

National Spotlight on Cerebral Palsy: Federal Funding to Find a Cure

Reaching for the Stars: A Foundation of Hope for Children with Cerebral Palsy.
(a global nonprofit foundation of parents and family members of children with cerebral palsy) and the
American Academy for Cerebral Palsy and Developmental Medicine
(a multi-disciplinary medical professional society) request:

Dedicated Cerebral Palsy federal funding

for the Centers for Disease Control and Prevention (CDC) and the National Institutes of Health (NIH)
to conduct nationwide research (causation, prevention and cure) and surveillance for Cerebral Palsy.

With this new dedicated federal funding commitment, we can make strides toward **finding a cure and best treatment for cerebral palsy (CP)** by understanding risk factors, the cause, which treatments are most effective, at-risk ethnic groups and why there are different clusters of prevalence and types of CP in different parts of the country.

Why we need this funding now:

No known cause, no known cure

- **Cerebral Palsy is the most common motor disability in children** affecting over 800,000 Americans, 1 in 303 children and over 3,200,000 American families.
- **Currently, there is no known cure for CP, and in most cases, (based on current scientific knowledge) it is currently not preventable.** Today, medical experts and researchers agree that the critical mechanisms leading to CP are not well understood. Best practice guidelines are evolving. Despite advances in genetics, obstetrics and neonatology, we STILL do not understand much more about the underlying causes or prevention of CP than we did half a century ago.
- **In more than 80% of CP cases, the cause is still unknown.** CP results from an injury to the brain during development, which can occur during pregnancy, around the time of birth or anytime within the first two years of life. Contrary to popular belief, only a small percentage of CP is caused by birth “asphyxia” (lack of oxygen to the brain at the time of birth).
- **No dedicated line item funding exists for Cerebral Palsy, despite the fact it is the most common motor disability in childhood affecting over 800,000 Americans, with higher prevalence than muscular dystrophy, Parkinson’s disease, childhood cancer, hearing and vision loss, spina bifida, hemophilia, fetal alcohol syndrome or cystic fibrosis.**
Source: CDC,; National Institute of Neurological Disorders & Stroke (NINDS/NIH)



- **CP is a broad group of disorders which disrupt a person's ability to move, sit, stand, walk, talk and use their hands.** The severity and type of the movement disorder and difficulties can vary: Some patients have only mild difficulties with balance, walking and fine motor skills, while others are completely trapped in their own bodies, fighting rigid limbs, and unable to speak or swallow.
- **75% of individuals with CP also have one or more additional developmental disabilities,** including epilepsy, intellectual disability, autism, hearing loss and deafness, vision impairments and blindness.



Cerebral Palsy prevalence is not decreasing in the United States

- **Despite advances in prenatal and neonatal care, a recent study in 2008 indicates the prevalence of CP is now as high as 3.7 per 1,000 8 year- olds.** In contrast, the prevalence of CP is significantly lower, in other countries such as Sweden (1.9 per 1,000 live births). The reasons for this difference need to be studied.
- **Prevalence information the CDC released in its recent report to Congress showed that 1 in 303 8 year-old children have CP .** Among African-American children, 1 in 243 8 year-old children are indicated to have CP (**Source: CDC-WI,CDC-ATL, AL ADDM sites 2002/04; MADDSP studies 1990's – current*). This is higher than the previous prevalence numbers which indicated 1 in 666 children have CP (*Source: CDC MADDSP data 90's – 2001*).
- **CP is one of the most common developmental disabilities in the United States, and is more common in any year than the many types of cancer, stroke, spina bifida or muscular dystrophy,** yet dedicated research funding remains practically nonexistent.

Financial burden on families and the health care system is exceedingly high

- **Living with CP is expensive.** Most children and adults with CP need long-term medical care. The average lifetime additional direct cost for just one person with CP is estimated to be **\$1.5 million above and beyond the cost of living for an average U.S. citizen.** Federal and state governments in the form of Medicaid and other social services currently absorb much of this cost.
- **It is estimated that the lifetime care and medical costs for all people with CP who were born in 2000 alone will total more than \$13.5 billion. The loss of productivity, lost wages of the individual with CP and their family members top \$30 billion.** Dedicated research is needed to investigate the cause and best interventions for CP to help reduce this substantial financial burden on our families, healthcare system and government.
- Recent CDC analyses show that the **average Medicaid costs for children with CP are 13 times higher than those without CP.**

