

Paying Respects, Paying Costs How DMR Treats Issues of Dying

The annual Memorial Day service at Warner/Pine Grove Cemetery in Belchertown will be held on Friday, May 22, at 3:00 p.m. The event, organized by DMR, pays respects to some 200 former Belchertown State School residents who are buried there, and others who have passed away since the institution closed. It is a fitting, respectful tribute.

However, with the aging of *Ricci Class* members, issues related to dying have been among the most vexing that **Advocacy Network** has been dealing with since our last newsletter.



*Monument at Warner/
Pine Grove Cemetery*

We previously told you about a resident of a private vendor home, whose cremated remains sat disregarded on a business office shelf for nearly two years. We have also heard a number of reports about insufficient funds having been set aside for proper funeral expenses. In some cases, beneficent funeral directors have provided services gratis, or vendors have stepped forward to pay burial costs out of their own pockets.

Nearly two years ago, we began to ask DMR

officials to provide us with timely death notices of *Ricci Class* members so we might pay proper respects and update our own records. We have asked repeatedly for information about how funeral arrangements are handled. Neither has been forthcoming.

Regarding death notices, DMR cites confidentiality and privacy regulations as reason for not informing **Advocacy Network** about the passing of a class member, even when obituaries have been published in newspapers. Absurd. Why should such information be kept secret from the very organization of parents and relatives who advocate for their family members?

Burial Protocol?

Well over a year ago, William Zimmer, Director of the Franklin/Hampshire Area Office told us that he had helped develop a “Burial Protocol” that would outline procedures for handling funeral arrangements. He said we would be provided with a copy. But subsequently, Terry O’Hare, Regional Director for Central-West, said there was no such document. On two occasions, we have brought this issue directly to Commissioner Elin Howe. Her most recent response was that “this has dragged on for too long,” and she would “get the ball rolling” immediately. That was nearly a year ago. The ball rolls slowly.

Here’s what we do know. DMR does use an internal “Electronic Death Reporting Form” (To Be Completed Within 24 Hours) for tracking deaths. But this is purely a data-collecting clinical form, with

Please see “Respects,” p. 5

From Your President

Hello, Everyone,

I know it's been a while since we've been in touch, but let me assure you that your **Advocacy Network** Board of Directors has been working hard for the benefit of all mentally retarded citizens in Massachusetts and beyond. We are all volunteers dedicated to the goal of ensuring that the folks we represent are protected with benefits that keep their lives thriving.

Through our affiliations with the Coalition of Families and Advocates for the Retarded (COFAR), and Voice of the Retarded (VOR), we are in touch with developments in the care of our loved ones in our region, across the state, and nationwide.

Let me give you a personal story.

A little more than a year ago, my brother Jack was clearly ill. He was doubling over and critically uncomfortable. Jack does not speak, so he was relying on those folks that work in the system to care and protect him.

He never got to a hospital for nearly three days! Finally, he was diagnosed with acute constipation. I found out later that this is the number one health issue out there for our folks in the system. Before you call me a neglectful guardian, I will tell you that Jack has had daily prune juice for many, many years to take care of this already identified problem. I even placed this requirement for daily prune juice into his ISP.

I guess it was decided by the agency where he resides and a new doctor (who really didn't even know Jack very well) that he didn't need prune juice anymore. A simple decision – a painful outcome for Jack.

He could have easily ended up with a perforated bowel. I was in constant communication with the house manager and agency, but I had to demand that the nurse come to his house. She was overbooked at other places. His doctor was away that Friday, and the on-call doctor didn't even know Jack.

Does this sound like a single incident? I don't

think so. I believe similar incidents are happening “under the radar,” and parents and guardians never know. I called DMR to find out if this hospital event was ever logged into HCSIS, the Home and Community Services Information System that DMR has to identify such incidents. HCSIS is supposed to be a tool to make changes in the way things are handled. No surprise—this never made the log to even be investigated by DMR.

Even if this incident were determined not to be “neglect,” HCSIS is what DMR uses to identify problems in their system. How do they use this tool if an incident that could have had a very dire outcome is never even logged in?

I requested that I be given a copy of the

Advocacy Network Board of Directors

President

Sheila Paquette, Westfield, MA

Vice-President

Donald Vitkus, Chicopee, MA

Treasurer

Frank Pietryka, Bernardston, MA

Secretary

Diana Duff, East Longmeadow, MA

Editor, *Advocacy Network News*

Edward Orzechowski, Palmer, MA

Board Members

Ernestine Booth, East Longmeadow MA

Ronald Bushior, West Springfield MA

Roland Charpentier, Westborough MA

Richard Gowen, Palmer MA

Everett Kosarick, Amherst MA

Gail Orzechowski, Palmer MA

Ronald Orzechowski, Granby MA

Kathleen Pietryka, Bernardston MA

Ted Wysocki, Wales MA

Yolande Wysocki, Wales MA

HCSIS log. Although Jack was sent to the hospital in an ambulance with no staff in attendance to help comfort him or to help communicate with medical personnel, that information was not included in the report.

