

Advocacy Network News

**New phone Help Line:
413-289-9030**
**New e-mail address:
adnetnews@comcast.net**

Effective Advocacy – Our Only Service

September/October 2007

Vol. 54 No. 2

New State, National Ties For Advocacy Network

COFAR Connection

Advocacy Network is in the process of renewing a former alliance with COFAR, The Massachusetts Coalition of Families and Advocates for the Retarded, Inc. [www.cofar-mass.org] Since early this year, several members of our Board of Directors have been attending meetings of COFAR's Executive Board at the Glavin Center in Shrewsbury, Massachusetts.

Family members who were founders of COFAR in 1983 were among the original plaintiffs in *Ricci v. Okin*, the landmark 1972 lawsuit in federal court, led by our founder, Ben Ricci.

Re-establishing ties with COFAR gives us a stronger link to families in eastern Massachusetts who share the same challenges as members of *Advocacy Network* in caring for relatives and friends afflicted with mental retardation, more direct contact with the Statehouse, and a continuing tie to Judge Joseph Tauro's influence in federal court.

Through Judge Tauro, COFAR has been deeply involved in a continuing battle to keep the state from shutting down the Fernald Developmental Center in Waltham, a DMR institution that houses some of the state's most profoundly mentally retarded and medically fragile persons.

As you most likely know by now, Gerry Morrissey was removed as DMR Commissioner by Governor Deval Patrick in April. The new Com-

missioner, Elin M. Howe, will be a guest at the COFAR Executive Board meeting in October. *Advocacy Network* will be represented at that session, to learn more about the focus of Commissioner Howe, who served as Commissioner of the New York State Office of Mental Retardation and Developmental Disabilities in the early 1990s.

VOR Annual Conference

As a result of *Advocacy Network's* renewed affiliation with COFAR, two members of our Board of Directors, Gail and Ed Orzechowski, traveled to Washington, D.C., in June to participate in the annual conference of Voice of the Retarded (VOR), a national organization that advocates for persons with mental retardation and developmental disabilities.

About 120 advocates from 28 states took part in the initiative.

The week's activities included updates from organizations across the country about national trends, training sessions for lobbying Congress, and appointments with members of Congress and their staffs. On Capitol Hill, Gail and Ed met with aides

Please see "VOR," p. 6



A Message from the President

Your *Advocacy Network* Board of Directors has been hard at work since our last newsletter. These are challenging times to advocate for retarded citizens and we must stay diligent and alert.

Our meetings are conducted at 6:00 p.m. in the John T. Hickey Conference Room at Holyoke Community College. Upcoming sessions will be held on October 3, November 7, and January 2.

As a member of *Advocacy Network*, you are always welcome to attend these meetings to talk to us directly about what help you might need to advocate for a family member or friend. You may also call our newly-established *Advocacy Network* telephone Help Line at

413-289-9030

visit our website at:

adnetweb@googlepages.com

or write to us at:

Advocacy Network

P.O. Box 2071

Amherst MA 01004-2071.

In recent months, our Board has been focusing on the following issues/projects:

1. Visiting group homes in the area to support proper placements. Keep in mind that family/guardians/advocates are the folks who really understand what "proper placement" should be.
2. Finding out how to acquire "Formal" guardianship. We have been working with Attorney Eileen Sullivan-Boss of West Springfield, Massachusetts. Do you have a "Back-up" guardian for your loved one? We can help there.
3. *Advocacy Network* sent representatives to Washington, D.C., in June (please see page 1) to advocate directly with Congress, through our ties with a national organization called Voice of the Retarded.
4. Also in June, *Advocacy Network* board members participated in the 2007 Human Rights Conference in Worcester to stay alert on how issues may affect us. We also are members of local Human Rights Committees. Do you know who your Human Rights contact is?
5. Very importantly, we have attended and

supported *Ricci Class* members ISP's these past few months. We do this in order to ensure that the best placements and services are identified and agreed to by guardians/advocates. We have made some major positive changes for many *Ricci* members, and other mentally retarded citizens of Massachusetts.

Our experience and up-to-date information could make a big difference in how services are determined. Remember, it is our job to help you advocate with clout! I encourage you to call on us to help you with the enormous task of getting the best care for our relatives and friends who cannot advocate for themselves.

Keep the Faith!

—*Sheila Paquette*

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

It Never Ends

Imagine that at your next visit to your personal physician, he or she hands you a baggie filled with half a dozen different medications—a bewildering assortment of capsules, bottles of colored liquids, and variously-shaped tablets—and simply says, “Here are your medications. Take them.”

