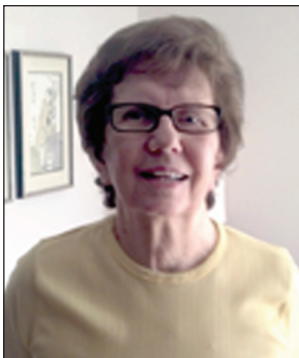


**“Coming together is a beginning; keeping together is progress; working together is success.” ~ Henry Ford**



Top (L-R) – Julene Hollenback, Superintendent, Arizona Training Program at Coolidge, and resident; Paula and Sam Golden, longtime VOR members; Jim, a resident at Bellefontaine Habilitation Center (MO). Bottom (L-R): Caroline Walsworth, longtime VOR member; Virginia Massa, resident of Holly Center (MD); Julie Huso, VOR Executive Director.

**Thank you for 30 years of advocacy for people with intellectual and developmental disabilities. If not us, who?**

## **Also Inside:**

**Around the Kitchen Table**

**My Sister: Nancy Sue Pratt**

**When Equitable Does Not Mean Equal: Respecting Diversity & Choice**

**Leaving an Advocacy Legacy: The Benefits of a Bequest**

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## “Going Home”

By Ann Knighton, President

My daughter, Erica, has profound intellectual disabilities along with a host of medical and physical challenges. When I visit federal and state elected officials, I make a point of detailing her disabilities. This is what I share:

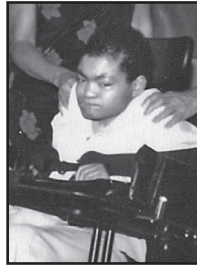
June 10, 2013

This is Erica Knighton. She is forty-five years old.

She has osteoporosis, kyphosis, hypothermia, as well as a seizure disorder, and a chromosome error. In recent years, she received a gastrostomy tube (G-tube) in her stomach through which she receives her food. Consequently, she is medically-fragile, and has profound intellectual disabilities.

Therefore, she benefits from living in an ICF/IID (Intermediate Care Facility for Individuals with Intellectual Disabilities), like Gracewood (East Central Georgia Health Care Facility).

Ann Knighton  
Erica's Mom  
VOR President and State Coordinator



While some disability advocates do all they can to distance themselves from their disabilities, Erica's survival depends on my being her voice and being realistic about her profound needs. I need elected officials to appreciate that Erica and her peers exist and need our collective support and voice, lest they be forgotten.

As VOR wrote recently for an article in *EP Magazine* (see page 6), “The human condition is not that convenient. Equitable – providing individualized care and employment options – does not mean equal. People with disabilities have vastly different needs, requiring vastly different supports across the continuum. Choices will be different. The provision of care and related costs of care must necessarily vary and be responsive to varying needs.”

## “Going Home”

Recently, Erica was hospitalized. She is fragile, so hospitalizations despite the good care she receives at Gracewood, are expected but not frequent. While updating a concerned friend, I reported that Erica would be “going home” soon. I later thought about that simple phrase and how naturally it rolled off my tongue. Gracewood is Erica's home in every way. “Going home” is no different an event for her than it is for me or you. To paraphrase *Merriam-Webster*, “home” is one's place of residence; a familiar or usual setting; a congenial environment. For Erica, Gracewood is home.

## Thank You

In the last issue of this newsletter, I quoted Richard Male, a nonprofit expert. He remarked that teamwork is the most important of VOR's many exemplary qualities. Our strength does indeed come from all of us working together. I am personally grateful to each and every member for their advocacy and financial commitment to VOR. If you can, please consider a year-end donation to VOR. I can think of no better investment. Thank you so very much.

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## VOR MISSION STATEMENT

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

# Around the Kitchen Table

By Julie Huso, VOR Executive Director

As the holidays approach and we come to the end of 2013, I've been reflecting on how Marty Pratt and a few others sat around a kitchen table 30 years ago and founded this national advocacy organization. These beginnings reflect the integrity and credibility of what we do to this day.

