

OPINION/ FORUM

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A Child's Race Against a Deadly Disease



Marian Wright Edelman
 Guest Columnist

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 — \$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, Tennessee, 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 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 is president of the Children's Defense Fund. For more information about the Children's Defense Fund, go to <http://www.childrensdefense.org>.

Feeding The Hungry Should be a SNAP



N. Joyce Payne
 Guest Columnist

AARP believes that no one — of any age — should go hungry. Yet many older people must make the devastating choice to either pay for their medications or their groceries.

The struggling economy has resulted in an increasing number of families left to wonder where their next meal will come from. One result is a dramatic rise in the number of individuals and families visiting food banks each week — and the associated stress on food banks to meet the new demand. The need for convenient and meaningful food assistance programs is critical.

Of particular interest to the AARP Foundation is the impact this has on older

Americans. There are an estimated 3.6 million people aged 65+ who live in poverty in the United States, according to a 2007 Census Bureau report, and millions of others who may qualify for Federal assistance programs like SNAP (formerly known as the Food Stamp Program), which can alleviate much of the worry and anxiety associated with paying for groceries each month.

For older adults with limited incomes, especially those who live alone, food assistance programs can help improve overall health. The healthier people are, the more likely they are to take care of their daily needs and live independently.

Unfortunately, only 34 percent of eligible older Americans receive food assistance — leaving millions of dollars untouched. The most common reason people do not receive SNAP benefits is that they don't realize they may be eligible. But recent program enhancements mean that more

people may be eligible to apply.

The old routine of standing in the grocery store line while people watch recipients tear food stamp coupons from a book is no more. Once a person's application is approved, benefits automatically get loaded on a debit-style card, which is accepted at most grocery stores, and there are no hidden fees. The average monthly benefit for older Americans is \$72 for individuals and \$90 per household.

In addition to supporting healthier food options, SNAP also contributes economically to communities. The USDA says that every \$5 in new SNAP benefits generates nearly twice as much (\$9.20) in total community spending.

SNAP can be a life-changing value for individuals, families and communities, but only if the millions of qualified individuals apply for the benefit. Currently, only 9 percent of SNAP recipients are age 60+, however, a much

larger number of the elderly population is potentially eligible.

And though SNAP is the federal name for the program, state programs may use SNAP or another program name to refer to this food assistance benefit. Individuals can find more information about how to apply for SNAP and receive information about other public benefits via AARP's Benefits QuickLINK Web site at www.aarp.org/snap.

In these tough economic times, AARP remains staunchly committed to connecting those in need with information and access to programs, which offer real relief and assistance in navigating their basic life needs. We encourage all older Americans and those who care for them, to learn more about SNAP and apply if they're eligible.

N. Joyce Payne, Ed.D., of Washington, D.C., is a member of the AARP Board of Directors and the chair of the AARP Foundation Board.

Black Political Power is Exaggerated



George Curry
 Guest Columnist

The annual Self-Congratulation Political Weekend in Washington, D.C., formally known as the Congressional Black Caucus Foundation's Annual Legislative Conference and informally known as CBC Weekend, is over. But after a series of feel-good panel discussions, with members of Congress darting in and out of rooms, and even a speech by President Barack Obama — with requisite non-stop partying thrown in for good measure — the true needs of most African Americans are no closer to becoming a reality than before Black political junkies descended on the nation's capital for the gathering.

To be fair, there is much to celebrate. The CBC has grown from 13 members when it was established in 1971 to 42 numbers, not counting "Dollar Bill" Jefferson, who is on his way to a federal prison. House Whip Jim Clyburn (D-S.C.) is the third-ranking Democrat, four African Americans chair important House committees and 17 head subcommittees, and a former CBC member is now president of the United States.

However, before you start signing "Happy Days Are Here Again," let's put things in perspective. When you add one African-American senator to the 42 House members, including two who can't vote except in committee, that's only 43 out of 535 members of the House and Senate, which is 8 percent.

It sounds good to say that the president is a former member of the CBC, though he wasn't all that active and never took on a leadership role in the caucus. But the sad truth is that for many reasons, including his need to be president of "all people," Barack



House Whip Jim Clyburn.

Obama is much more moderate than most members of the liberal Congressional Black Caucus. Consequently, he is more willing to make compromises that may, in the end, not serve the best interest of most African Americans. That does not mean he isn't concerned about issues that are paramount to Blacks. Instead, that simply means that he is a politician doing what politicians do best — compromising.

The combination of a president determined to govern from the center of the political spectrum and limited African-American representation in Congress can sometimes spell bad news for Blacks. The debate over whether the public option will be part of health care legislation making its way through Congress is a case in point.

Of nearly 50 million Americans without health insurance, most are people of color. Therefore, in some instances, this is a matter of life and death.

Candidate Barack Obama was clear in his belief that in order to drive down medical costs, the federal government

needed to provide a public option, similar to Medicare, that would provide competition that would force the insurance companies to offer more reasonably priced premiums, discontinue turning away those with pre-existing conditions and removing caps on how much coverage they will provide those in need.

But President Obama is now singing a different tune. While reiterating his preference for a public option, he has scolded fellow Democrats, urging them to be open to other alternatives. In his recent speech before a joint session of Congress, President Obama said that under his plan, it is acceptable that the public option be extended to small businesses and people without any coverage, a figure he estimated to be less than 5 percent.

To bring back an old TV commercial and refrain from an earlier presidential campaign: Where's the beef?

Extending the public option to less than 5 percent of the population while leaving more than 95 percent of the public to rely on the whim

of private insurers is not my idea of change we can believe in.

NAACP President Benjamin Jealous pointed out the hypocrisy of conservatives who normally tout the advantages of a free market yet favor non-competition when it comes to health care. They object to a public option in which the federal government would infuse more competition into the \$2.5 trillion a year health care industry.

According to statistics compiled by the Kaiser Family Foundation, insurance premiums have risen each year between 5 percent and 14 percent. Over that same period, wages have increased only 2 percent to 4 percent, meaning Americans must use more of their income for insurance.

"What a public option is all about is trying to give Americans the very essence of free market capitalism, choice and competition," Jealous told reporters.

Both the CBC and President Obama are very good with words. The CBC has issued statements arguing that the public option should be incorporated into any health care reform proposal that becomes law.

In his speech to the CBC Saturday night, President Obama was eloquent as usual. He said, "This economic crisis has made the problem in the communities of color much worse." He said the crisis has hit those groups "with particular ferocity."

But being sensitive and using the right language is no substitute for direct action. Having an African-American president and Blacks holding a record number of leadership positions in Congress is meaningless if, in the end, they can't bring about real change for those who need it the most.

George E. Curry, former editor-in-chief of *Emerge* magazine and the NNPA News Service, is a keynote speaker, moderator, and media coach. He can be reached through his Web site, www.georgecurry.com.