No explanation of what each one is called, what it is for, how often to take it, or when.

That’s basically what happened when a local man—we’ll call him Bill—picked up his mentally retarded sister for a Christmas visit at the privately-operated, state-licensed home where she lives.

The attending staff person just handed Bill the baggie of mixed pills, with no instructions whatsoever. Furthermore, the worker was not certified to be handling or administering medications.

That incident was only one of a laundry list of situations Bill had encountered in trying to get care for his sister at this house in Western Massachusetts.

Bill said his sister had been left unattended in a vehicle on more than one occasion. Her dentist had been changed without his knowledge. The house provided no hierarchy of contacts for Bill to call if his sister was having a problem. And no staff at the house seemed to have any idea what an ISP is. We’re not talking about an awareness of what was contained in his sister’s particular Individual Service Plan—simply no knowledge whatsoever of what an ISP is.

Cases like this are the reasons *Advocacy Network* exists. Bill came to us for help, and has since become a lifetime member.

If you are encountering problems on your own securing services, please let us know. Several of our board members also serve on Human Rights Committees, and it is our mission to see that those rights are not violated.

Every house—whether state-operated or run by a vendor contracted by the Department of Mental Retardation—is required to have a Human Rights Officer to look into such situations. The house manager or your Service Coordinator should

be able to tell you who that person is.

And remember always that the ISP, the Individual Service Plan, is a binding legal document. Detailing every requirement you see fit to include, it is *the* most important document to provide a life of dignity and security for your relative or friend. The late Ben Ricci worked tirelessly with Attorney Beryl Cohen in the federal court of Judge Joseph Tauro to create the ISP, and we will continue to work with you to assure that what is stated in the ISP is, in fact, carried out.

New Phone Help Line, New Webpage, New E-mail Address

Advocacy Network has established a new telephone line, and we’ve changed our e-mail address. Whether you need assistance with developing or monitoring an Individual Service Plan (ISP), have questions about membership, or perhaps have your own suggestions for how we can serve you better, you now have three ways to contact us (please see below).

In addition, we invite you to visit our new webpage:

www.adnetweb.googlepages.com

Contact Us At:

***Advocacy Network*
P.O. Box 2071
Amherst MA 01004-2071**

adnetnews@comcast.net

413-289-9030

Death with Dignity

At the annual memorial service conducted at the Warner/Pine Grove Cemetery in Belchertown, DMR officials on May 25 paid fitting tribute to some 200 former residents of Belchertown State School who are buried there, and to 20 others who passed away over the previous year.

But shortly before the ceremony, *Advocacy Network* had learned that the cremated ashes of another individual had been sitting disregarded on the shelf of a service provider's business office for nearly two years. More on that situation in a moment.

CentralWest Regional Director Terry O'Hare and Donald LaBrecque of DMR led the ceremony at Warner/Pine Grove, while singer-guitarist Christen DeTour of Commonwealth Community Services provided a moving musical tribute.

State Representative Thomas Petrolati of Ludlow also contributed remarks, both in tribute to the deceased, and to those who conducted the annual remembrance.



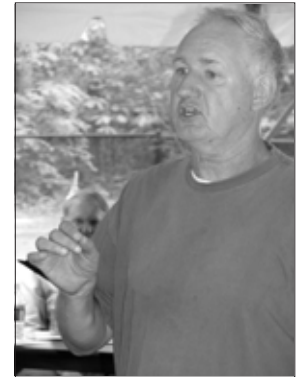
Christen DeTour paused beside each grave to sing for the deceased.

Once called simply Pine Grove, the cemetery in recent years was renamed Warner/Pine Grove, in honor of former BSS resident Al Warner whose mission—assisted by Ben Ricci—was to restore the once derelict grounds with its deteriorating numbered cement markers to a place of reverence with names and dates on granite markers. Al himself is now buried there, beneath a properly inscribed headstone.

Advocacy Network Vice-President Donald Vitkus, also a former resident of Belchertown State School, reminded those in attendance—lest we forget what occurred there—of the abuse once

endured by those who lived in the institution, and the neglect they received even in death.

Ironically, *Advocacy Network* had learned not long before the ceremony of the unburied ashes mentioned above. The cremated remains of a resident of a DMR private vendor home in the Pioneer Valley had been left unceremoniously on the shelf of a business office for nearly two years. We are told that the urn was the subject of black humor about “Larry,” (not his real name).