Growing up, I can recall the importance my parents placed on having family meals together. I can still feel the bonding that occurred by sharing conversation and food. When I became a parent, I embraced this tradition, making family meals together non-negotiable. It was an invaluable opportunity for me to communicate with my children, learning things about their lives that I may not have learned any other way.

*Isn't this the same story for the VOR family?* Our Board and Committee members gather regularly by conference calls and VOR is in regular communication with our membership, via email (at least weekly for many members who receive our *Weekly E-News Update*), phone, this print newsletter, and at our Annual Conference in Washington, D.C. Sharing and working together are only one phone call or email away. This connectedness is something to be proud of and says a lot about our NATIONAL organization and reflects those values instilled by Marty Pratt around his own kitchen table 30 years ago.

*VOR advocates are "doers" – doing what needs to be done with VOR's full support. It is this "can-do" collective spirit that will lead us into the future.*

**TOGETHER**, we will promote VOR's Quality in the Community Initiative to ensure high-quality, person centered, community-based services for all individuals with I/DD through advocacy and legislation. We have experienced too many cases of abuse, neglect and deaths due to closures and closed admissions.

**TOGETHER**, we will continue to advocate for residential and service choice. We will continue to work together to STOP the elimination of specialized residential care and supports for people with I/DD.

**TOGETHER**, we will continue to support and empower individuals with developmental disabilities and their families to carry out their roles as the primary decision-makers regarding services and supports.

**TOGETHER**, we are stronger! We can't do this alone. We need your advocacy and financial support. For financial stability and growth into the coming year, we have set an aggressive goal of \$55,000 to be raised by the end of December!

**Please take a moment RIGHT NOW** to help us meet this achievable goal. A reply card/envelope is enclosed for your convenience. Working together, as a family will allow VOR to remain strong, grow, and forge into the future with success.

Thank you for welcoming VOR's advocacy into your home and around your kitchen table. Together we must prevail.

*P.S. Please take a moment to share this newsletter with other family members and let them know why VOR is important to you!*



## Worth Reading: Long-time VOR Member Publishes a Memoir

George Mavridis, long-time VOR Legislative Committee member and Massachusetts Co-State Coordinator, has published a memoir of his cousin. "Joanna, God's Special Child," is his thank you to his cousin for bringing out the brother, father and advocate in him for the past 45 years.

"I was pleased to have the honor of meeting Joanna while attending the annual Thanksgiving meal at Fernald," said Julie Huso. "Although brief, I experienced the relationship George had with Joanna. As I read his book, I was very touched. George does a very good job of sharing his journey with such an amazing person and how this very special person changed his life."

George has attended VOR's Annual Conference and Washington Initiative for the past decade, often carrying with him a letter "from" Joanna – written by George in Joanna's voice to help Members of Congress and their staff recognize that their work impacts real people with real needs.

"Joanna, God's Special Child" is available on Amazon.



## My Sister: Nancy Sue Pratt

By Linda Pratt Patla



Nancy and Linda

My sister, Nancy, was born on November 21st, 1956 in Montreal, Quebec, Canada. My parents were instructed to institutionalize her and not bring her home. My parents, however, did bring her home from the hospital and told us that she was different from other babies. At the age of 7, I interpreted different as being special and told all my friends that I had a new baby sister and that she was special, and she was.

We were not a very affectionate family, but with Nancy's arrival, all of that changed. She loved us unconditionally. She taught us how to love one another and show that love to others. She was there to greet us when we came home, give us hugs whenever we needed them, or not, and cheered us on to victory. Even though Nancy's IQ was that of a 3 year old, she was more mature and smarter than that. Nancy seemed to be very aware of God's presence and loved having Bible Studies and Prayer meetings in our parents' home.

Nancy lived at home for 22 years and then was placed in Mt. St. Joseph, a beautiful residential facility, in Lake Zurich, Illinois. She lived there for the next 21 years, until her death in 2000.

At Nancy's memorial service, my younger brother, Jim, shared this story. It shows how our family viewed Nancy's life. "God told our family that He was sending us a special gift," Jim said. "We all waited and waited and finally one cold November night in 1956 the present arrived. We three children were so excited. It was beautifully wrapped and we took great care in opening it. Imagine our surprise and disappointment to realize that the gift we had been waiting for all this time was broken. When we told God that we thought He had made a mistake, God said, 'No this gift is not broken. Wait and See. She is exactly as I intended her to be, and she is what you need.' Do you know what? As usual, God was right."

