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Fighting for the option to care for Huntington's disease patients at home

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At Risk for Huntington's Disease

HD is a genetically caused brain disorder that causes uncontrollable bodily movements and robs people's ability to walk, talk, eat, and think. The final result is a slow, ugly death. Children of parents with HD have a 50-50 chance of inheriting the disease. There is no cure or treatment.

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TUESDAY, JUNE 11, 2013

Fighting for the option to care for Huntington's disease patients at home

With the [woefully inadequate care](#) that some nursing homes have provided to Huntington's disease patients, a number of HD families have fought hard to create alternatives.

Few embody the fight for quality care better than Raima and Mike Fernald of Saco, Maine. They have *twice* advocated for bills in their state legislature to improve the predicament of Raima's two HD-stricken sons, John Irving III and Chris Irving, fathered by her first, HD-affected husband, John Irving, Jr.

Both sons died in Raima's arms – Chris in March 2012 at 37 and John last month at 39 – after a long and painful struggle by the Fernalds to overcome bureaucratic inertia and bring them to the couple's home in Saco, a coastal town south of Portland.

“That was my whole goal, having them come home,” said Raima, 55, whom I interviewed at length twice last week. “I did not want them to die in a strange place or different place. Their father died in a hospital. Nobody really knew where he was. I found out only a few days after he died because a newspaper reporter was doing an article and was compelled to find me. He died alone and I could not let that happen to my boys.”

Though HD dramatically shortened their lives, John and Chris helped establish an important legislative legacy in Maine.

In 2007, together with other advocates, the Fernalds successfully pushed for passage of *An Act To Prevent Inappropriate Transfers of Residents of Nursing Facilities*.

Even as they mourn their double loss, the Fernalds are now advocating for a pending bill, LD 488, *An Act to Improve Access to Home-based and Community-based Care in the MaineCare Program*. (MaineCare is the state's Medicaid program.)

“We're very supportive of the bill,” said Louise Vetter, the CEO of the [Huntington's Disease Society of America](#), noting that the society reviewed the legislation “to make sure it was strong” and “doesn't have loopholes that could negatively affect families down the line.”

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According to Vetter, LD 488 is the “best current example” of advocacy to facilitate home-based care for HD patients. The bill is “unique in terms of the issues and the involvement of the Maine Affiliate” of HDSA.

“There is evidence that home-based care is more efficient in overall cost savings and effective quality of life,” Vetter noted.

However, she added that the country is currently in a “wait and see” mode about the future of home-based care because the [Patient Protection and Affordable Care Act](#) (Obamacare) has yet to take full effect. The act supports home-based care, but lacks clarity on implementation, which will take place at the state level, she said.



Raima and Mike Fernald (family photo)

Exorbitant but inadequate care

From about 2003 to 2007, Chris spent time in four different institutions in another state, Raima said.

“They had no place in Maine to care for him, because Chris was considered to be a high-risk liability because of trying to kill himself,” Raima explained. “Because of his behaviors, no one wanted to take him.”

Raima said the care was inadequate in all of these institutions. She recalled her very negative experience at the last one, where Chris spent the longest period, about 16 months. She said she observed blood smears on the bathroom wall, which she attributed to the apparent lack of dental care; bursitis on Chris’s knee; ripped clothing on Chris; and food on the floor.

“I had to go in and shave him,” she said. “I had to go in and cut his hair. I had to do all of that. He looked horrible. I even have pictures. The hygiene on him was not good.”

“We heard that the cost of his care was more than \$300,000 a year, because he was shipped out of state. That was told to us by the Department of Human Services. That’s why they finally stood up and listened to us. They knew they were spending too much money. The care was not being overseen for that kind of money!”

According to Raima, the Maine Department of Health and Human Services claimed that, despite the large sum spent for Chris, it could not afford to send anybody to evaluate his care.

“That’s sheer stupidity,” she said, adding that she kept detailed notes on her sons’ care, including the information about the out-of-state costs.

Attorney Jack Comart, the litigation director for the non-profit legal aid provider Maine Equal Justice Partners, confirmed the high cost of the out-of-state care. In his recollection, the annual cost for Chris exceeded \$350,000. He said that the cost per individual in the Maine group care home later occupied by Chris and John was \$140,000 a year. Once they came home, the costs dropped even more – to just \$52,000 per person, according to Comart, who has assisted the Fernalds and advocated for the legislative bills

With the passage of the *Inappropriate Transfers* bill, some 25-30 outsourced Maine patients with various conditions returned to the state, where they could be closer to their families, Raima said.

Chris entered a group home in 2007, and in 2008 John joined him.