Advocacy Network Vice-President Donald Vitkus asked us not to forget the past.

Immediately after Larry died in December of 2005, a well-attended church memorial service was conducted, but later the urn containing his ashes was put on the shelf and largely forgotten until it was brought to the attention of *Advocacy Network*.

Through our prodding, Larry's ashes now lie in a cemetery in northwestern Massachusetts. There were flowers and prayers at the burial—neither arranged by DMR. As yet, there is no marker for Larry, but we will see to that, too.

The lesson here is that some things don't change, unless a spotlight is focused on them.

You should be aware that DMR regulations provide a mechanism for funeral arrangements by setting aside a portion of monthly Social Security benefits, but it needs to be initiated early enough to accumulate the money necessary to cover the expenses. Chapter 115 CMR, section 3.06 [Charges for Care] line 6 (g) [Adjustment to Charges] reads “... funeral related payments and expenses of the individual.”

If you have not already included this provision in your loved one's or friend's ISP, be sure to ask your Service Coordinator to add a paragraph about funeral arrangements. (Please see the related item below.) Don't expect that DMR will automatically

bring this to your attention.

And if you encounter any resistance or obstacles, be sure to let us know so *Advocacy Network* can help.

Every person who passes away in the DMR system deserves dignity in both life and death.

You Probably Don't Want to Talk About It....

It is something that people don't often bring up in general conversation or discuss around the dinner table, but making burial arrangements is an important part of planning for ourselves and those for whom we are guardians. Included in the ISP under the "Legal" section should be a paragraph or two outlining what you want to happen when your loved one or ward passes away. It could be something as simple as stating which funeral home will be making

the arrangements at the time of death, where the prepaid burial fund is secured, and where the plot is located. Discuss these issues with your Service Coordinator, and clearly state your wishes. Also request that the Service Coordinator place this information in *all* the ISPs they handle for every individual.

Have you taken time to do this important part of your relative's or friend's Individual Service Plan? Please let us know.

—Erni Booth & Diana Booth Duff



Monument at Warner/Pine Grove Cemetery

Ricci Scholarships Established

The legacy of Ben Ricci will be carried on in two college scholarships in his name, one at UMass, sponsored by DMR, the other at Springfield College, established by Ben's family.

In a June ceremony at the University of Massachusetts in Amherst—where Ben served his career as Professor in Exercise Science—DMR Commissioner Gerry Morrissey presented the Ben Ricci Scholarship Award to two recipients.

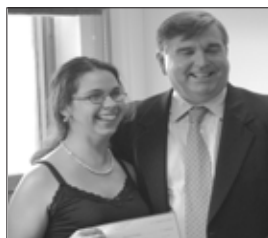


Lisa M. Comeau receives Ricci Scholarship from Commissioner Morrissey

Lisa M. Comeau, now completing her major in Management Science and Accounting, has been working in the disabilities field for more than ten years. She is now administrator of eight commu-

nity residences supporting men and women with developmental disabilities in the North Central and Worcester DMR areas, and serves as the Human Rights Committee Coordinator for the Central Region Sub-Committee.

"Lisa has been inspired by Ben Ricci's legacy for the disabled population," said Commissioner Morrissey, "and finds great personal satisfaction in watching people who were once institutionalized grow and succeed in their personal goals in community settings."



Com. Morrissey presents Ricci Scholarship to Shawna Shappy

Shawna Shappy is entering her junior year in the Commonwealth Honors College at UMass, where she is studying the Psychology of the Exceptional Child, with a concentration in Early Intervention and Special Education.

"Shawna has been singularly goal directed," Commissioner Morrissey said. "A volunteer position at Vermont Children's Hospital while in high school inspired her early to focus her career goals toward working with children with disabilities."

Commissioner Morrissey presented each recipient with a \$1,000 cash award and certificate, sponsored by DMR.

In addition, the Ricci family has created the

Benjamin Ricci '49 Scholarship Fund at Springfield College, Ben's alma mater. According to a release from the school's Development Office, "The scholarship recognizes a student who embodies Benjamin Ricci's outstanding leadership, dedicated service, and commitment to the principals of rehabilitation for persons with developmental disabilities. The Chairman of the Department of Rehabilitation and Disabilities Studies, in consultation with the Director of Financial Aid, will select the student who must be in good academic standing and entering his or her senior year at Springfield College."

This scholarship was just established in April, and the first recipient will be in the fall of 2008. Anyone interested in directing a gift may send checks payable to Springfield College, Gift Records, 263 Alden Street, Springfield, MA 01109. Please reference the Ricci Scholarship in the memo line of the check.

