



# The COFAR VOICE

The Official Newsletter of the Massachusetts Coalition of Families and Advocates for the Retarded, Inc.

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**DMR, ArcGB combine to push 91-year-old woman out of Fernald home, page 5**



Barbara, Eric, and Frank Voss at Seven Hills Picnic

## In the Courts:

### What Does US District Court Find Wrong With This Picture? Groton 43 Fight "Rolland" Evictions

Rolland v. Patrick began ten years ago as a case to move elderly people with MR/DD out of nursing homes that did not meet their individual needs, and back into treatment. But, without consulting the people involved or their families, DMR and the usual cast of tax-supported class-action lawyers have now made a "settlement" by which DMR is *required* to move 640 people out of nursing facilities and into community residential placements over the next four years. There is no way to opt-out, and the court on May 22 rejected the objection of 43 severely disabled individuals at Seven Hills Pediatric Center in Groton, more than half the residents there.

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## At The State House: Stroll for Better Budget, Laws

BOSTON – They were parents and brothers and sisters, in-laws and cousins, guardians and just friends. They came from all over the state April 12, and carried a message to every state representative and senator. The results came back quickly as the House Ways and Means

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Rep. Todd M. Smola (R. Palmer) meets with Dick Gowan of the Advocacy Network during the State House stroll April 10. Rep. Smola, whose district includes the Monson Developmental Center, later co-sponsored a floor amendment to restore funding for the "state schools."

### **Also In This Issue:**

**COFAR advocacy helps jail alleged abuser**

**Rolland Settlement Shows Need for HR3995**

**Editorial: Reform Corporate Guardianships**

**COFAR, VOR, file Ricci appeal amicus brief**

## At The State House

### Budget, Continued from Page 1

Committee, despite pessimistic revenue predictions, reported out a budget that partially restored cuts across the DMR budget, removing pet earmarks and adding funds for two of COFAR's top priorities: the six developmental centers and the state-operated group homes that serve the most disabled of the disabled.

House members' floor amendments, including several suggested by COFAR later restored funding for the Turning-22 budget where cutbacks threatened to leave 600 families with no services at all for six months, and moved the facilities and state-ops line items closer to DMR's original requests. Event organizer and COFAR Vice President Thomas Frain said, "The safety-net budgets were taken very seriously by the House. At the State House Stroll, COFAR members put a human face on the necessity to preserve supports for the most disabled people served by the Commonwealth."

The State Senate, however, cut back most DMR budgets even farther than the governor's initial requests. And floor amendments, again including some influenced by COFAR, all failed to pass. This sets up a major debate behind the closed doors of the Conference Committee early this month. Advocates will also be watching the governor's line-item vetoes more carefully in a year of pessimistic revenue forecasts.

"The Senate did add enough money for some additional staff for the Disabled Persons Protection Commission," added Frain. "This was another 'stroll' priority, and one that other advocates do not actively support, so if we can get the Senate version of that into the final budget, it's another strand of the safety net." The Senate budget also had an outside section renaming DMR as the Department of Developmental Services in June, 2009. The renaming language does not affect definitions of eligibility.

The stroll materials also included talking points on non-economic bills, an argument for more neutral budget language about facility closings, and a description of who COFAR families are. To read and download the stroll materials, see the COFAR website publications page, <http://www.cofar.org/page6.html>

Track the state budget process on the COFAR blog, <http://www.cofar-mass.org/cblog/>.

### *Currie Barss, 87*

COFAR founding member, Currie Barss, of Bolton passed away February 27. She was an active board member and advocate for many other families until failing health made it too difficult for her to participate. Although she was an avid gardener and published garden writer, Currie's family generously suggested donations to COFAR instead of flowers.

### Editorial

## Corporate Guardianships Must Be Reformed!

One clear fact emerged from the February 27 hearing in Judge Tauro's courtroom (See, "91-Year-Old Woman," page 5) -- The system of corporate guardianship needs a major overhaul.

Testimony from the head of the ARC of Greater Boston was that corporate guardians are contracted for 20 hours service per year, at \$50 per hour. ArcGB does this by dividing the work among case managers. Some attorneys have made a specialty of DMR guardianships, and may have 50 or 100 or more wards at a time.

