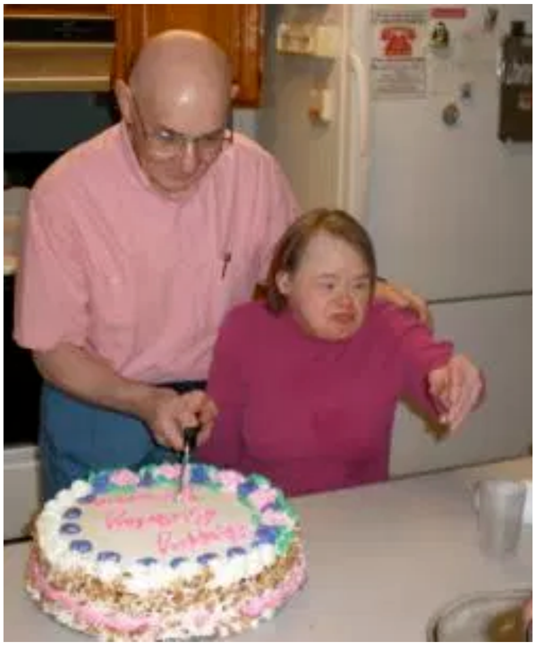
Wave the VOR Flag by George Mavridis

My Washington Initiative trips started in early 1992 when I accompanied former VOR President Mary McTernan on a March trip to see members of the Massachusetts delegation.

Why have I gone each succeeding year? Archie Manoogian, past editor of the *Fernald League Flicker* (local advocacy organization) newsletter said "George, as Fernald League President you have to go and 'wave the flag.'" I have held several different positions locally and with VOR over the years but Manoogian's reason still governs my return to Washington each June.



George Mavridis and his niece Joanna Bezubka on Joanna's 60th birthday.
Joanna, who had Down Syndrome, died in 2012 at the age of 60 of Alzheimer's Disease.

What does "waving the flag" mean? It means visiting the health aides in the offices of your senators and representatives, and educating them about VOR's position on specific bills or on our positions on issues that affect the lives of our loved ones. It means keeping in touch with these aides each year, and coming back to update them or to educate the new aides who have taken their places. Oftentimes, we find that these aides don't know anyone with an intellectual or developmental disability. More often, they know someone who is less severely disabled and is integrated into the community, but they have never encountered anyone who is profoundly disabled – someone whose disabilities are such that they require 24 hour nursing care and supervision for their complex needs. They don't know the level of care required for an individual with severe intellectual, behavioral, and medical problems, or the toll that constant threats to this level of care takes on families of the disabled.

This leads to explaining guardianships and the rights guaranteed to intellectually disabled persons and their guardians in the Supreme Court Olmstead decision and the legislature's American with Disabilities Act, etc.

"Waving the flag" means setting up a communication channel with these health aides, and keeping those channels flowing. As you follow up on your meetings, they will realize your knowledge about the issues and see the library of past VOR positions on our web site, and hopefully they will be willing to receive your information about pending legislation and issues close to our hearts.

"Wave the flag" also means visiting the offices of representatives and senators who may be from states other than you own. Personally, I visit other New England congressional offices and when they tell me that I am not from their district I remind them that there are members of this vulnerable population and their guardians who live in the district, I make it clear that I am representing the guardians who could not make it to Washington this year.

My Aunt Blanche asked each time I returned from a VOR Washington Initiative trip if we settled all the issues concerning the care of her niece, Joanna and the other intellectually disabled persons. She was disappointed each year when I said, "No, Auntie. Not yet." And that is why I return and I urge you to participate in VOR's Washington Initiative each year.

Former VOR President Ann Knighton always says, "If not us, who?" Come to Washington and "wave your VOR flag". We hope we see you in June, but if you cannot make it to Washington this year, please consider supporting VOR's Legislative Initiative financially through a donation.

Sincerely,

George Mavridis
Member, VOR Board of Directors