This summer I had the opportunity to go to a teacher's conference in a country in Central Asia. The interpreter for the conference, Dina, has a 24 month old Down syndrome daughter named, Abby. Of course I was immediately drawn to Abby. During the conference, Dina sought me out. She wanted to know what it was like to grow up with a Down syndrome sibling. Dina has a 6 year old son and was concerned for him. The more we shared with one another, the more I realized that this country, in Central Asia, was where the USA (or Canada) was when Nancy was born as far as the care and treatment of people with developmental disabilities. Dina had been told to institutionalize Abby just like my parents had been told to do with Nancy. She did not do that, but brought her home to live. Also, there are no support groups (Dina has started one) and no programs or schools for these children. Parents do not take their children out in public. They do not want to be ostracized. I shared with Dina how blessed our family was to have had Nancy and then the story of her being a gift to us. That story meant so much to her and gave her a reason and purpose for Abby's life.



Nancy and Linda with their mother, Ellen.

Even though it will be 13 years this October since Nancy died, she is still touching lives. I feel privileged to have had her as my sister and the gift of being able to share her life with others.

### **'Tis the Giving Season: A Complimentary VOR Subscription - Perfect Gift for Your Family & Friends!**

In celebration of 30 years, VOR is offering complimentary, electronic subscriptions to its *Weekly E-News Update* and *The Voice*, its tri-annual newsletter, through June, 2015. To extend this offer to those on your holiday gift list, send the names and email addresses of those you would like to receive the VOR subscription to [jhuso@vor.net](mailto:jhuso@vor.net), and reference "Complimentary Subscription," in the subject line. We'll send a special holiday e-greeting to those on your list and get the subscriptions started right away. This information will never be shared or sold.

## Introducing VOR's Newest Board Members

“VOR’s Board of Directors sets the vision for VOR, offering critical governance,” remarked Knighton, VOR’s President in June. “We are mindful of the fact that we are elected by the VOR membership and are grateful for their trust.” VOR expresses our gratitude to every VOR Board Member and takes this time now to introduce you to the four new Board Members whose terms began July 1, 2013.



**Cindy Bartman** (New Jersey): Cindy is an advocate for her brother, Cliff, a resident at Hunterdon Developmental Center, a state-operated Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID). Since 2008, Cindy has served as the President of the Association for Hunterdon Developmental Center, and before that held various other leadership positions. She is the Treasurer and an active member of “Save New Jersey Developmental Centers,

Inc.,” a coalition of families, friends and caregivers of the residents of New Jersey’s Developmental Centers. Cindy has served as VOR’s State Coordinator and has attended the VOR Annual Conference and Initiative for many years. She resides in Waldwick, NJ, with her husband, Pete, her mother for whom she cares for, and, the newest member of their family, a puppy named Rudy Bear.



**Gilbert Fonger** (Illinois): Gil joined Marklund in February, 2011, as President/CEO, after serving for more than 20 years in a number of positions in the nonprofit field, with the past four years in the I/DD field. Marklund offers private ICF/IID and Skilled Nursing Facility services for children and adults. Prior to Marklund, Gil served as chief development officer at Little City Foundation, which services people with I/DD, and prior to that he held various executive positions with the YMCA of Metro Chicago, and served as a pastor for more than 10 years in Florida. He and his wife, Paula, have a daughter with special needs who lives at home, and a son in college.

**Terry Kopansky, EdD** (Tennessee): Terry serves as the Executive Director, Mur-Ci Homes, Inc., a private ICF/IID in Antioch, Tennessee. During a 32 year career with the Metropolitan Nashville Public Schools, Terry served as a special education teacher, District Consultant for Special Education, and principal of two special education schools. For nineteen years, Terry taught a variety of graduate and undergraduate special education courses as an adjunct professor at Belmont and Travecca Universities in Nashville, Tennessee. Having spent the major portion of his professional career serving children and adults with special needs in specialized settings, Terry has long recognized the value of such options and continues to be a strong advocate for a full continuum of services as opposed to the “one size fits all” inclusion approach.