Trying a group home

Located in Saco, the group home represented a significant improvement for Chris. John also moved there. Caregivers trained for this specific assignment watched over them 24/7.

“They were the only two clients in that group home,” Raima explained. “This particular group home was put together from the bill that was passed.”



Above and below, Chris Irving (left) and John Irving III (family photos)



Even so, problems developed.

“Some of the care was okay, but some of the things were ridiculous,” said Raima. “Things did happen there, too, that told me that they were not paying attention.”

At 5 one morning, even with two caregivers present, Chris escaped from the facility. Because he was “falling all over” and his “shoes

were half on,” a woman thought he was drunk and called the police, who took him to the hospital, where he spent several days before returning to the home, Raima recalled. In late 2010, John became severely dehydrated and nearly died.

A bureaucratic bias against the family home

After several years in the group facility, and with the worsening of the men’s symptoms, the Fernalds became convinced that bringing them home was the only way to provide proper care and a life of dignity.

However, in reviewing patient needs, the Maine Department of Health and Human Services determined that the state – despite having spent much more money for the group home and for the out-of-state facilities – would pay for only a limited number of caregiver hours at the family home.

In 2007, for instance, Chris would have qualified for only 15-20 hours per week, making it virtually impossible for him stay at home, because Raima had a job, usually working as a secretary or bookkeeper. With so few home care hours, the family had opted for the group home.

According to Comart, the systemic bias against the family home stems in part from the state’s goal of protecting patients from abuse at home and assuring that they receive professional care.

“They assess them differently if they come home or if they’re in a facility,” said Raima. “That’s wrong. Their needs don’t change.”

In late 2010, with a reevaluation of their more serious medical condition, the men qualified for 59 caregiver hours each.

“That was at least something to work with,” Raima said. “But I’d still be doing a lot of it myself. I quit my job to take care of them. I didn’t have to. But I did because at this point, with them being in facilities and group homes, I wanted to be the one to oversee the care.”

On February 27, 2011, John and Chris came to live in the Fernalds’ basement, which Mike had turned into a bedroom using several thousands of dollars in assistance from a charitable organization, Motivating Miles.

Raima, Mike, and/or caregivers attended to the boys 24/7.



Raima shaving Chris at the Fernald home (family photo)

“I actually lived there for two years,” Raima said. “Mike lived upstairs alone. I slept on the couch. John and Chris had their own beds. A caregiver would come every day. Each one had a caregiver all day long.”

Earning \$10 an hour, Raima received money for 40 of the 118 total hours allotted for Chris and John. Professional caregivers covered the other 78 hours, paid at the same rate.

To qualify as a paid caregiver, Raima paid \$250 to take a 60-hour class that certified her as a personal service specialist and became an employee of the same home healthcare company that provided the other caregivers, she said.

That still left 50 hours – two full days – of uncovered care, which, of course, fell back on the family.

“I still had to be here 24/7,” said Raima. “There always had to be two while they were here. After Chris passed away, there was only 59 hours left. I could do 40, but got only 19 hours of outside help.”

Advocating for home-based care

With Mike also helping care for the two brothers, the Fernalds conceived and advocated for LD 488, the *Home-based and Community-based Care* act.

“We couldn’t deal with the fact that John and Chris would get so many hours in a group home, but at home fewer hours,” Raima said. “We were very unhappy with that the whole time they were home. We didn’t have enough help.”

Agitated and irregular sleep is a symptom of HD, so care became especially difficult when both men walked around their room at night.

“We fought to get more hours,” Raima said.

As amended, and if passed and signed by the governor, LD 488 would initiate a program to benefit 25 Maine patients, who would receive for home care up to 25 percent more than the maximum allowed for home care, which, as noted above, is currently \$52,000. With the supplement, the total for home care could be as much as \$63,000.



In 2011, the local newspaper featured the family's fight against HD (family photo).

The bill states that additional funds will become available as long as Maine's Department of Health and Human Services “determines that such additional services are medically necessary, are likely to delay or prevent the institutionalization of the person and are not likely to result in the cost of services under the waiver for that person exceeding the estimated cost of comparable services in a nursing facility for that person.”

For the program in fiscal year 2013-2014, the bill projects \$93,265 in spending from the state's general fund and \$150,916 from its federal expenditures fund.

Because part of the funding is from the federal Medicaid program, the state would have to obtain approval from the federal government, said attorney Comart.

Under federal Social Security legislation passed in 1983, any state can apply to expand home-based care.

Testimony from the HD community

On March 7, 2013, Raima, Comart, and ten other individuals offered personal or written testimony in support of the bill before the Committee on Health and Human Services.