Every family guardian knows how many times we have the only person in a crisis who knows all the complications, all the meds, all the options, all the staff, and what works and doesn't work for our loved ones. And if we did a quick survey on the hours per year required to prevent medication errors, explain our loved ones to new staff and professionals, monitor injuries for possible abuse, support the many transitions of decentralized system -- would that be 20 hours per year, or more than 200? Maybe corporate guardianship as it is would work if DMR service coordinators went back from caseloads in the 50s to caseloads in the 20s. But it cannot be made to work in the present decentralized and privatized system.

DMR doesn't mind that corporate guardians aren't effective advocates, and can be pressured in specific cases. We do mind that system, and will press for real reform.

## In the Courts

### Rolland, Continued from Page 1

Among the Groton Plaintiffs is Laura Putterman, a 33-year-old woman, resident for 24 years, tube-fed, functionally blind, unable to speak or understand speech, or perform any voluntary bodily function. Another resident, D.B., has cystic fibrosis, cerebral palsy, and diabetes. According to his parents, “He cannot walk,



talk, or feed himself. He is unable to control any member of his body – arms, hands, head, legs, feet, etc.”

But because the court has agreed to settlement by-the-numbers, the individual needs or treatment plans of these individuals don’t matter. The “Groton Plaintiffs” and their families, backed by COFAR are exploring other legal avenues and/or a public information campaign to save their loved ones from being moved against their will from a safe and effective program.

### **One Family’s Story**

You wouldn’t know it from his wonderful smile, but Eric Voss, 27, has had a hard time in life. Eric was born with cerebral palsy such that he has never been able to control any part of his body, has never spoken, has to be fed by a tube, and has mental retardation and a long list of medical complications. Ten years ago, after surgery for a damaged hip at Children’s Hospital, his sodium blood level went so high he was in a coma and on life support for weeks, suffering further brain damage. His sodium levels still have to be monitored closely.

Eric’s parents checked out pediatric nursing homes across Massachusetts, and felt lucky when he was accepted at Seven Hills Pediatric Center in Groton. Not only could the center handle Eric’s complex medical needs with round-the-clock nursing services, but it also has real educational, social, and entertainment opportunities.(The center has been ranked among the top four percent of all nursing homes nationally.) They also thought they had found a permanent home for Eric, since Seven Hills’ brochure said, “Children at Seven Hills Pediatric Center enter prior to their 22nd birthday and traditionally remain throughout their lifetime.” In the nearly seven years Eric has lived at Seven Hills, the foundation has made two multi-million dollar expansions, so buildings are as modern and progressive as the treatment offered.

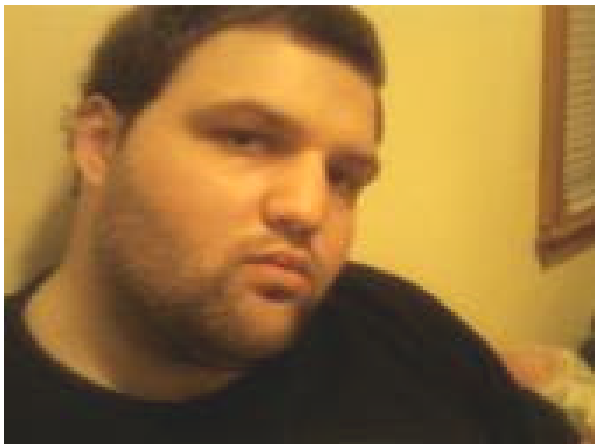
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“The language [in the Proposed Settlement Agreement] is insulting to all of us who have struggled to provide the best possible care for our children under terribly difficult circumstances. The notion seems to be that we need to be ‘educated’ about the benefits of community placements and that if only we open our minds to the possibilities, we will recognize the wisdom of professionals and see the light.” – Voss Affidavit

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And Eric likes it there. He can’t say so in words, but his father explains, “We take him out to family events and outings [in a conversion van with lift for his wheelchair], and he likes that, but when we get back to Seven Hills he’s so smiling and happy, he feels at home.”