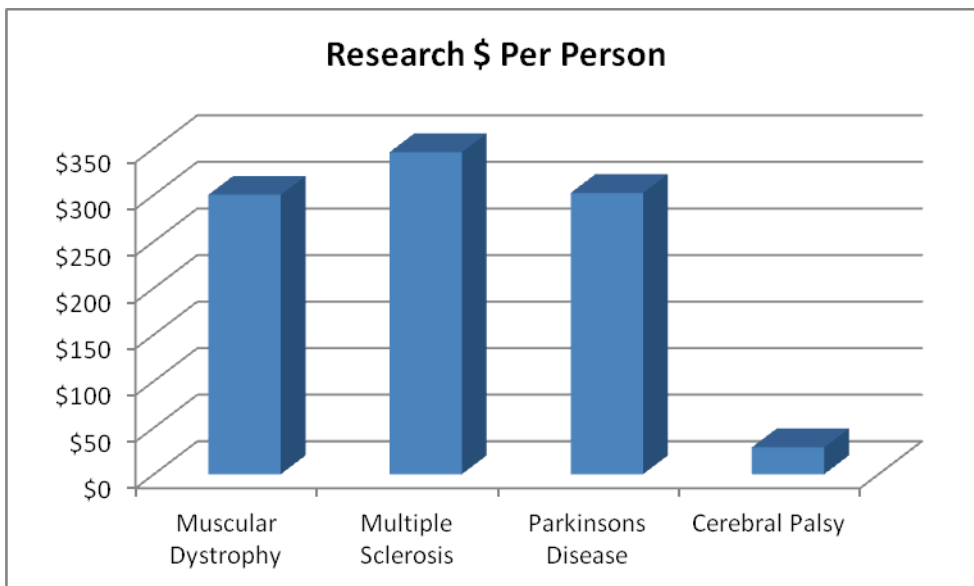
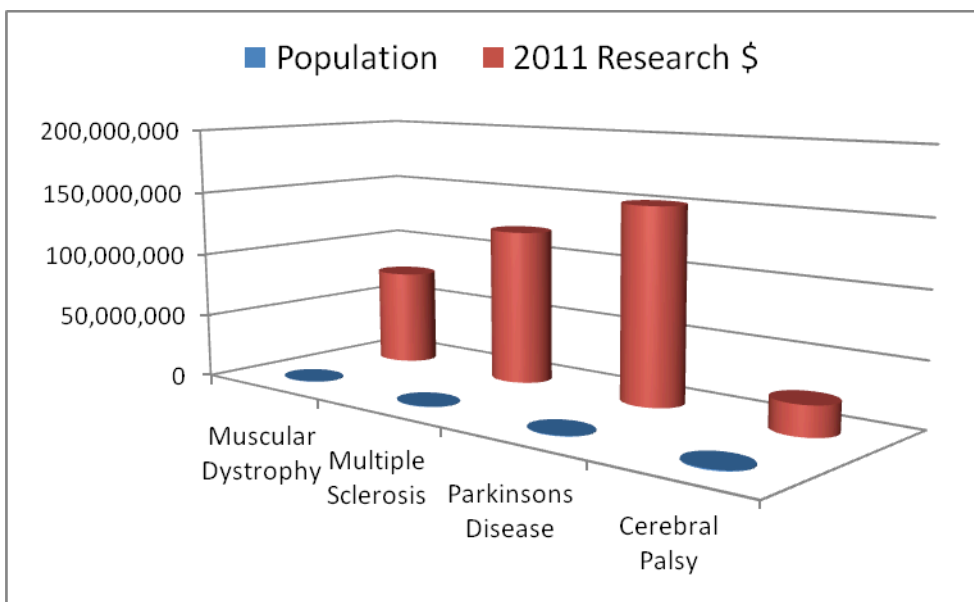
No current dedicated federal funding stream for CP research

- **CP affects roughly 800,000 children, adolescents and adults in the United States, yet is grossly underfunded relative to other disorders.** Currently, there is no line-item CDC funding appropriated for CP research. NIH funding is not targeted toward innovative, curative research, and 2008 data indicates that up to four times more NIH funding was appropriated for research and surveillance of disorders which affect less than half as many persons as those living with CP.
- **A sustained federal funding commitment to the CDC in the form of surveillance and epidemiology research and NIH research RFA's for cure, prevention and causation will bolster research efforts through the CDC and the NIH and assist scientists in developing effective strategies for the prevention and treatment of CP.**



2011 NIH Research Funding by Disease State

NIH Disease State	Population	2011 Research \$	Per Person
Muscular Dystrophy	250,000	\$75,000,000	\$300
Multiple Sclerosis	350,000	\$121,000,000	\$346
Parkinsons Disease	500,000	\$151,000,000	\$302
Cerebral Palsy	800,000	\$23,000,000	\$29



RFTS at a Glance

1. Launched in 2005, “Reaching For The Stars: A Foundation of Hope for Children with Cerebral Palsy.” (RFTS) is a global 501(c)3 nonprofit foundation. RFTS, Inc. is the **largest parent-led, global non-profit education and research foundation for pediatric cerebral palsy** with presence in U.S., Canada, Asia and Australia.
2. RFTS membership includes parents and caregivers of children with Cerebral Palsy who are concerned that little progress has been made for prevention, new treatments or cure of Cerebral Palsy and want to change the status quo.
3. The RFTS Medical Advisory Board is made up of leading cerebral palsy clinicians and researchers. RFTS is an official external partner of the CDC and partners with many organizations including the AACPDM.

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AACPDM at a Glance

1. AACPDM www.aacpdm.org Founded in Chicago in 1947, the American Academy for Cerebral Palsy and Developmental Medicine (AACPDM) is a multi-specialty, multi-disciplinary professional society dedicated to promoting excellence in research and services, and disseminating educational information for the benefit of people with cerebral palsy and childhood-onset disabilities, and the health professionals who care for them.
2. Membership in the AACPDM exceeds 1,200 professionals representing 20 medical and allied health specialties from all 50 states and 32 countries.
3. Based on epidemiologic data, AACPDM members provide care for at least half of all children with physical disabilities in the United States before their 21st birthday.

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