**Joanne St. Amand** (New Jersey): Joanne is a sister, a volunteer and a retired research scientist who worked at BASF Corporation (formally Engelhard Corporation), Iselin, NJ for 34 years. She has been a volunteer with her church, her community and non-profit organizations. Her 58 year old sister Rosemary was born with profound I/DD and has lived at Woodbridge Developmental Center since she was 20 years old. Joanne is an advocate for the intellectually disabled and became a member of the Woodbridge Developmental Center Parents Association in 1985. She is currently the president of the WDCPA, as well as a board member for the Foster Grandparents / Senior Companion program in NJ, and the president of “Save New Jersey Developmental Centers, Inc.” She has been recognized as an outstanding volunteer in Cranford, NJ. Joanne resides in Cranford with her husband, Bob.

### VOR Board and Officers July 1, 2013 – June 30, 2014

Welcome new\* Board Members and Officers!  
Thank you returning Board Members!

Ann Knighton (GA), President  
Jill Barker (MI), First Vice President\*  
Jill Goldstein, Second Vice President\*  
Geoffrey Dubrowsky (NJ), Treasurer  
Sybil Finken (IA), Immediate  
Past President and Secretary

Cindy Bartman (NJ)*	Terry Lafleur (LA)
Gil Fonger (IL)*	Linda Lotzi (PA)
David Hart (MA)	Mary Reese (MD)
Terry Kopansky (TN)*	Joanne St. Amand (NJ)*
Mary O'Riordan (CA)*	Mary Vitale (MO)
Mary McTernan (MA)	

# When Equitable Does Not Mean Equal: Respecting Diversity and Choice

*VOR presents its Key Principles in Support of Ensuring the Rights and Opportunities of All People with Disabilities. The organization calls on the broader community of advocates to support and promote these principles.*

The world of disability advocacy boasts its own language, for better or worse. In some instances for the better, hurtful labels to describe a type of disability have been replaced by words that do not yet have a pejorative connotation.

In other cases, however, terms of common usage, such as “choice,” “inclusion,” “integration” and “community,” have been incorrectly redefined to mean only certain choices or certain places according to the user’s ideology. In these instances, some individuals with disabilities have suffered due to a lack of individualized care in favor of ideology.

Consider the situation facing residents of Apache ASL Trails, an apartment complex serving seniors with hearing impairments. “ASL” is in reference to American Sign Language and Apache ASL Trails boasts architectural features designed to meet the unique needs of its residents, such as flashing lights instead of doorbell or phone sounds, and wiring in common areas that pipe announcements directly to residents’ hearing aids. Beyond architectural conveniences, the complex features a sense of community among similarly-disabled residents who are able to communicate and socialize.

If this scenario involved college students or non-disabled seniors, there would be no argument from advocates or the federal government about the community and cost efficiencies fostered when similarly-situated individuals live together.

Yet, the U.S. Department of Housing and Urban Development (HUD), without interviewing a single deaf tenant who are happy and “not lonely anymore,” filed a discrimination complaint against the developers of Apache ASL Trails, the construction of which was supported in part by federal funds. Incorrectly citing

*Olmstead*, HUD alleged that the complex is engaging in housing discrimination because most residents are hearing impaired and thus are not “integrated” enough with the general population.

Regrettably, this is not an isolated example of a misguided ideology empowered by a misinterpretation of *Olmstead*. Rather than support “inclusion” and “integration,” these actions impose limitations that can lead to isolation and, at times, risk.

## Employment Inclusion

Advocacy and policies around the employment rights of individuals have marched down a similar path.

Competitive employment - adults with disabilities having the right to work full time and receive at least minimum wage in regular workplaces – is the ideal for many individuals with disabilities, but not all. Some individuals with more serious disabilities require reduced hours, more training, and additional assistance. For these individuals sheltered and supported employment options allow for a meaningful and productive day that may otherwise be out of reach.

