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When Not Knowing a Celebrity Could Prove Fatal

By ADAM COHEN
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When Loren Eng, a briskly efficient Stanford Business School graduate, lobbies Congress for research funds for the disease that is crippling her 2-year-old daughter, she takes along almost everything she needs to make an airtight case.

She has figures showing that the disease, spinal muscular atrophy, is badly underfinanced compared with similar diseases. She has doctors saying that with enough research money, a treatment may be at hand. And she has a photo of cute-as-a-button Arya, who is getting weaker by the day.

Members of Congress listen sympathetically, then usually say the same thing: the best thing Ms. Eng can do is to find a celebrity.

Celebrities are all-purpose experts these days. Sean Penn is an authority on Iraq, and Congress takes testimony from boy-band singers. In medical research, celebrities can strongly influence budget decisions, helping their favorite diseases, but at the expense of equally worthy, less well-connected, ones.

It's no secret that stars have long been a potent force in attracting private money for disease research — especially since 1966, when Jerry Lewis held his first Labor Day muscular dystrophy telethon (a cause that includes diseases like spinal muscular atrophy). What is less known is how much stars can affect government agencies like the National Institutes of Health, which sits on a budget of more than \$20 billion.

Since Christopher Reeve started lobbying for research on spinal cord injuries, and Michael J. Fox gave Parkinson's a famous face, government financing for both has soared. After Mr. Fox told the Senate of his struggles with Parkinson's — and posed for photos with star-struck senators — Congress urged the N.I.H. to ramp up its Parkinson's work. The upshot has been as much as \$200 million more in research grants over two or three years, says Robin Elliott, executive director of the Parkinson's Disease Foundation. "You'll have no one disputing this on any side," Mr. Elliott said. "Celebrity counts."

Which is precisely Ms. Eng's problem. The severe forms of spinal muscular atrophy — which cause increasing muscle weakness, and often death, in children — cannot compete. The disease's victims often die in infancy, leaving it without celebrity sufferers. Parents are usually too overburdened to lobby for research when their children are sick, and too upset if they die.

Ms. Eng figured that her best shot with a celebrity was Robert De Niro. He did a public service announcement to help the disease's victims years ago, and she happens to live in his Upper West Side building. She left a note for him with the doorman, asking for help. Within minutes, she reported, the note had been refused. She re-sent the note by mail, she said, and never got a response.

Ms. Eng has run into high-priced P.R. agents who promise to use their Hollywood connections to rope in a star. And she has learned the disease world's dirty secret: some celebrities demand to be paid, either by drug companies or by patient groups. The Wall Street Journal reported that Rob Lowe was receiving as much as \$1 million from a drug company for talking publicly about a treatment for infections caused by chemotherapy.

There is something wrong with a system that favors sick people who have access to sitcom stars over those who don't. Congress and the N.I.H should make the medical bureaucracy more open to patient groups, and they should do a better job of setting priorities.

The decisive factor in allocating funds should be "social cost": how many people get a disease, how young it strikes, and how close a treatment or cure is. The government already does this. But as a National Academy of Sciences study found a few years ago — and as the spinal muscular atrophy experience demonstrates — the process needs work.

Based on its human toll, spinal muscular atrophy should fare better. It has roughly the same number of victims as amyotrophic lateral sclerosis, called A.L.S. or Lou Gehrig's disease. But while A.L.S., which has strong celebrity ties — in addition to the Yankee great, the physicist Stephen Hawking is a famous sufferer — receives \$30 million in N.I.H. research funds a year, spinal muscular atrophy gets just \$5 million.

Another crucial factor, along with the number of victims, is the prospects for a cure or treatment, and by this measure, too, spinal muscular atrophy is getting a raw deal. Researchers believe it is one of the neurological diseases closest to a breakthrough. If it were financed at the level of A.L.S., they say, a treatment could be just a few years away.

There is talk on Capitol Hill that celebrities may be losing their luster. Senator George Voinovich of Ohio caused a stir by boycotting testimony by the Backstreet Boy Kevin Richardson on the impact of a specialized form of coal mining on the environment. The senator called it "a joke."

Still, Ms. Eng's business background tells her that branding matters, even for diseases, and that spinal muscular atrophy does not trip off anyone's tongue. She recently met with a sympathetic congresswoman who kept mentioning A.L.S. in her responses. "I had to tell her, 'A.L.S. is a very serious disease,'" Ms. Eng recalled, "but we're here today to talk about spinal muscular atrophy.'"

Ms. Eng recently got some good news on the celebrity front. Howie Long, the TV sports commentator and onetime Oakland Raider, is a spokesman for a related charity and may

sign on. And she has learned that she has a friend who has a friend who is good friends with Mr. De Niro, so Ms. Eng might get him in the end. The real problem, of course, is not that one disease does not have a movie star vouching for it. It's that we have a system in which that makes such a difference.