How do we protect our family members when we don't know when decisions get changed? How do we know how much to demand?

You probably have very similar stories to tell. Please call us at 413-289-9030 and tell your

stories! We need to hear your problems so that we can investigate and make recommendations. We are all dealing with the same critical events that impact the quality of our loved ones' lives. Help us to be more effective. Help us spread the word that **Advocacy Network** is still here to make a difference for all folks who need a voice.

Keep the Faith!

—*Sheila Paquette*

Closure Plan Opposed

Familiar battle lines have been drawn between state officials and families on opposing sides of Governor Patrick's plan to close four central facilities over the next four to five years. The Monson, Fernald, and Templeton Developmental Centers, and the Glavin Regional Center in Shrewsbury are all on the chopping block. That would leave only the Hogan Regional Center and Wrentham Developmental Center, both in Eastern Massachusetts, in operation.

The Governor and DMR are touting "Community Services Expansion," "less restrictive settings," and "cost savings" as reasons. Parents and guardians liken the plan to a massive eviction notice for the nearly 500 residents whose lives would be disrupted, perhaps even endangered,

with less accountability for care in vendor-operated homes, and no savings gained.

The Fernald League is filing a federal lawsuit, claiming that the Patrick administration is discriminating against Fernald residents by allowing the facility to deteriorate before it is closed.

State Representative Karyn Polito (Rep) of Shrewsbury has asked Gov. Patrick to reconsider the closings. She is also seeking a feasibility study to examine the financial implications of the plan.

Al Bacotti, who retired from DMR as Director of Glavin, says moving residents to privately operated group homes will actually cost more. Bacotti says it now costs \$200,000 a year for each of two residents recently moved out of Glavin. At

Please see "Opposed," p. 6

Let Advocacy Network Help You

Advocacy Network maintains a telephone help line, U.S. Post Office box, e-mail address, and Internet website. If you need assistance with care problems, help with an ISP (Individual Service Plan), navigating DMR regulations, or any other needs, please don't hesitate to contact us.

We're here to help you!

You Can Reach Us At:

Advocacy Network

P.O. Box 2071

Amherst MA 01004-2071

adnetnews@comcast.net

www.adnetweb.googlepages.com

413-289-9030

Carousel Trust Fund Offers Grants

Many of our readers are aware of the carousel that was located on the grounds of Belchertown State school for more than forty four years, but not as many may know about the Belchertown State School Carousel Trust Fund.

The carousel was produced by master carvers Solomon Stein and Harry Goldstein. This partnership built 17 carousels. Two of the better-known were located in Central Park in New York, and Bushnell Park in Hartford. Stein and Goldstein horses were characterized by their large size, aggressive facial expressions, and decorative ribbons and flowers. The date most often cited for construction of the Belchertown carousel is 1922.

In 1946 the trustees of BSS established the Patients' "Merry-Go-Round Fund." The following year Dr. Arthur Westwell, dentist at BSS, acting on behalf of the trustees, purchased the carousel from the Forest Lake Amusement Park in Palmer for \$800.00. The official dedication of the 48-horse carousel was held on October 17, 1948. The carousel would survive for many years, thanks to

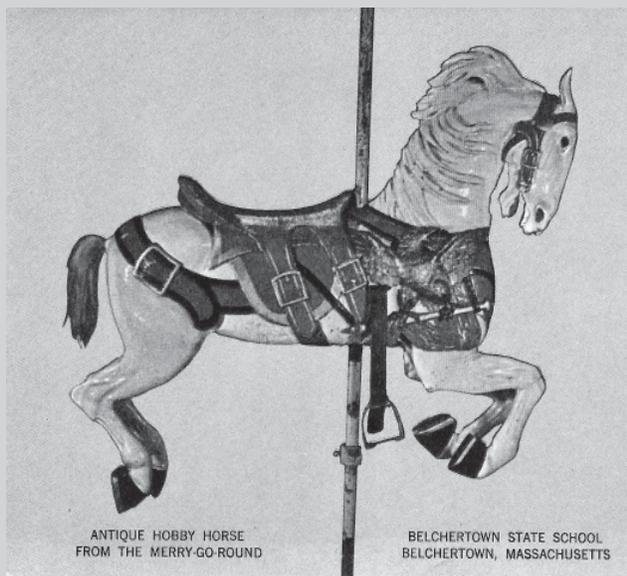
renovations and the purchase of a building to house the merry-go-round. The Belchertown Friends Association played a major role in both the renovation and fundraising for the building.