Recognizing the need for a continuum of employment options, the New Jersey Legislature recently voted to save its sheltered employment for its citizens with disabilities. In other states, disabled employees who count on sheltered employment options may not be so lucky. Like other areas of disability advocacy, “choice” and “inclusion” have come to mean only competitive employment. Federal funding cuts and advocacy are pushing states to drop their sheltered employment options to provide disabled individuals the “right” to receive competitive employment. However, this could

well be an empty “right.” Even in robust economic times, unemployment rates for individuals with disabilities remain very high. Historically, employers have not had the time or funds to train, supervise and support someone with a disability.

“For those who are not capable of working in community settings but are still capable of work, and want to work, and enjoy the company of their colleagues and the staff at a sheltered workshop, this can be a meaningful alternative – and one vastly superior to spending their days in less productive (or nonproductive) activities at their residences.” (Testimony of Linda Blumkin, VOR member, before a New York Office for Persons with Developmental Disabilities Town Hall Meeting (September 13, 2013).

Full inclusion / competitive employment advocates claim to be protecting rights, yet they may actually be limiting rights by limiting choices.

## A New Vision for People with Disabilities: Respecting Diversity and Choice

In an effort to correct for past sins, the disability community has over-corrected. There is nothing person-centered about policies which support forcing all individuals to accept services and supports in small, “community-based” settings. Instead, this is a potentially dangerous quest for “sameness.” The human condition is not that convenient. **Equitable – providing individualized care and employment options – does not mean equal.** People with disabilities have vastly different needs, requiring vastly different supports across the continuum. Choices will be different. The provision of care and related costs of care must necessarily vary and be responsive to varying needs.

*Continued on page 10...*



## VOR Joins other State and National Groups in Call for Inclusive Federal Definition of “Community”

VOR was among sixteen state and national organizations joining on a letter to Kathleen Sebelius, Secretary of the U.S. Department of Health and Human Services’ (HHS), and Marilyn Tavenner, Acting Administrator for the Centers for Medicare & Medicaid Services (CMS), calling on these officials to reject a proposed federal rule to define “community.” If finalized, the proposed rule will define community so narrowly that many current and future housing options for people with intellectual, developmental disabilities, and autism, would be deemed “too institutional,” and be denied Medicaid home and community-based funding.

“Each person is entitled to the most integrated setting for that person’s needs, determined on a case-by-case basis,” the groups wrote, citing Olmstead. “Many autistic adults and others with I/DD are adversely affected by unstructured settings. These settings can be isolating, provide too little assistance and/or supervision, and are thus detrimental to the individual.”

VOR and the other organizations joining the letter have been outspoken opponents of the proposed rule. The groups call on Secretary Sebelius and Administrator Tavenner to embrace principles in support of individual choice, as required by Olmstead, and to reject a definition of “community” which would prevent innovative housing options and lead to home closures and isolation. At the urging of advocates, Members of Congress from California, Delaware, Iowa, Michigan, Nebraska, and Nevada have also expressed concern about the proposed rule.

### Save The Date!

VOR 2014 Annual Conference  
and Initiative

*“Making it Happen:  
Reforming Policy and Law  
in Support of Person-Centered  
Quality and Choice”*

**Conference**  
Sunday, June 8, 2014  
Hyatt Regency

**Congressional Initiative**  
Week of June 9, 2014

**Details coming soon:**  
[www.vor.net/events](http://www.vor.net/events)

### VOR + Holiday Shopping Celebrating Home – Bringing Families Together Fundraiser

VOR is pleased to announce once again our annual partnership with Celebrating Home, a company which sells candles, candle holders, gift wrap, cookbooks and more. Celebrating Home products make great gifts for family and friends.

**Here’s the best part:  
VOR will receive 50%  
of all sales!**

For more information, visit  
[www.vor.net/donate-now](http://www.vor.net/donate-now)

## VOR Responds to Commission on Long Term Care Recommendations

VOR supports the Commission on Long Term Care’s recommendations, released September 12, 2013, that called on Congress to recognize the need for a long term care delivery system (LTSS) that is truly person-centered by focusing on individual needs to ensure that “people can access quality services in settings they choose,” and “improve focus on quality across settings of LTSS - with particular attention to home and community-based services.”

