

Thirty Years and Counting Seeing Beyond Today with Teamwork & Enthusiasm













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Top (L-R) - Linda Lotzi, Irene Welch, Ralph Kennedy, Kathleen Miller, Tracy Kennedy, Bob Hazard, Don Putnam, Rebecca Underwood, Berlinda Bazzell. Bottom (L-R) - Richard Male, Theresa Senior, Tamie Hopp, Ann Knighton, Richard and Darla Part, Linda and John Patla, Cyndy and Jim Pratt, Terri Anderson, Linda Lotzi.

Also Inside:

The late-Martin Pratt, Polly Spare, and Jane Anthony Earn Awards Thanks to Annual Meeting Sponsors!

VOR Seeks Congressional Hearings and Quality in the Community

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President's Message

"Allow me to dream a moment" By Ann Knighton, President

I often use these words when speaking to family advocates who worry about the future. To me, dreaming leads to hope, which leads to action.

The last time I used these words, I was sitting across the table from three Department of Justice (DOJ) attorneys. As we have for the last few years, we were expressing again our dismay at the terrible settlement agreement that, by its letter, will close our family members' homes based on arbitrary quotas and timelines. Individualized care planning? I don't think so.

My dream in this context was for the settlement agreement to be deemed null and void so we could start over and actually involve the people who matter most in planning for the future: the very residents who will be displaced from their long-time, specialized homes and their families/legal guardians, who know them so very well (certainly better than the advocacy organizations that were consulted and cheered the settlement agreement and the state and federal officials who signed on the dotted line).

If I sound angry, it is because I am. And, I am pretty sure that the DOJ attorneys who had the pleasure of meeting with me and others from Georgia recognized my anger. I am just as sure that they found my "dream" question – "can't we just start over?" – a rhetorical one.

Dare I say, however, we did make some headway in this meeting. For the first time in my meetings with DOJ, there was recognition that **quality trumps quotas**. Although good to hear, more importantly, DOJ attorneys also provided assurances that they relayed a similar message to State officials – the very officials who have claimed they are "just doing their job" when moving people out of state facilities according to a certain schedule. This sort of political finger pointing was not a surprise to us. What did become apparent to us, however, was that DOJ could help like no other entity could: DOJ can control the timeline of settlement implementation and if quality sincerely matters, they will. Already, the State has placed a moratorium on transitions in light of quality concerns. We desperately hope this temporary salve is a result of DOJ interventions.

Dare to dream.

"Of the many exemplary qualities that your organization practices, the most important has been teamwork. The strength and power of an organization does not come from the individuals themselves, but from the individuals working together and the strength that comes with that."

~ Rich Male, speaking at VOR's Annual Conference



Ann Knighton with Rep. John Barrow (D-GA)

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VOR MISSION STATEMENT

VOR is a national organization that advocates for high quality care and human rights for people with intellectual and developmental disabilities.

Photo Credit (cover, throughout):Cyndy Pratt

the voice

VOR Presents Certificates of Appreciation to Retiring, Current and Incoming Board Members



At the June 8, 2013 VOR Annual Board of Director's meeting, Ann Knighton, President, presented retiring and current board members with a VOR Certificate of Appreciation in "recognition of service on

VOR's Board of Directors and for dedicated advocacy on behalf of individuals with intellectual developmental disabilities and their families across the country."

"VOR's Board of Directors sets the vision for VOR, offering critical governance," remarked Knighton. "We are mindful of the fact that we are elected by the VOR membership and are grateful for their trust. These certificates are just a small way for me to thank my fellow Board Members for all they do for VOR."

Thank You Retiring Board Members; Special Farewell to David Swain

June 30, 2013 marked the end of board terms for several retiring board members. Due to term limit requirements, Mary Kay Cowen (LA) retired from the VOR Board, as did Steve Johnson (CA), David Swain (NV) and Barb Cukierski (IL). VOR appreciates very much the past volunteer contributions of these effective leaders.

We extend a special farewell and sincere gratitude to David Swain for his two decades of service as a VOR Board Member, Officer and Committee Chair. For many years, David served as VOR's Treasurer and Finance Committee Chair, among his other volunteer leadership contributions. Thank you, David!

Welcome New and Returning Board Members!