Alleged rapist and stalker Buddy E. Smith

## *COFAR ADVOCACY HELPS TO JAIL ABUSER*

It took 28 months from when a young man with MR/DD and his family first went to Fall River Police. But the leading suspect in a terrorizing series of gang-rapes, assaults, and stalking incidents is finally behind bars as of May 6. Bail for Buddy Edward Smith, 22, of Fall River was formerly revoked after a May 21 hearing at which a Rhode Island direct care worker identified him as having been driven up to the window of a rural group home and peering in for several minutes in violation of a no-contact order.

The alleged abuse spanned about four years and various locations in Greater Fall River and Rhode Island. Fall River police originally refused to take a report or issue a complaint when approached in January, 2006. And former Bristol County District Attorney Paul Walsh insisted that the family pay for a forensic examination, delaying the first arrest in the case until June of that year. When Smith allegedly continued the abuse, a grand jury indicted his uncle, William Senay, Jr., 52, of Fall River, on similar charges later than year, but Smith remained free on \$1000 bail.

"This the worst alleged case of sustained abuse in New England since the 'Raynham House of Horrors' was exposed more than ten years ago," said COFAR Executive Director Colleen Lutkevich. "It will be a long road back for the family." Smith and Senay will be tried July 21. COFAR press work around the case has emphasized the importance of the DPPC and Mass. Senate bill 802, which would make it easier for victim-witnesses with any disability to testify, and give prosecutors more confidence to pursue such cases.

## HR3995, If Law, Would Have Prevented Misuse of "Rolland"

How could a positive effort like a waiting-list suit turn into a frightening attack upon an excellent facility like the Seven Hills Pediatric Center and upon profoundly disabled young adults like the "Groton 43?"

The class-action suit was filed in 1998, and was settled in 2000 with a "diversion plan" that would keep people from being sent to nursing homes from DMR facilities or when family members were unable to care for them, if they could benefit from active treatment. And if they didn't want to leave nursing homes they were in, they didn't have to.

So far, so good, but DMR never held up its end of the bargain, few eligible people were returned to active treatment, and so the lawyers went back to court to force DMR to draw up a list of eligible people. The latest settlement order defined eligibility by seven criteria, at least four of which would disqualify the "Groton 43" – "(4) the presence or absence of an advanced medical condition that would have a significant adverse effect on the individual's safety; (5) the presence or absence of fragile health condition such that the main supports are nursing services for medical and basic needs; (6) the presence or absence of a substantial risk of substantial transfer trauma which cannot be mitigated by individual clinical intervention; and (7) adequate levels of support in the community system to ensure safety."

But DMR had already made the list, of 666 people, including 31 of the profoundly disabled residents at the Groton facility. That mistake (and some others along similar lines) was folded into a mandatory timetable for moving 640 people over four years into community residential whether they wanted to go or not, and whether it is safe and beneficial for them to go or not.,

The Groton families never knew they were included in the settlement class until it was a done deal, never had a chance to opt out, and have so far been refused court standing to oppose the settlement.

Ironically, the head of the ARC of Massachusetts, viewing the settlement as a victory, said, "The state is looking to help people stay in their homes. I hope this will be one more development to encourage that way of thinking." For the Groton 43, coming from residential schools and hospitals, the Seven Hills Pediatric Center has been their home, some for more than 20 years.

HR3995, sponsored by US Rep. Barney Frank is designed to prevent no-warning, no-opt-out class action suits by tax-supported lawyers. It now has almost 30 congressional sponsors, including the original sponsor, Rep. Frank, and Massachusetts Congressmen McGovern, Lynch, and Capuano. If your Representative isn't on that list, keep calling and emailing to counter the ARC's national campaign against this legislation. See the COFAR website for sample letters.

# 91-Year-Old Fernald Resident Transferred Against Her Will *Unholy Alliance of ArcGB Guardians, DMR, to “Move Them All Out.”*

“A.T.,” a “feisty” woman of 91 who has lived at the Fernald Center for 50 years, was moved out to a state-operated group home in Bedford in February. Because she was well-known to staff and visitors, and well-known to oppose change, the move surprised members of the Fernald League, who went to visit her at the new home. They were turned away, told that A.T.’s guardian had insisted that she have no visitors.