Please Renew Today

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

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 and fill out the form on page 8, then mail it with your check to the address at the top of the page.

Thank you!

"VOR" cont.

from the offices of Massachusetts Representatives John Olver of Amherst and Marty Meehan of Lowell, and others from Delaware, Rhode Island, Maine, Vermont, and New Hampshire.



Gail Orzechowski attends VOR training session.

One of the main thrusts of the week's lobbying efforts sought to freeze the use of funds by what are called Protection and Advocacy agencies in each state to initiate class action lawsuits against

large institutions (such as Fernald in Waltham), regardless of whether families and guardians agree to be represented in the case against the facility. Across the country, there is a distinct movement at the state level to close large institutions, regardless of how parents and relatives feel about the care their family members are receiving at these locations.

The D.C. conference also included a presentation from the 2005 Surgeon General's Office—A Call to Action: To Improve the Health and Wellness of Persons with Disabilities. Speaker Eileen Elias, Deputy Director of the U.S. Department of Health and Human Services, said, "The disability [such as retardation] is often not the problem in health care. It's what happens when secondary health issues are ignored, for example, undiagnosed cancers because of improper screening."

Two observations from our participation in the VOR Washington initiative:

- Funding begins at the national level, and it is our job to educate Congressional leaders about the needs of the mentally retarded.
- Families from across the nation encounter the same kinds of problems, obstacles, pressures, and frustrations as our own members of *Advocacy Network*. It is comforting to know that others like us are battling the same issues in every state and every community, and that there is strength in numbers.

More information about Voice of the Retarded is available online at:

www.vor.net

Advocacy Network's Honor Roll of Donors

Advocacy Network thanks all donors listed here, and those who wish to remain anonymous, for your generous contributions in support of persons afflicted with mental retardation. We warmly welcome and deeply appreciate every donation, no matter the amount. Our late friend Ben Ricci exhorted all of us to "*Keep the Faith!*" Each of your gifts 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!***

Frederick and Judith Biegner, Amherst MA

Lucy Wilson Benson, Amherst MA

Margaret and John Garvey, East Longmeadow

Everett Kosarick, Amherst MA

Dana and Mary Snyder, North Kingstown RI

DMR Offers Training Sessions

Through its Office of Learning & Development, the Department of Mental Retardation offers a variety of training workshops which are geared toward both persons who work in the disabilities field, and families and guardians of the mentally retarded.

Some are one-time workshops, while others are offered on an on-going basis. Topics are published quarterly in a publication called "Learning Matters," which is available in either hard copy or digital formats.

The October—December 2007 issue includes such topics as: Basic Human Rights, The Human Rights System, Strategies for Community Integration, Individual Support Planning, Rights Parents and Guardians Need to Know, Adult CPR, and Standard First Aid.

Workshops are provided at several locations, and some require registration fees. For more information, call the Training Line at 413-284-5087, or e-mail: Jeffrey.Monseau@dmr.state.ma.us

DPPC Hotline

Report Incidents of Suspected Abuse

by calling the

Disabled Persons Protection Commission

24 hours - 7 days a week,

including holidays

1-800-426-9009

**ADVOCACY NETWORK
P.O. BOX 2071
AMHERST MA 01004-2071**

**Non Profit Org.
US Postage
PAID
Permit No. 129**



A *dvocacy Network*
ll volunteers
dvocating for
ll retarded persons

Questions or Concerns?

Contact us at:
Advocacy Network
P.O. Box 2071
Amherst MA 01004-2071
E-mail: adnetnews@comcast.net
Tel: 413-289-9030

Time to Renew for 2008

Please take a moment today to renew your support for *Advocacy Network* with the form below.

Thank you for your continuing support!

ADVOCACY NETWORK CHARITABLE TRUST

Membership Dues

January 1 to December 31, 2008

Please Print Clearly

Membership \$20

Supporting Membership \$50

\$ _____ Other Donation

Life Membership* \$200 or more

Benefactor** \$1000 or more

*Payment may be spread over two years

**Payment may be spread over five years

Yes, you have permission to list my name and town on the Honor Roll of Donors page

Please do not include my name and town on the Honor Roll of Donors page

I prefer to receive *Advocacy Network News* via E-mail

First Name

Initial

Last Name

Address

City

State

Zip

Telephone (_____) _____

Check # _____

E-mail _____

Thank you!

Check here if above address differs from mailing label