On July 1, 2013, VOR welcomed several new and returning Board Members (as elected by the VOR Membership) and new Officers. A special thanks to these VOR members for going "above and beyond" and dedicating their time and skills as VOR's leaders (see sidebar).

VOR BOARD AND OFFICERS

July 1, 2013 - June 30, 2014

Welcome New* and Returning Board Members and Officers

Ann Knighton (GA)
President

Jill Barker (MI)*
First Vice President

Jill Goldstein (NY)*
Second Vice President

Geoffrey Dubrowsky (NJ)
Treasurer

Sybil Finken (IA)
Immediate Past President
and Secretary

Cindy Bartman (NJ)*

Gil Fonger (IL)*

David Hart (MA)

Terry Kopansky (TN)*

Mary O'Rioridan (CA)*

Mary McTernan (MA)

Terry Lafleur (LA)

Linda Lotzi (MD)

Mary Reese (MD)

Joanne St. Amand (NJ)*

Mary Vitale (MO)

the voice Summer 2013

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Sibling's Perspective



Jennifer and Matt

About Matt, My Twin Brother

By Jennifer Viox

My name is Jennifer Viox. I am 37 years old and my twin, Matthew Capps, is a resident at Mount Aloysius ("Mt. Al") in New Lexington, Ohio.

My brother Matt has been living at Mt. Al for nearly twenty years. Without the help of the wonderful, fully trained personnel of places like Mt. Al, my family would have nowhere to turn to for help with my brother. Being severely handicapped is a challenge on its own; trying to live outside his Mt. Al home would not be beneficial to him.

When I was a little girl, I remember how hard it was on my parents. Both were working full-time and raising their three kids, plus the challenges that come with having a child with multiple disabilities. Matthew has severe intellectual disabilities ("mental retardation"), Autism, ADHD, cerebral palsy, and behavioral issues. He cannot speak, other than with mostly unknown sounds, which occasionally, along with body language, conveys a thought. He does use simple signs, thanks to the help of his therapists.

In a home like Mount Al, he is able to keep to a schedule, which is imperative for people like him. He also gets bussed to and from work (a sheltered workshop). This makes him feel important and needed. We all need that in our lives, don't we? He sees his therapists, who work with him to keep his mind going, and he gets to go to church every Sunday and sings to his heart's content and as loud as he wants with no one judging him. They just continue to praise God. He needs a high fiber diet because of some internal issues he has,

and the dietician is there to make that happen. He takes medicine that he needs on a very regular basis, and the nurses are there to make it happen. He gets to go swimming, and blows bubbles. For these outings and for everyday things, like getting ready for bed, showering, brushing his teeth, and shaving ... and he needs help guiding him on what to do.

When I was younger I would get embarrassed when people would look and whisper about him. Why? Because I was young. Why would people do this? Because they were uneducated. Why did I always care how I felt? How about how Matt felt? Because he is full of love and doesn't understand why everyone doesn't love his hugs. He is completely accepted where he now lives.



Matt with his mom and dad, Fran and Harris Capps, and his older brother, Daniel.

Matt is my twin and I would sometimes feel guilty that he is the way he is. Why did it happen to him and not me? Then I mentioned that one day to my mom. She told me something I will never forget. He is happy with who he is, he is happy with where he is, and we would never want to change him. My twin brother, Matt Capps, is the most loving, kind soul. Anyone would be blessed to know him. For people like him to lose the place that gives him the most important things in life... the place they can call home, would be absolutely tragic.

RENEW YOUR VOR MEMBERSHIP AND GIVE A GIFT MEMBERSHIP!

For a limited time, when you renew your membership with VOR you can gift a VOR membership to a friend, colleague, family member or anyone that is currently not a VOR member. Thank you for participating and helping to ensure a strong future for VOR by increasing our membership! If you would like membership materials, contact Julie Huso at jhuso@vor.net or 605-370-4652.

VOR: New in 2013

- ✓ VOR Quality in the Community Initiative.
- ✓ E-Advocacy component to VOR's website. Reaching your elected official with one click. Visit our Legislative Action Center here: http://www.vor.net/legislative-voice
- ✓ New growth opportunities! Complimentary subscriptions to non-members and more.
- ✓ Ongoing Webinars.

