grant letter. A study proposal with inclusion/exclusion criteria is required. The registry advisory committee reviews the study for relevance and integrity, and if the study is approved, the registry coordinator mines the database using the provided inclusion/exclusion criteria to obtain the number of participants who would qualify for the study. The researcher then receives a letter with the number of eligible study participants and a statement that the researcher will be allowed to use the Cerebral Palsy Research Registry, through the registry coordinator, as a recruitment tool. Researchers are informed that participant eligibility does not guarantee study participation.

Researchers interested in using the Cerebral Palsy Research Registry for subject recruitment are asked to submit the project proposal, institutional review board approval documentation, inclusion/exclusion criteria, and a study flyer to the registry coordinator. The registry advisory committee reviews the study for relevance and integrity. Once the study is approved, the registry coordinator mines the database for inclusion/exclusion criteria and develops a list of appropriate participants who will be contacted by either postal mail or e-mail. Unless permission from the participant for direct contact from the researcher or his or her team is given, contacting the researcher for study questions or enrollment is the participant's responsibility. Researchers who are not affiliated with the Cerebral Palsy Research Registry or one of its participating institutions are charged a nominal fee for administrative costs for this service.

Nine research studies have used the Cerebral Palsy Research Registry as part of their subject recruitment strategy. These projects targeted the World Health Organization's International Classification of Function, Disability and Health model of enablement and were diverse in study design and execution, including surveys, quantitative basic science experiments, and

motor control intervention studies (Table 4). Researchers are cautioned that it is their responsibility to confirm diagnosis and medical and developmental conditions when using Cerebral Palsy Research Registry participants in their studies. A cohort study using de-identified data from the Cerebral Palsy Research Registry regarding health care disparities using medical and developmental outcomes was presented at a professional conference.³⁴

Expansion of the Cerebral Palsy Research Registry

Role as a Coordinating Center

Interest in a US cerebral palsy database continued to grow, and in 2009 different pediatric institutions and organizations inquired about joining the Cerebral Palsy Research Registry. This led to the development of the Cerebral Palsy Research Registry as a coordinating center. In 2010, the Cerebral Palsy Research Registry received additional institutional review board approval as a coordinating center, development of inter-institution legal agreements was begun, and new protocols, policies, and procedures were established.

Northwestern University Biomedical Informatics Center became a key player in the technological security and expansion of the Cerebral Palsy Research Registry as a coordinating center. The center's expertise in registry development and administration allows for the Cerebral Palsy Research Registry's continued growth by adding participating institutions, accommodating additional site-specific variables to the questionnaire, and updating the security of the database.

Data from all participating institutions are funneled into the Cerebral Palsy Research Registry's database and will be made accessible to the registry coordinator, while participating institutions will only have access to their specific institution's data.

Two institutions, a large university and a hospital-based cerebral palsy center, were chosen to pilot the role of participating institutions and will assist in determining whether collaborating with institutions outside the original Cerebral Palsy Research Registry team is feasible and effective. Adding participating institutions to the Cerebral Palsy Research Registry is scheduled to begin in 2011. Also interested in joining the Cerebral Palsy Research Registry, as a participating institution, was the pediatric section of a professional organization. Organizations historically do not have institutional review boards; therefore, collaboration becomes more complicated, but not impossible, in regard to legal and security issues. It is believed that with continued dialogue between professional organizations and the Cerebral Palsy Research Registry team, positive collaboration will be achieved in the near future.

Study Limitation and Future Direction

The Cerebral Palsy Research Registry has been designed to assist cerebral palsy research primarily by linking researchers with participants who qualify for research studies based on the study's inclusion and exclusion criteria and secondarily by creating pilot studies from the registry cohort data that can be later elaborated upon in larger, diverse studies. This is done by collecting medical, developmental, and social data on persons with cerebral palsy and their families and updating the participants' status yearly. Limitations to this system, especially with online registration, are that participants are able to self-report their condition, which may lead to an erroneous diagnosis of cerebral palsy or misleading reporting of physical abilities or social demographics; this project is not a population-based database; and enrollment in the Cerebral Palsy Research Registry is voluntary so that persons/families who are most likely to join are those interested in research.

Future directions of the Cerebral Palsy Research Registry include expanding the number of research studies that use the registry for study participants, hiring a full-time recruiter, enlisting clinic and hospital personnel with recruitment efforts, increasing the number of participating institutions and organizations, and facilitating the relationship between persons with cerebral palsy, their families, and researchers to promote appropriate and pertinent research studies. The Cerebral Palsy Research Registry will become self-sustaining only by pooling the talents and resources of institutions and organizations for a common goal of increasing our understanding of the complexities of cerebral palsy by promoting cerebral palsy research.

Conclusion

Population-based cerebral palsy registries play an important role in determining prevalence, etiology, distribution, frequency, and severity of cerebral palsy in a defined country. A great deal of our current understanding of cerebral palsy has resulted from international epidemiological cerebral palsy registries. In the United States, however, a population-based cerebral palsy registry is not realistic at this time, because of several factors: a large population; disjointed and fragmented health care, social support, and school service delivery systems; and minimal interinstitution collaboration.

