PREVENTION, DIAGNOSIS AND TREATMENT

Stoke in children is uncommon but not as rare as once thought. Risk of stroke in children is greatest in the first year of life, and peaks during the weeks before and immediately after birth. Stroke occurs in about one of every 4,000 live births. Risk of stroke from birth through age 18 is nearly 11 per 100,000 children per year. Stroke is one of the top 10 causes of death for children. About half of strokes in children are ischemic (caused by a blood clot) and half are hemorrhagic (bleeding in the brain). One in five children who has had a stroke will have another one.

HOW STROKE AFFECTS CHILDREN

Of children surviving stroke, 50% to 80% have permanent neurological deficits. Stroke is the leading cause of paralysis on one side of the body, the most common form of cerebral palsy in children born at term. Other long-term disabilities caused by infant stroke include:

• one-sided neglect (ignoring or forgetting their weaker side)
• difficulty with speech and language or trouble swallowing
• decreased field of vision and trouble with visual perception
• loss of emotional control and changes in mood
• problems with memory, judgment and problem-solving
• behavior or personality changes, improper language or actions

CAUSES OF CHILDHOOD STROKE

About half of children who have a stroke have had a previously identified risk factor. Sickle cell disease and congenital or acquired heart disease are the most common risk factors. Others include: head trauma; head and neck infections; inflammatory bowel disease; autoimmune disorders and dehydration. Maternal risk factors include history of infertility; infection in the fluid surrounding an unborn baby; premature rupture of membranes during pregnancy and pregnancy-related high blood pressure.

EXTENT OF THE PROBLEM

Stroke incidence in children has been stable for the last 10 years. Childhood death from stroke fell by 58% between 1979 and 1998, but the decline appears to be due to fewer fatalities after stroke, not a decrease in stroke incidence.

• About 3,000 U.S. children and young adults had a stroke in 2004.
• 20% to 40% of children die after a stroke.
• Boys have a nearly 1.3-fold higher risk for stroke than girls.
• African American children are at higher risk for stroke and for death from stroke, compared to Caucasian and Asian children.

PREVENTION, DIAGNOSIS AND TREATMENT

Stroke risk factors, symptoms, prevention efforts and treatment often differ in children and adults. However, speedy diagnosis, treatment, rehabilitation and therapy can minimize death and disability in both children and adults.

Delayed or misdiagnosis of stroke in children is common because they often have different symptoms. In newborns the first sign of stroke is often seizures in an arm or leg (which is much less common in adults). Some children with stroke appear normal at birth and later show signs of developmental delay.

Because an initial stroke is often the first sign of a problem in a child, preventing a first childhood stroke can be difficult. The American Stroke Association’s guidelines for managing stroke in children consequently focus on promptly recognizing and diagnosing the stroke and taking steps to reduce the odds of another stroke by addressing underlying risk factors.

Although the clot-busting drug tPA is key to treating adult ischemic stroke, its use is generally not recommended in young children, especially infants, because it has not been tested for safety and efficacy in children.

More research is needed to better understand the unique aspects of diagnosing and treating stroke in children.

COST FOR FAMILIES AND SOCIETY

The exact costs of childhood stroke are unknown at this time. One study found that the average cost of medical care in the first year after childhood stroke is nearly $43,000, and the healthcare needs of these children can last for decades. In another study, five-year healthcare costs were 15 times higher for children with stroke. Other familial and societal impacts include: altered family relationships and home life, lost income and productivity, and educational costs such as the need for special services and placement.

ADVOCATING FOR CHILDREN WITH STROKE

The health care reform law, the Affordable Care Act, includes provisions to address barriers faced by children with stroke, such as health insurers denying coverage of a pre-existing condition, lifetime insurance limits and under-insurance, which results in high out-of-pocket medical bills. When the law is fully implemented in 2014, it will help address many of these barriers.

We are working to advance public other policies that will allow children and adults with stroke to live longer, fuller lives. These policies include:

• More public funding for research on pediatric stroke
• Support for the CDC’s Birth Defects Centers to advance knowledge of the risk factors of pediatric stroke
• Support for activities to increase awareness of pediatric stroke among parents, families, caregivers and healthcare providers
• Monitoring the implementation of healthcare reform to ensure access to adequate, affordable insurance, including coverage for rehabilitation services.

The American Stroke Association is working to reduce risk, disability and death from stroke through research, education, fund raising and advocacy. We envision a world where stroke risk is reduced, rapid treatment is obtained and stroke is ultimately eliminated as a major health problem. We’re striving to change healthcare delivery to provide optimal care and maximum recovery for those who do have a stroke. We spend more money on stroke research and programs than any other organization except the federal government.
Our research funding overall

Each year, the American Heart Association spend about $110 million nationwide on all types of heart and stroke research. Much of that amount goes to basic research, so it’s hard to say which medical problems these studies will help answer. They can ultimately impact all age groups and types of vascular disease.

We do not pre-allocate a specific amount of money for any one research topic; our funds are awarded proportionally to the number of applications received. If more applications related to pediatric stroke are submitted, more will be funded.

Research funding for pediatric stroke

From 2000-2012, we funded at least 585 research studies* related to pediatric stroke at a total cost of $84 million.

*The exact number of studies funded on any specific topic is difficult to determine because applications are reviewed by one of 22 study groups according to the topic the applicant designates. Most applications related to pediatric stroke are reviewed by the Brain study group, but others aren’t “counted” as stroke because they’re reviewed by study groups such as Thrombosis (sickle cell disease), Imaging (imaging the brain in stroke) Molecular Biology (genetics) or Cardiovascular Development (cerebral vasculopathies in children).

Advocacy for research funding and better health care for children

We fight childhood stroke and heart disease through lobbying efforts in Washington, DC., where our grassroots volunteers annually urge their legislators to increase federal funding for research on vascular diseases, including pediatric stroke.

We also support legislation that make it easier for children with stroke, heart disease and/or other conditions to get health insurance coverage and address other concerns they face.

Using research results to diagnose, treat and prevent pediatric stroke

The 2,500+ members of our Stroke Council include neurologists, neurosurgeons, other pediatric healthcare providers and scientists working in the area of stroke. Through this council, we fund the publication of scientific papers such as Management of Stroke in Infants and Children, a comprehensive overview of childhood stroke with recommendations for physicians on optimal diagnosis and treatment.

Our Cardiovascular Disease in the Young Council and our Stroke Council are working on a scientific paper on neurodevelopmental outcomes in congenital heart disease. Part of this paper will deal with brain injury or stroke related to surgery for congenital heart disease.

Each February, we host an International Stroke Conference for health professionals and researchers in the fields of cerebrovascular disease and stroke, including pediatric stroke.

Educating and supporting the families of children with stroke

Visit StrokeAssociation.org and search on “about stroke” and then “stroke in children” to find:

• helpful medical information, including a downloadable fact sheet and a pamphlet on sickle cell disease and stroke.
• article on the psychological issues families face after pediatric stroke.
• discussion boards for stroke survivors and family caregivers.
• links to the Web sites of support groups and other organizations:
  - Children’s Hemiplegia and Stroke Association
  - Hemi-Kids
  - Childhood Stroke & Hemiplegia Connections of Illinois
  - Pediatric Stroke Network
  - Sickle Cell Disease Association of America

Call our toll-free Stroke Warmline at 1-888-4STROKE to talk with stroke survivors and caregivers trained to answer your questions and offer support, to learn about stroke support groups in your area and to receive our free Stroke Connection magazine.

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