2013 - VOR Celebrating 30 Years!

By Julie Huso, Executive Director



According to the U.S. Census, about 1.2 million adults and 1.7 million children have an intellectual disability. Another 944,000 adults have other developmental disabilities, including autism and cerebral palsy. Other sources estimate that 3% (about 87,000) of all citizens with intellectual disabilities have severe or profound intellectual disabilities. These individuals are most at risk due to the prevailing ideology in

support of aggressive deinstitutionalization which eliminates access to specialized care and health care services, as well as constant pressure in many states to limit or eliminate specialized services in the community. Without VOR, there would be no effective voice for these individuals.

In support of residential choice, quality and family decision-making, VOR has actively worked on a public awareness campaign designed to edu-

cate the general public regarding the tragic injustice befalling individuals with I/DD around the country, especially in those areas where a center is threatened and quality community options are lacking.

In 2013, we launched a "Quality in the Community" initiative to identify and pursue uniform, humane quality standards in community settings across all states, with an emphasis on staff competency and access to specialized health care and supports. Although proponents of deinstitutionalization promise a better life in the "community," the promise is far from well-documented reality, resulting in tragedy for thousands of impacted citizens. VOR is expanding outreach to families whose disabled family members live in community settings without adequate services.

In summer 2013, VOR will unveil a new e-advocacy feature designed to enhance the effectiveness of our Legislative/Government Affairs program. With one click, you can reach your elected officials with a letter provided by VOR. Visit http://www.vor.net/legislative-voice.

VOR is also expanding the effectiveness of our State Coordinator program to continue its advocacy support role and to assist in regionally-targeted membership and financial growth objectives. Quarterly webinars are being offered to all coordinators and members.

VOR has the great fortune of having families of individuals with I/DD as our leaders, members and donors. The family connection results in an unmatched commitment to our advocacy:

Does VOR have your email address?

xecutive Director's Messag

If not, you're missing important information! Send your email address to info@vor.net to receive our e-news and alerts.

"Seeing Terry and Glenda and how they are with Jamie, I also feel a sense of gratitude for people like the Lafleurs. I cannot remember the last time I met people so kind, selfless and genuinely good. Jamie is a beautiful spirit - an 'angel,' as Terry calls her - who still has that sense of wonder that we all, at some time or another, wish we still had. She may not have wings, but Jamie, like her mother and father, are all angels of the same feather." ~ "Angels of a Feather," by Nancy Duplechain (Bonnes Nouvelles Evangeline, July 2012, featuring Terry Lafleur, VOR Board Member, and daughter Jamie).

You can help spread the word. Please reach out to your family members, individuals in your parent/family group, friends and others you may know and share your passion about VOR and our mission. Thanks to each of you for being part of the VOR family and forging ahead with continued loyalty through your membership and donations.

2013 Annual Conference and Initiative Success! 30 Years and Counting: Seeing Beyond Today with Teamwork and Enthusiasm

By design, this year's Annual Conference balanced reverence and respect for our past leaders, who deserve VOR's gratitude for the foundation they provided for us 30 years ago, with a determination to face the future with vision and tenacity. Past leaders were honored (see page 7) and our keynote speaker, Richard Male – an expert in the nonprofit field – applauded VOR for how much we've accomplished against all odds.

Looking forward, VOR's President Ann Knighton highlighted VOR's recent accomplishments in her President's Message and shared her time with Hugo Dwyer and Jill Goldstein. They chaired two committees -- Marketing and Communications and Membership -- which are helping to position VOR for increased growth and awareness.

Time and attention was also paid to VOR's new Quality in the Community Initiative which aims to proactively address the disconnect between the promise of quality community living and reality. A panel of facility and community-based providers offered their insights on delivering high quality care to individuals with intellectual disabilities and spoke to the challenge of

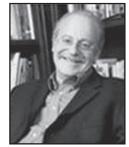


Renee Naylor (Westcare, OR), joined Terry Kopansky (Mur-Ci Homes, TN), Ralph Kennedy (Tennessee Family Solutions) and Brad Whitehead (Lanterman, CA) on the Quality Panel.

ensuring consistent quality across all settings. A central theme was strategies to empower direct care staff to view their job with passion and become a "cause outside themselves."