Working with multiple institutions to collect contact information and medical, developmental, and social variables on children and adults with cerebral palsy in the form of a Cerebral Palsy Research Registry is a realistic and feasible way to begin a national cerebral palsy database and facilitate research in the field. The Cerebral Palsy Research Registry has proven its capability to collect several variables across a variety of races, ages, genders, and socioeconomic backgrounds and a range of fine and gross motor and communication functional levels.

The creation of this expandable US Cerebral Palsy Research Registry is likely to significantly contribute to our knowledge about cerebral palsy in multiple arenas. A research registry such as this can promote understanding and identify barriers as we seek to optimize function and participation for individuals and families of persons with cerebral palsy. This can be achieved by providing longitudinal data, conducting cohort studies, encouraging multisite collaboration, assisting researchers with subject recruitment, and inviting persons with cerebral palsy and their families to join in the research process.

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References

1. Centers for Disease Control and Prevention. [February 16, 2011] <http://www.cdc.gov/nchs/births.htm>.

2. Yeargin-Allsopp M, Van Naarden Braun K, Doernberg NS, et al. Prevalence of cerebral palsy in 8-year-old children in three areas of the United States in 2002: a multisite collaboration. *Pediatrics*. 2008; 121:547–554. [PubMed: 18310204]
3. Rosenbaum P, Paneth N, Leviton A, et al. A report: the definition and classification of cerebral palsy April 2006. *Dev Med Child Neurol Suppl*. 2007; 109:8–14. [PubMed: 17370477]
4. [February 16, 2011] ACPR Report 2009. <http://www.cpresearch.org.au/pubs/pdf/ACPR-Report.pdf>.
5. Blair E. Epidemiology of the cerebral palsies. *Orthop Clin North Am*. 2010; 41:441–455. [PubMed: 20868877]
6. Research Foundation of Cerebral Palsy Alliance. [February 16, 2011] <http://www.cpresearch.org.au/research.html>.
7. Colver AF, Dickinson HO. Study protocol: determinants of participation and quality of life of adolescents with cerebral palsy: a longitudinal study (SPARCLE2). *BMC Public Health*. 2010; 10:280. [PubMed: 20504349]
8. Simard-Tremblay E, Shevell M, Dagenais L. Determinants of ambulation in children with spastic quadriplegic cerebral palsy: a population-based study. *J Child Neurol*. 2010; 25:669–673. [PubMed: 19794101]
9. Hagberg B, Hagberg G, Olow I. The changing panorama of cerebral palsy in Sweden 1954–1970, I: analysis of the general changes. *Acta Paediatr Scand*. 1975; 64:187–192. [PubMed: 1130174]
10. Stanley FJ, Watson L. Methodology of a cerebral palsy register: the Western Australian experience. *Neuroepidemiology*. 1985; 4:146–160. [PubMed: 3831788]
11. Cans C. Surveillance of cerebral palsy in Europe: a collaboration of cerebral palsy surveys and registers. *Dev Med Child Neurol*. 2000; 42:816–824. [PubMed: 11132255]
12. CP Register Australia. [February 16, 2011] <http://www.cpresearch.org.au>.
13. Australian Bureau of Statistics. [February 16, 2011] <http://www.abs.gov.au>.
14. US Department of State. [February 16, 2011] <http://www.state.gov/r/pa/ei/bgn/2880.htm>.
15. Office for National Statistics UK. [February 16, 2011] <http://www.statistics.gov.uk/CCI/nugget.asp?ID=6>.
16. Canada's Population. [February 16, 2011] http://www.sustreport.org/signals/canpop_ttl.html.
17. National Health System in England. [February 16, 2011] <http://www.nhs.uk/NHSEngland/Pages/NHSEngland.aspx>.
18. Health Canada. [February 16, 2011] <http://www.hc-sc.gc.ca/hcs-sss/index-eng.php>.
19. Australian Government-Medicare Australia. [February 16, 2011] <http://www.medicareaustralia.gov.au/about/whatwedo/health-system/index.jsp>.
20. Moster D, Wilcox AJ, Vollset SE, et al. Cerebral palsy among term and postterm births. *JAMA*. 2010; 304:976–982. [PubMed: 20810375]
21. Yeargin-Allsopp M, Murphy CC, Oakley GP, et al. A multiple-source method for studying the prevalence of developmental disabilities in children: the Metropolitan Atlanta Developmental Disabilities Study. *Pediatrics*. 1992; 89(4 pt 1):624–630. [PubMed: 1372970]
22. Grether JK, Cummins SK, Nelson KB. The California Cerebral Palsy Project. *Paediatr Perinat Epidemiol*. 1992; 6:339–351. [PubMed: 1635884]
23. Cerebral Palsy International Research Foundation. [February 18, 2011] <http://www.cpirf.org/>.
24. [February 16, 2011] Cystic Fibrosis Foundation Annual Report 2009. <http://www.cff.org/aboutCFFoundation/AnnualReport/>.
25. NIH Research Portfolio Online Reporting Tools. [February 16, 2011] <http://report.nih.gov/rcdc/categories/>.
26. Cans C, Surman G, McManus V, et al. Cerebral palsy registries. *Semin Pediatr Neurol*. 2004; 11:18–23. [PubMed: 15132250]
27. Eliasson AC, Krumlinde-Sundholm L, Rosblad B, et al. The Manual Ability Classification System (MACS) for children with cerebral palsy: scale development and evidence of validity and reliability. *Dev Med Child Neurol*. 2006; 48:549–554. [PubMed: 16780622]