Prior to the closing of Belchertown, the Massachusetts legislature passed an act establishing the Belchertown State School Carousel Trust Fund, to benefit persons with mental retardation in Western Massachusetts. The money for the trust fund would come from the sale of the carousel.

Later, Governor Weld signed the trust bill into law, and the state declared the carousel surplus property. An auction of the carousel took place in April of 1993, from which the fund realized \$381,486.43. The annual interest generated by this money funds a wide variety of activities for the mentally retarded in the western part of the state.

How You May Apply

What kinds of activities have been funded? Among the requests funded this year were a summer vacation, membership in a health club, horseback riding lessons, travel to visit family, and



ANTIQUE HOBBY HORSE
FROM THE MERRY-GO-ROUND

BELCHERTOWN STATE SCHOOL
BELCHERTOWN, MASSACHUSETTS

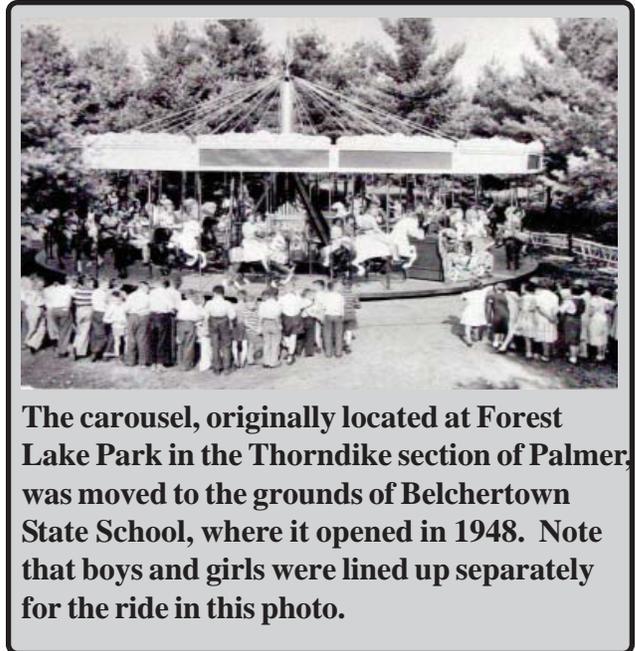
This beautiful horse, one of 42 from the Belchertown carousel, was hand-carved by master craftsmen of the Stein and Goldstein Artistic Carousel Manufacturing Company of Brooklyn, New York, in 1910.

cultural and recreational activities.

What is the maximum award? The maximum amount expended on any request is \$400.00.

What is the process of applying for an award? Applications can be obtained from the individual's service coordinator. What else should you know? The trust fund law created a committee for the expenditure of the monies. A committee member is appointed for a three-year term. The committee will generally not fund expenses that should be covered by DMR or a provider agency. The requests exceed the amount of available annual funding, so it is important to make the requests specific and thorough.

—*Richard Gowen*



The carousel, originally located at Forest Lake Park in the Thorndike section of Palmer, was moved to the grounds of Belchertown State School, where it opened in 1948. Note that boys and girls were lined up separately for the ride in this photo.

“Respects,” cont.

absolutely no mention of contacting survivors, clergy, or funeral directors.

Secondly, DMR regulations include a provision to allow you to deduct funeral expenses, over a period of time, from monthly Charges for Care: *115 CMR: Department of Mental Retardation*

3.06: Charges for Care-Department Facilities (6) Adjustment to Charges. If an individual who has necessary expenses but does not have sufficient funds to pay for these expenses in a particular month, the monthly fee-pay or charge may be reduced by an amount that will enable the individual to pay such expenses. Expenses deemed necessary may include, but are not limited to, the following: (g) Funeral related payments and expenses of the individual ...

But this information is itself “buried” in the dense Code of Massachusetts Regulations. The Department certainly does not advertise it. Many, perhaps most, parents or relatives have no idea that it is possible to set aside money through the Depart-



Advocacy Network board members recently discussed lack of DMR response on deceased Ricci Class members, and a “Burial Protocol” with Attorney Beryl Cohen at his Boston office.

ment to pay for a Funeral Trust. Supposedly, it is the job of each Service Coordinator to tell guardians about this option, but, in fact, many Service Coordinators themselves don't know that it exists.

So you need to ask. Get it in writing in your loved one's Individual Service Plan (ISP). The process needs to be started early so there's enough money set aside when the time comes. A funeral director will help you establish the Funeral Trust, which assures there will be enough money to cover expenses, even in future years when costs have increased.