Richard Male also touched on the importance of VOR's Quality in the Community Initiative. "VOR's programs have not only stood the testament of time, but have grown to meet the changes of the times," he stated. VOR's new quality initiative "allows VOR not only to expand its longstanding national programs of pro-

tecting and saving our institutions, but emphasizes the need for quality standards in community-based facilities, when institutions are closed. This is a powerful new direction for the organization and VOR has taken the challenge head on."



Rich Male

"I want you to realize that you are here not by accident, not because you were following the 'political tide and climate,' not because you were loved or even liked. You are here today because you have had the chutzpah, the courage, the will to stand by your values and say 'we are not giving up.' . . . We have the courage to realize that VOR has lasted 30 years because we are doing things right and we have a belief in who we are and where we are going."

~ Richard Male, VOR Keynote

The Annual Conference also featured a Legislative Briefing, led by Peter Kinzler, Chairman of VOR's Legislative Committee (2012-2013); Larry Innis, VOR's Washington Representative; and Tamie Hopp. In keeping with VOR's long standing opposition to federally funded deinstitutionalization, while also pursuing quality in the community, VOR's

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legislative priorities sought Congressional hearings on the impact of actions by the Department of Justice, National Council on Disability, and DD Act programs (see page 9) while also seeking Congressional sup-



Tamie Hopp and Ann Knighton

port for national background checks for direct care workers and further study of the relationship between quality care and other staffing issues, such as training, retention and wages. Citing an increase of nearly 1600% in community-based settings since 1977 – an increase without adequate oversight – VOR made the case that Congressional attention to these issues was long overdue.



Peter Kinzler

"Keep up the good work! I found this to be very educational and encouraging.

Thanks for all you do!" ~ 2013 Participant

2013 Voice Award Recipients: Polly Spare and the late-Martin L. Pratt

At the 2013 VOR Annual Conference, VOR presented Polly Spare, former long-time VOR President, and the late-Martin L. Pratt, VOR's founder and first President, the 2013 Voice Awards. Both VOR leaders left an indelible mark on VOR's long history and contributed to the very fact we are celebrating our 30th year advocating for people with intellectual and developmental disabilities.

Marty's three children, Jim, Linda, and Richard were on hand with their spouses to accept Marty's award. Linda spoke of her father's determination to make the world a better place for their latesibling with intellectual disabilities, Nancy, and all her peers. His dedication and vision led to the founding of VOR 30 years ago in an effort to bring together like-minded advocates from around the country to successfully defeat legislation which would have ultimately eliminated choice and specialized services by de-funding the Medicaid Intermediate Care Facility (ICF/IID) program.

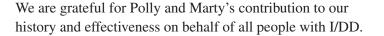


Martin L. Pratt



Jim Pratt, Linda Patla and Richard Pratt accepted the Voice Award for their latefather, Martin Pratt.

Polly attended the Conference with her daughter, Kathryn, and her family. She also received the Voice Award in recognition of her leadership and vision on behalf of VOR and people with I/DD. Polly served as VOR's president for 9 years in the 1990s. She brought VOR awareness and credibility to new heights and secured access in offices that VOR still enjoys to this day. She remains active nationally and in her own State of Pennsylvania, and remains an inspiration to VOR members.





Polly Spare

2013 Advocacy Award Recipient: Jane Anthony, VOR Virginia State Coordinator



Jane Anthony, long-time VOR State Coordinator and former Board Member and Officer received the 2013 Advocacy Award. The Advocacy Award, presented for the first time this year, recognizes VOR State Coordinators and leaders who, through hard work and vision, focus their energies on VOR growth and awareness to advance our shared advocacy. Jane, who was

recognized for her "dedication to VOR's awareness, advocacy and growth on behalf of people with intellectual disabilities," has served VOR at all levels – as Officer, Board Member, Committee Member, and State Coordinator. She has also served as a leader in her own state of Virginia and has excelled at helping families see and appreciate the state-national connec-

tion of our advocacy and issues, even in the midst of her unprecedented state level challenges. Congratulations, Jane!

"When we give cheerfully and accept gratefully, everyone is blessed."

- Maya Angelou

Thank you to our Sponsors: Making it all possible

Financial support from our Conference Sponsors make the event possible. Thank You!

