

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

**Reaching for the Stars: A Foundation of Hope for Children with Cerebral Palsy** (an organization of parents and family members of children with cerebral palsy), the **American Academy for Cerebral Palsy and Developmental Medicine** (a multi-disciplinary medical professional society), and the **Cerebral Palsy International Research Foundation** (an organization dedicated to fostering global research for CP and related developmental brain disorders) request:

## **\$10 million in dedicated federal funding**

for the Centers for Disease Control and Prevention (CDC) and the National Institutes of Health (NIH) to conduct nationwide research 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**

- **Currently, there is no known cure for CP, and in most cases, (based on current scientific knowledge) it is not preventable.** Today, medical experts and researchers agree that the critical mechanisms leading to cerebral palsy 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 cerebral palsy 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).
- **Cerebral palsy 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, mental retardation, autism and visual impairments or blindness.

### **CP is increasing in the United States**

- **CP is increasing in this country.** A recent study in 2008 indicates the prevalence of CP is now as high as 3.6 per 1,000 8 year-olds, a marked increase over previous reports of 2.0 per 1,000 live births. In contrast, the prevalence of CP is significantly lower, and is declining, in other countries such as Sweden (1.9 per 1,000 live births). The reasons for this difference needs to be studied.
- **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.**

### **Financial burden on families and the health care system**

- **Living with CP is expensive.** Most children and adults with CP need long-term medical care. The average lifetime 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.** Dedicated research is needed to investigate the cause and best interventions for CP to help reduce this substantial financial burden.

### **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 of \$10 million will bolster research efforts through the CDC and the NIH and assist scientists in developing effective strategies for the prevention and treatment of CP.**



## AACPDM at a Glance

1. Founded in Chicago in 1947, the American Academy for Cerebral Palsy and Developmental Medicine (AACPDMD) 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 AACPDMD exceeds 1,200 professionals representing 20 medical and allied health specialties from all 50 states and 32 countries.
3. Based on epidemiologic data, AACPDMD 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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## RFTS at a Glance

1. Launched in late 2004, Reaching For The Stars: A Foundation of Hope for Children with Cerebral Palsy (RFTS) is a national 501(c)3. RFTS, Inc. is the **only parent-led, national non-profit education and research foundation for pediatric cerebral palsy in the United States.**
2. RFTS membership includes 10,000 + parents and caregivers of children with cerebral palsy across the country who are concerned that little progress has been made for a treatment or cure.
3. The RFTS Medical Advisory Board is made up of leading cerebral palsy experts around the country.

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## CPIRF at a Glance

1. The Cerebral Palsy International Research Foundation (CPIRF) is a not-for-profit 501(c)3 organization **dedicated to funding research and educational activities directly relevant to discovering the cause, cure and evidence-based care for those with cerebral palsy and related developmental disabilities.**
2. Since its founding in 1955, CPIRF has contributed more than \$40 million internationally for research grants to support approximately 500 research projects in the biomedical and clinical sciences and in bioengineering.
3. CPIRF also contributes to national and international meetings and organizes scientific workshops designed to identify research opportunities and provide knowledge concerning CP prevention, cure and care.

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