VOR submitted written comments, calling on the Commission to recognize the need for an array of long-term care options to meet the diverse needs and choices of people with disabilities. VOR also sought Commission support for national background checks, livable wages, licensing, certification, and ongoing training for direct care workers.

In response, the Commission supported a “LTSS system that is able to support family caregivers and attract and retain a competent, adequately-sized workforce capable of providing high quality, person- and family-centered services and supports to individuals across all LTSS settings.” The Commission also recommended that the “federal government work with states to enable national criminal background checks for all members of the LTSS workforce.”

“In June, VOR called on Congress to support national background checks and to further study the relationship between key direct staffing issues and quality of care,” said David Hart, Chairman of VOR’s Legislative Committee. “Likewise, the Commission’s recommendations support greater attention to background checks, livable wages, adequate training, and retention. In this regard, we’re quite pleased.”

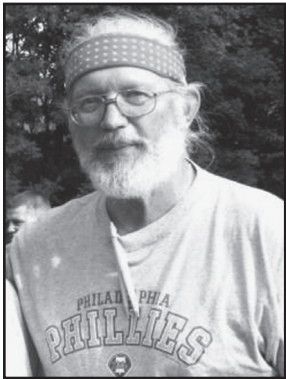
The Commission on Long Term Care was comprised of 15 Senate, House and Presidential appointees.

**Illinois: Judge Rules Murray Center Lawsuit Can Move Forward**

Federal Judge Marvin Aspen rejected the State’s (Defendant’s) Motion to Dismiss, allowing a lawsuit filed by the Murray Parents’ Association and developmentally disabled groups (Plaintiffs) to move forward on all major claims, including the Americans with Disabilities Act (ADA), Equal Protection, and Medicaid. Plaintiffs are trying to block the closure of the Murray Developmental Center in Centralia, Illinois. In an earlier decision, the Judge granted the Plaintiff’s request for a temporary restraining order, preventing any transfers from Murray Center, unless by choice, until further review by the Court.

Regarding Olmstead, the Supreme Court’s landmark ADA decision, Judge Aspen wrote, “In light of the Supreme Court’s admonitions, Defendants’ reliance on Olmstead here is misplaced. Surely Olmstead requires Defendants to provide community-based treatment when the three prerequisites, including patient consent, are satisfied. But Defendants’ efforts to comply with Olmstead do not justify the alleged forcing of CILA [community] placements on class members and their guardians who vigorously oppose such placements. While Defendants may wish to encourage community-based treatment for all who qualify and consent pursuant to Olmstead, Plaintiffs’ complaint alleges far more draconian conduct.”

**Pennsylvania: Solving the Guardianship Challenge One Group at a Time**



Tom Kashatus, President of the White Haven Center Relatives & Friends Association, solved a problem that was the result of a P&A lawsuit. Although a federal judge allowed families to intervene, residents without guardians were at risk. The lawsuit required that all residents who “did not oppose” be moved to smaller settings, even when the individual was unable to communicate; silence was taken as consent to move. In response, Kashatus arranged for a group guardianship proceeding at White Haven Center. Thanks to the understanding of Judge Richard Hughes of Luzerne County Court of Common Pleas and the help of Wilkes-Barre, Pennsylvania attorney Frank Hoegen and his paralegals, Mary Wargula and Angela Simko, the White Haven Center Relatives and Friends Association, Inc., a 501(c)3, is now the official guardian on record for those adjudicated by the court as requiring guardianship. Association members are assigned to individuals and have the responsibility to be sure there is

someone knowledgeable about the desires and needs of these residents. Prior to appointing guardianship, however, the Judge had to determine guardianship was appropriate. Attorney Charles Petrillo of Wilkes Barre served as court-appointed counsel for these residents for that purpose. “We couldn’t think of a better way for our Relatives and Friends group to carry out our mission on behalf of these residents,” said Kashatus who also praised the work of Judge Hughes, attorney Hoegen and his staff, and attorney Petrillo. “Without their cooperation and expertise, we could not have helped these residents who needed us.” For more information, visit [www.vor.net/get-involved](http://www.vor.net/get-involved).