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In memory of my sister Mary Beth Engberg -

Mark Engberg (MD)

Bob and Jane Anthony (VA)

Parents & Associates of Northern Virginia Training Center (VA) (parentsandassociatesnvtc.com)

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Larry Innis, VOR Washington Representative American Health Care Association



A Special Thanks to EP Magazine (eparent.com) for their partnership this year, through promoting VOR's event and offering a great advertising benefit to our top sponsors.

Keeping it in the Family, Almost



Left to Right: Bob and Joanne St. Amand and Cindy Bartman.

Cindy Bartman and Joanne St. Amand are good friends. They are both effective advocates for residential choice in New Jersey and nationally, on behalf of their siblings and their peers. Both are also newly appointed VOR Board Members, and both are charitable at heart. In this spirit, Cindy donated a painting created by her brother, Cliff, a resident at Hunterdon Developmental Center, for auction at VOR's Conference. She was loathe parting with it, but recognized its value. She was not, however, above bidding on the painting herself. After all, that was the one avenue that would allow her to keep her brother's painting and benefit VOR. When the winning bid was announced, Cindy didn't win. But her good friend Joanne did, which was almost as sweet. She can visit her brother's painting anytime! VOR is grateful to Cindy and Joanne for their leadership and generosity.

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Legislative Update

Taking Initiative: VOR Seeks Congressional Hearings

From June 8 - 12, 2013, nearly 70 volunteers representing 22 states attended the VOR Washington Initiative, hand carrying our message in support of high quality care and human rights for all people with intellectual and developmental disabilities (I/DD) to every Congressional office and several Administration offices. Participants were mosty families and some caregivers of people with profound intellectual disabilities.

Americans with profound I/DD are being seriously threatened by closure of their homes by reduction in budgets and a shift of basic government philosophy that dictates all people are allegedly better served living in a community setting, even if needed medical and personal care is reduced to a point where lives are being threatened. VOR called on Congress to hold hearings to investigate the human impact of federally-funded deinstitutionalization actions by agencies such as the Department of Justice, National Council on Disability, and DD Act programs. In addition, VOR sought Congressional support for community-based standards to address widespread deficiencies and tragedies.

"We had a very productive week in Washington, D.C. and left committed to the challenges that impact our children," said Ann Knighton, President of VOR. "Generally, Members of Congress are empathetic to our concerns. It's hard to argue against individual choice, family involvement and quality care across all settings. Our challenge now is to turn this empathy into action on behalf of all people with intellectual and developmental disabilities."

Peter Kinzler announces his retirement; David Hart to Chair VOR's Legislative Committee

Peter Kinzler "retired" from his career two years ago, but never really retired. He increased his volunteer activities, serving as Chairman of VOR's Legislative Committee, a post he has held for the past 6 years, while also working with families in Virginia to respond to a Department of Justice and State Settlement Agreement that threatens four state centers.

"I will remain involved," remarked Peter upon announcing his retirement as Chair.

"I'm grateful to Committee members for their hard work which has enabled VOR to be so well known and influence our cause so effectively. We are a credible resource, due largely to our status as family members, our compelling message, and the hard work of this Committee."

David Hart, a VOR Board Member and long-time Legislative Committee member from Massachusetts, has been selected as Peter's replacement.

"David has committed a lot of time and energy to this Committee and over many years," said Tamie Hopp, VOR's Director of Government Relations and Advocacy. "He's attended the VOR Conference and Initiative annually for more than a decade and he is fully informed on VOR's current and past legislative priorities and strategy. Most importantly, he demonstrates an ability to engage Committee members in decisions and implementation."

VOR is grateful to both Peter and David for their leadership contributions.

VOR's Quality in the Community Initiative

Pointing to the remarkable expansion of community-based services - a nearly 1,600% increase in private community residences serving 98% of I/DD population – coupled with a relative lack of oversight, VOR continues to make its case for quality community standards. In June, VOR participants made its case to Congress, calling for mandatory background checks, and David Hart testified in support of a VOR proposal submitted to the Uniform Law Commission (ULC). Our proposal sought a model uniform state law. Although the ULC ultimately declined VOR's proposal, it cited empathy for our concerns. "While the problem your proposal addresses is real, and the idea has merit," wrote Richard Cassidy, Chairman of the ULC's Scope and Program Committee, "a proposal of this nature would not be appropriate for uniform state legislation." In other words, states should do more, but strategies need not be uniform. VOR will continue our efforts at the federal and state level, promoting awareness and reform.