As facts emerged in an emotionally charged February 27 hearing before US District Court Judge Joseph Tauro, The ARC of Greater Boston (formerly GBARC), has been A.T.’s corporate guardian since 2001. Despite the longstanding position of the ARC of Massachusetts that all developmental centers be closed, at least seven ArcGB wards had remained at Fernald, some under ArcGB guardianship for as long as 16 years. Apparently the professionals in the guardianship department believed that their wards were better served at the Fernald Center, or respected their wishes to remain in their longtime home. All that changed in August, 2007, when Judge Tauro lifted a two-year suspension of transfers out of Fernald, and DMR opened a new state-operated group home in Bedford expressly for Fernald transfers. (See previous *COFAR Voice* issues about the procurement and expense of four such group homes.)

Linda Curran, then ArcGB’s guardianship case manager for the wards at Fernald, testified that when she asked A.T. about transfers, “She clearly stated, ‘No.’” Curran testified that she was told by ArcGB CEO Terri Angelone that the ARC of Massachusetts wanted all facilities closed, and all residents moved to community placements, and “We’ve got to move them out of there.” She was told that she had no choice in the matter, and had to work with DMR placement coordinator (and Deputy Assistant Commissioner of Facilities Management) Christine Oliveira to move her wards.

Oliveira and Angelone denied these conversations in their testimony, but Angelone admitted that Curran’s refusal to consider the Bedford home as a placement for A.T. and others made it necessary to reassign those cases to another guardianship case manager. Curran was not fired, but later resigned her job, helping to train a successor until a few days before the court hearing.

Carrie Johnson, who took over Curran’s caseload, testified that she had considered each ward

individually, although three ArcGB wards transferred from Fernald to the Bedford home on the same day, Feb. 7, 2008. A.T. was more resistant, and as late as the day before her transfer, Johnson had noted in her case file that A.T. “just wanted to be left alone.” However, on February 13, A.T. went out for coffee with some Bedford staff, and then asked to take a nap at the Bedford home. She never left, and Johnson said A.T. was happy at the new home.

Johnson also testified that she had refused to put Fernald social worker Karen Liazos in touch with A.T.’s sister (and former conservator) Nellie, since that was Johnson’s role. She also reported to Oliveira four Fernald staff members who, in her hearing, reminded A.T. to tell her guardian about her opposition to moving out of Fernald, resulting in threats of discipline. And Johnson confirmed that she had ordered no visitors for A.T. at the Bedford home, an order which has been extended indefinitely.

On cross examination, Johnson described a careful and extended process for easing the transfer. However she was unable to describe A.T.’s medical conditions, name any of her medications, recall staff members’ names at Fernald or the Bedford home, or confirm whether A.T. bought anything on the shopping trips from the group home. Johnson had also listed “going to the movies” as an activity A.T. enjoyed at the group home, but confirmed in cross examination that A.T. is legally blind and hard of hearing.

Judge Tauro asked the office of U.S. Attorney Michael Sullivan to investigate the transfer of A.T. He refused a motion from the Fernald League to suspend all transfers. (There had been, between August 14, 2007 and February 27, 2008 either 11 or 12 transfers.) The monitor’s report is expected this month. Check the COFAR website for news.

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## **COFAR, VOR, File Ricci Amicus Brief**

COFAR and our national umbrella organization, VOR, filed a joint amicus brief against the appeal of Judge Tauro’s August 14, 2007 order that a global announcement of the closing of Fernald was a violation of individual ISP rights. The 45-page brief, co-written by COFAR Vice President Thomas Frain, Esq. and Alex Hahn, Esq. focuses on the pivotal 1999 Supreme Court decision, *Olmstead v. Zimring*. See [www.COFAR.org](http://www.COFAR.org) for the full text.

COFAR is a family support, education and advocacy organization funded by member families. **Become a COFAR member and receive *The COFAR Voice*.** For membership information and information on how to donate and to be on our mailing list, visit our website at [www.COFAR.org](http://www.COFAR.org), or write to:

COFAR  
3 Hodges Street  
Mansfield, MA 02048  
Phone: 508-339-3379  
Fax: 508-339-5034

David Hart, President [djhartd@comcast.net](mailto:djhartd@comcast.net)  
Colleen Lutkevich, Executive Director [colleen.lutkevich@verizon.net](mailto:colleen.lutkevich@verizon.net)  
Mark Zanger, Newsletter Editor [mzanger@comcast.net](mailto:mzanger@comcast.net)

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**COFAR**  
3 Hodges St.  
Mansfield, MA 02048