28. Gainsborough M, Surman G, Maestri G, et al. Validity and reliability of the guidelines of the surveillance of cerebral palsy in Europe for the classification of cerebral palsy. *Dev Med Child Neurol*. 2008; 50:828–831. [PubMed: 19058397]
29. Harvey A, Baker R, Morris ME, et al. Does parent report measure performance? A study of the construct validity of the Functional Mobility Scale. *Dev Med Child Neurol*. 2010; 52:181–185. [PubMed: 19549200]
30. Krageloh-Mann I, Cans C. Cerebral palsy update. *Brain Dev*. 2009; 31:537–544. [PubMed: 19386453]
31. Mesterman R, Leitner Y, Yifat R, et al. Cerebral palsy—long-term medical, functional, educational, and psychosocial outcomes. *J Child Neurol*. 2010; 25:36–42. [PubMed: 19502577]
32. Palisano RJ, Rosenbaum P, Bartlett D, et al. Content validity of the expanded and revised Gross Motor Function Classification System. *Dev Med Child Neurol*. 2008; 50:744–750. [PubMed: 18834387]
33. WHO International Classification on Functioning, Disability and Health (ICF). [February 16, 2011] <http://www.who.int/classifications/icf/en/>.
34. Hurley, DM.; Msall, ME. Impact of social factors on medical, communication and behavioral comorbidities among children in the cerebral palsy research registry.. Poster presented at: the Child Neurology Society; Providence, RI. October 13-16, 2010;

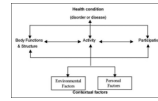


Figure 1. The World Health Organization International Classification of Function, Disability and Health.³³



Figure 2.
The Cerebral Palsy Research Registry Web site homepage.

Table 1

National Institutes of Health Funding Distribution 2009

Disorder/Disease	Prevalence	Private Funding	Federal Funding
Muscular dystrophy	1 in 8000	\$394 million	\$83 million
Cystic fibrosis	1 in 3100	\$152 million	\$99 million
Cerebral palsy	1 in 278	\$2 million	\$25 million
Autism	1 in 150	\$15 million	\$196 million

Data obtained from the Cerebral Palsy International Research Foundation,²³ Cystic Fibrosis Foundation 2009 Annual Report,²⁴ and National Institute of Health RePORT.²⁵

Table 2

Key Variables Collected in the Cerebral Palsy Research Registry

Contact Variables	Medical Variables	Developmental Variables	Participation Variables	Other Variables
Name	Date of birth	Educational plan	Housing	Mother's date of birth
Guardian	Multiple birth	Expressive language	Employment	Mother's residency
Address	Birth weight	Receptive language	Activities	Mother's education
Phone number	Gestational age	Behavior		Race
E-mail address	Limbs affected	Food intake		Spoken language
	Abnormal tone	GMFCS		Medications
	Cause of CP	MACS		Surgeries
	Height/weight	FMS		Assistive technology
	Seizure/epilepsy			Equipment
	Vision			Rehabilitation therapies
	Hearing			
	Breathing			
	Hydrocephaly			

Abbreviations: CP, cerebral palsy; FMS, Functional Mobility Scale; GMFCS, Gross Motor Function Classification System; MACS, Manual Ability Classification System.

Table 3

Cerebral Palsy Research Registry Participant Database Summary: December 2010

	n
Gender	
Male	225
Female	172
Race	
African American	114
Asian	7
Hispanic	58
White	196
Other	22
Language	
English	379
Spanish	15
Limb distribution	
Monoplegic	3
Diplegic	83
Hemiplegic	74
Triplegic	25
Quadriplegic	192
GMFCS	
Level I	56
Level II	26
Level III	47
Level IV	83
Level V	81
MACS	
Level I	67
Level II	52
Level III	31
Level IV	34
Level V	72

Abbreviations: GMFCS, Gross Motor Function Classification System; MACS, Manual Ability Classification System.

Table 4

Research Studies Using the Cerebral Palsy Research Registry as a Recruitment Tool

Body Structure/Function	Activity/Participation
<ul style="list-style-type: none"> • Video game–based rehabilitation • Loss of independent joint control of the upper extremity in children with hemiplegic cerebral palsy • Comparison of anticipatory postural adjustments in children with cerebral palsy and their nondisabled peers • Evaluation of postural control and coordination during reaching • Dance for motor learning in children with cerebral palsy 	<ul style="list-style-type: none"> • Quality of life and levels of participation in children with mild to moderate cerebral palsy • Barriers and supports to sports and recreation in youth with disabilities • Impact of social factors on medical, communicative, and behavioral comorbidities among children in the Cerebral Palsy Research Registry • Medical home in children with cerebral palsy