“Not all people will want to, or be able to care for their loved ones at home, just as not all families should be allowed to, but the ones that can should receive more help to do so,” Raima stated. “Right now the State spends an enormous amount of money to send people out of State and in State nursing homes at a considerably higher cost that they would spend if they provided more fairness and flexibility in the current MaineCare program to allow willing family members to care for their loved ones. Many people will not do so because they cannot financially do so. The current program is unfair to consumers and their families, and it creates an unfair incentive to put loved ones in facilities, group homes, nursing homes, and at a greater cost to the State.”

“No one can care for a person with HD at home without a huge amount of financial, professional, and physical support,” stated Nancy Patterson, 55, the chairperson of the HDSA Maine Affiliate. LD 488, she added, would provide an affordable option for families to keep their loved ones at home and “alleviate the financial, social, and emotional strain” caused by HD.

Assessing the bill and its chances

The bill unanimously passed both the Maine House and Senate. However, because the bill would require increased state spending, it must pass muster at a joint House-Senate appropriations committee before going to Republican Governor Paul LePage.

Comart, however, is skeptical about the chances for the bill’s passage.

“I’m not confident in the end they’ll adopt it,” he said. “It’s sort of a shame. It’s not a lot of money to fund it... We have a big budget deficit. We have a Tea Party governor. He cut taxes mostly for the wealthy last year. That created a big budget deficit. That’s being funded by lots of cuts in programs.”

LePage has vetoed many bills, including some that don’t include increased spending, Comart added. LePage has not yet stated a position regarding LD 488.

Like Vetter, Comart noted that LD 488 resonates with a national trend towards home- and community-based care stimulated by the passage of Obamacare. This trend goes against the “bias” in the Medicaid program in favor of putting people in institutions, he added.

“It’s been an issue for a while,” Comart said. “People generally don’t want to go in nursing homes. They want to stay in their home.”

However, even though LD 488 and home-based care in general represent savings in the long run, the fiscal stress of both the federal and state governments makes it “really challenging” to move in that direction, Vetter said.

In Maine, which has the nation’s tightest nursing home eligibility standards, there are waiting lists for some nursing homes, Comart said. To the extent people move into community or home care, the state would not save money if beds are filled off a waiting list, he explained.

Engaging in the public process

Comart called for Maine families to support the bill.

“Families need to get as involved as they can in this public process,” he said. “I know it’s hard to go to legislative hearings, but it does make a difference for legislators to see and hear from families facing these problems.”

Comart pointed to the example of the Fernalds, who have raised HD awareness in other ways, including the publication of a children’s story about the disease.



Above, Mike (left) and actor Chuck Norris during a Mike Huckabee presidential campaign event in 2008. Below, Mike in a clown costume. Mike advocates for HD whenever he can. (family photos)



“They’ve been great advocates,” Comart said. “They’ve been out there publicly. They come to the public hearings. They send out e-mails about things. They met with the governor. They’ve done everything on top of caring for their two sons. It’s pretty amazing.”

“People need to not take no for an answer,” Raima said. “If you’re talking to one person and not getting anywhere, go see someone else.”

She added: “We all have to step up to the plate and fight for our HD loved ones.”

Posted by [Gene Veritas](#) at 2:53 PM



Labels: [advocacy](#) , [caregiver](#) , [community-based care](#) , [group home](#) , [HDSA](#) , [home-based care](#) , [Huntington's disease](#) , [Maine State Legislature](#) , [Medicaid](#) , [nursing home](#) , [Obamacare](#)

3 comments:

 **Wilderness Kids said...**

Thank you so much for the Blog Gene <3

[2:33 AM, June 12, 2013](#)

 **Wilderness kids of Maine said...**

Happy Fathers day June 16th Still have time to ship your Fathers day Maple Syrup Gift <3

Remember Friends this helps us to cover the cost of Raising Awareness and passing Bills like LD 339 Resolve 61 & Bill LD 488 for hd families.. We don't ask for donations Just buying the Kids products will go a long way with their efforts for our love

ones with hd
With Love
The Wilderness Kids of Maine >3

[2:57 AM, June 13, 2013](#)



Unknown said...

Still Waiting Mr. Paul LePage for LD 488 to be passed and save the state some more Tax Payers money... If the Bill does not pass then We The good People of Maine will assume you don't mind wasting Tax Dollars and Pay 3 times as much for Poor Facility Care ♥ :(

Hello People of Maine ... Time to Wake up ♥ :(can anyone else see what is taking place here with the state continuing to waste Tax dollars when there is a simple solution for this lack in the system these boys have all ready saved you millions a year in out sourced money ♥

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[3:51 AM, June 21, 2013](#)

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