

A child's race against a deadly disease

Written by Marian Wright Edelman, President of the Children's Defense Fund
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Two-year-old Case Hogan is a bright, happy child with a sunshine smile who is in a desperate race against a degenerative disease that is causing the gradual deterioration of his body. A medical diagnosis revealed that Case has Hunters Syndrome, also known as MPS II. This rare, incurable genetic disorder interferes with the body's process of breaking down and recycling molecules known as glycosaminoglycans or GAGs that build up and are stored in the joints, organs, and brain.

Hunters Syndrome sufferers experience a progressive physical decline and, in most cases, profound mental handicaps by late childhood. Hunters Syndrome also often involves cardiac damage, skeletal abnormalities, respiratory impairment, and other difficulties. Case already suffers from developmental delays, impaired speech, and stiffening joints that often cause him to lose balance and fall. Children with this condition have an average life span of about 15 years.

Like more and more families in America, the Hogans are confronted with paying health care costs for a sick child that are rapidly escalating beyond their reach. Case receives six-hour-long intravenous enzyme replacement treatments every Thursday, which cost \$7,500 each; that's \$390,000 a year. Aside from doctors' visits, he needs about 250 therapy sessions a year; 100 sessions of physical therapy, 100 of speech therapy, and 50 of occupational therapy. The therapy keeps the joints in his knees, shoulders and wrists loose and slows the progress of the disorder while helping Case maintain and develop his motor skills and dexterity. The medical treatment and therapy have been invaluable. They've changed Case from a listless child to an energetic, lively boy who actively engages with other children and is becoming more independent.

His progress comes at a price, however. Fighting this degenerative disorder has placed Case's parents in great financial peril. His mother, Melissa, is a self-employed consultant and his father, Christopher, is a small-business employee. They have insurance through Christopher's employer. The insurance policy has a \$5,000 annual deductible, and after that, it pays 80 percent of Case's medical expenses up to \$8,000 (and 100 percent after that). But the policy only covers 60 of the required 250 therapy sessions. And the Hogans, who live near Nashville, TN, have had to pay tens of thousands of dollars for gas, food, and travel to out-of-town specialists and for child care for their two other children, causing the family to slip deeper into debt.

Presently, Case is eligible for supplementary financial assistance under the early intervention provisions of the Individuals with Disabilities Education Act (IDEA). The IDEA assistance has been a great benefit to the family, but Case is only eligible for the program until he turns three on March 12, 2010, a cut-off date that weighs heavily on his parents. The increasing costs of health care are one of the main reasons more than 8 million children have no health insurance. It's an appalling state of affairs when even two-income families like the Hogans have trouble cobbling together enough money to ensure their children receive all the medically necessary care they require. Too many middle-class families have too few financial options to help pay for their children's medical bills—they earn too much to be eligible for the Children's Health Insurance Program (CHIP)—which Congress is about to abolish—but not enough to buy private insurance. And even when they buy private insurance, it rarely covers all their child's

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medical costs. Parents should never be in the position where they just can't afford their child's health care and face family bankruptcy.

Why are millions of children in America still uninsured or underinsured, and still more are on the verge of losing what health coverage they do have? The answers cannot be: Because your parents make too much money or not enough money; or, You could get help if you lived in another state; or, It's too complicated to treat what's wrong with you. Nor should the answer be—as it is for two-thirds of the children who are uninsured today but are eligible for CHIP or Medicaid—You must face insurmountable bureaucratic barriers to receive coverage.

That's why Congress must pass a health care reform bill this year that guarantees children the comprehensive health and mental health care they need—care that is affordable and simple to get and keep. Under the current health reform proposals, millions of children could face higher costs for health coverage and have fewer benefits. It would be a tragedy if millions of children end up worse rather than better off after health care has been "reformed."

Marian Wright Edelman, whose new book is *The Sea Is So Wide And My Boat Is So Small: Charting a Course for the Next Generation*, is president of the Children's Defense Fund. For more information about the Children's Defense Fund, go to <http://www.childrensdefense.org/>.