For more information, please call the *Advocacy Network Help Line: 413-289-9030.*

a recent COFAR board meeting, Bacotti said moving residents out of Glavin and other facilities “is morally wrong. It’s not a ‘choice’ if you’re evicted. Government shouldn’t be in the business of telling people where to live.”

Advocacy Network agrees.

More than three decades ago, Ben Ricci filed our class action lawsuit that eventually led to the closure of Belchertown State School, where so many of our family members lived under terrible conditions. The remaining *Ricci Class* members now live largely better lives in both state and vendor-operated homes. So why should we be concerned about the Department’s closure plan?

Several reasons.

First of all, conditions in these institutions now

are not what they were thirty-plus years ago at Belchertown. Parents and families of residents at these facilities are happy with the care their relatives are now receiving in the institution.

From the perspective of **Advocacy Network** members, places like Monson, Fernald, Templeton, and Glavin are a backup, a safety net, to the community system. They provide medical and behavioral services for individuals who cannot safely live in community settings. If one of our family members currently in a community home develops problems that require more extensive treatment, where will he or she go if the central facilities no longer exist? To a nursing home ill-equipped to serve this population?

In addition, our **Advocacy Network** board members, many of whom also serve on various Human Rights Committees, constantly encounter serious violations of care, health, and building codes in community homes, both state and private. Monitoring of these settings is already scanty. How would DMR provide effective oversight when residents are in even more scattered locations? .

Many of the current residents of Monson, Glavin, Fernald, and Templeton have spent most of their lives where they are. These facilities *are* their “communities,” their “homes.” These individuals are medically fragile people who require stability.

Forcing them to move—to uproot them, to *evict* them—at this stage of their lives, would be a terrible injustice.

Please Renew Today

Your dues dollars help us remain a strong voice for services for your relatives and friends with mental retardation.

We know these difficult times, so we have not increased *Advocacy Network* dues. But with so many serious state budget cuts being discussed, it is essential that we stay vigilant.

Help us continue to be your advocacy group by renewing your membership now, by becoming a new member, or by making a new donation.

Please clip the form on page 8, and mail it with your check to the address at the top of the page.

Thank you!

We’re Looking for Photographs

We’re developing a new **Advocacy Network** brochure to publicize the services we offer, and we’d like to include a photo or two of the people for whom we advocate. The individuals do not have to be *Ricci Class* members, but we would need to obtain a signed release for publication. Do you have a photo you’d be willing to share?

Please contact:

Ed Orzechowski

Editor, *Advocacy Network News*

P.O. Box 2071, Amherst MA 01004-2071

E-Mail: adnetnews@comcast.net

Phone: 413-289-9030

Advocacy Network Honor Roll of Donors

Our deep gratitude to all listed here, and to those who wish to remain anonymous, for your support of persons afflicted with mental retardation. Our late friend Ben Ricci exhorted all of us to *"Keep the Faith!"* Each of your generous contributions, no matter the amount, helps us to carry on his mission of advocating for those who cannot speak for themselves.

Thank you all for your support, your compassion, and your generosity!

Lucy Wilson Benson, Amherst MA
Frederick and Judith Biegner, North Kingstown RI
in Memory of Thomas Paul Andrew
John Garvey, East Longmeadow MA
Johnny and Marilyn Hayes, Buzzards Bay MA
in Memory of Sharin Hayes
Frances Jones Highsmith, Fort Atkinson WI
Sandra E. Japiske, Annandale VA
David and Mary Snyder, Amherst MA
Elaine Stromberg, Worcester MA
Joseph W. Wooler, Amherst MA

In Memoriam

Gail M. Duperault, Springfield MA
Robert C. Ellingham, Chicopee MA
Kristen L. Seaman, Greenfield MA
Anina "Annie" Sinni, Southwick MA

Will Your Loved One Be Safe in the Hospital?

At some time our loved ones will have an overnight stay in a hospital setting. This could be for an illness, a medical observation, or a surgical procedure. It is extremely important that you specify that you do not want your child to be left alone without staff who are familiar to him or her. Speak with the House Manager and Service Coordinator to make sure there is coverage, and that your wishes are carried out. Review your Individual Safety Assessment document, which should be part of your ISP. This document asks questions such as: *Can the individual recognize danger? Remain at home alone? Need to be*

checked by staff during their overnight sleep hours? Question 9 involves *Protocol for Individual If Hospitalized*. This is where you would need to clarify your loved one's needs. For example, "Suzie needs staff with her at all times," "Peggy needs a staff person with her 24 hours a day," or "Joe needs a staff person to visit during each shift to ensure that his needs are being met, to answer questions, and assist with any issues that might come up." Please check Question 9 in the Individual Safety Assessment to make sure it meets your wishes.

— *Diana Booth Duff*