State News: www.vor.net/events

Legal Briefs

New Jersey: Families Sue Governor Over Plan to Close State Centers

Accusing the Christie administration of interfering with medical decisions and violating civil rights, a group of families filed a class action lawsuit against the state today to stop the closure of centers in Woodbridge and Totowa that have provided a home for 700 people with developmental disabilities for decades. A task force jointly appointed by the governor and state Legislature decided last summer the Woodbridge Developmental Center and the North Jersey Developmental Center would close by 2017, but a group of relatives and guardians for people living at the centers say the decision is unfairly disruptive and for many, a risk to their health and safety. Filed in federal court in Newark in June, the lawsuit seeks to preserve the residents' state and federal civil rights to live where they are the safest and happy, the families' attorney Tom York of Harrisburg said. (Source: Star-Ledger, June 19, 2013) More information is available on VOR's website at http://www.vor.net/get-help/legal-resources.

Illinois: State Ordered to Disclose Info in Murray Center lawsuit

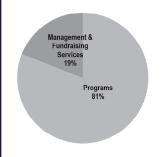
The federal lawsuit against the closure of the Murray Developmental Center gained some more momentum this week as a judge ordered the State to turn over pertinent information as part of the discovery process. At a July 17, 2013 status hearing, attorney Judith Sherwin, representing the plaintiffs, including the Murray Parents Association, the Illinois League of Advocates for the Developmentally Disabled, and individual family members of residents of Murray Center and six other state-operated developmental centers, argued that process was being hindered by the state withholding necessary documents. The information includes all documented evidence and answers to written questions regarding their policy and actions which led to the state's decision to close Murray center as well as the effects of closing the Jacksonville Developmental Center. Judge Marvin Aspen granted the plaintiffs' motion. In May, Aspen granted the plaintiff's motion for a temporary restraining order preventing the state defendants including the Illinois Department of Human Services from relocating Murray Center residents to community integrated living arrangements (CILAs) until a ruling is made on the motion for preliminary injunction. (Source: Sentinel News, July 19, 2013). More information is available on VOR's website at http://www.vor.net/get-help/legal-resources.

Making a Will Bequest to VOR!!

Will bequests are the most popular and personal way of making a difference beyond your lifetime. A bequest is a charitable gift of property to be delivered at the donor's death. You can create a will bequest simply by directing in your will that your interest in certain money or property be transferred from your estate to VOR.

Why? (1) Charitable bequests present an excellent way to pass on assets that may otherwise be substantially taxed. (2) The donor's estate may be entitled to an estate tax charitable deduction for the full, fair market value of the bequest; and (3) You will be supporting a charitable organization that you believe in and passing on a legacy.

If you would like additional information on how to leave a bequest to VOR please contact Julie Huso, Executive Director, 605-370-4652 or jhuso@vor.net.



VOR Invests Your Membership and Donations Wisely! 81% of every dollar spent is for legal, legislative, family and mission-based advocacy (VOR Annual Report 2012)

VOR is 100% privately supported with the vast majority of contributions from families of individuals with intellectual and developmental disabilities. VOR receives no government financing. We are grateful to all members for your confidence in VOR and for your financial support of VOR's mission. We invest your contributions wisely, maximizing funding for programs which directly impact our shared mission.

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Jhuso@vor.net

Julie M. Huso 836 S. Arlington Heights Rd, #351 Elk Grove Village, IL 60007 605-370-4652 Voice 605-271-0445 Fax

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Dir. of Govt. Relations & Advocacy

Tamie Hopp PO Box 1208 Rapid City, SD 57709 605-399-1624 Voice 605-399-1631 Fax Thopp@vor.net Washington, D.C.

Larry Innis 529 Bay Dale Court Arnold, MD 21012-2312 410-757-1867 Voice/Fax LarryInnis@aol.com



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TRIBUTES

Thank you to all individuals who requested or gave donations in honor of someone special, or in memory of a loved one. For those who have lost someone special, please accept our deepest sympathy.

In Memory

Pamela Chase
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