**Texas: Family Supported Equal Information Access Bill Signed by Governor**

HB 2276 passed the Texas Legislature without opposition and, on June 14, was signed by the Governor. This equal information-access bill simply requires the authority in each Texas County (as the gatekeeper to all services) to give each person a brochure containing information about all programs available including the state supported living centers across Texas and which centers have openings nearest to them. The State of Texas will offer a brochure that lists all options. The brochure will be signed by case managers and individuals, or their legal representatives, to ensure that information about all services is being presented and represented in a fair and equitable manner. In the past, individuals and their families were often not made aware of available services at state supported living centers.

*...Continued on page 10*



## Leaving an Advocacy Legacy: The Benefits of a Bequest

Will bequests are the most popular and personal way to 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, a nonprofit 501(c)(3) organization.

### Federal Estate Tax Savings

Charitable bequests present an excellent way to pass on assets that may otherwise be substantially taxed. An outright gift to VOR from your estate, whatever the amount, is entirely free from federal estate taxes. This means that VOR is able to use the full amount of the bequest, whereas, if it were left to an individual, a significant amount might go to federal estate taxes. Also, bequests are generally not subject to state inheritance or estate taxes. In addition, the donor's estate may be entitled to an estate tax charitable deduction for the full, fair market value of the bequest.

### Types of Bequests

- |  |   |   |
|--|---|---|
| ■ <b>CASH BEQUEST</b><br>VOR receives a specific dollar amount from your estate. | ■ <b>BEQUEST OF PROPERTY</b><br>VOR receives specific assets, such as securities, real estate, or tangible personal property. | ■ <b>RESIDUARY BEQUEST</b><br>VOR receives all or a percentage of the remainder of your estate after the payment of any specific bequests and expenses. |
|--|---|---|

### Another Option: Gifts of IRAs/Retirement Plan Assets

You can designate VOR as a beneficiary of part or all of the remainder of your IRA or qualified pension or profit-sharing plan upon the death of your survivor beneficiary (e.g., your spouse) Non-charitable distributions from retirement plans can be subject to both income and estate taxes. In a large estate, these taxes can leave less than 30 cents on the dollar of the plan's balance for your children or other heirs. However, by naming VOR as the beneficiary of the remainder of your retirement plan, 100 percent of the plan's balance is available for VOR's use, since the distribution avoids both income and estate taxes.

To arrange for VOR to be a beneficiary of part or all of the remainder of your IRA or related retirement plan upon your passing, you must notify your plan's administrator. A "change of beneficiary" form will be required.

### Sample Language for Bequest or to add VOR as a Beneficiary

**Specific or Residuary Bequest:** "I give \_\_\_\_\_ (insert dollar amount or item of property to be donated or % amount) to VOR, Inc., a nonprofit corporation as described in section 170 of the Internal Revenue code, located at 836 S. Arlington Heights Rd., Elk Grove Village, IL 60007, to be used in VOR national advocacy on behalf of people with intellectual and developmental disabilities."

#### **Beneficiary Designation Language for a Spouse and VOR:**

"The beneficiary is my spouse as long as he/she survives me. The beneficiary of any amount(s) remaining in the plan after the death of my spouse, or of the entire amount in the plan upon my death if my spouse does not survive me, or of any portion thereof that my spouse may disclaim, is designated to VOR, for its general charitable purposes and advocacy work.

#### **THANK YOU FOR YOUR CONSIDERATION**

If you would like additional information please contact, Julie Huso, Executive Director, VOR. Julie may be reached at [jhuso@vor.net](mailto:jhuso@vor.net) or at 605-370-4652.

**Legal Disclaimer:** Because each state has its own laws, you are encouraged and advised to contact your personal attorney and tax accountant to receive professional advice to determine the best way for you to make a lasting gift to VOR.

## California: Sonoma Families Rally in Support of Center; Task Force Deliberations Offer Guarded Optimism

Family members, employees and concerned local residents rallied in support of Sonoma Developmental Center, a state-operated facility. About 60 people attended, many of whom have family members who they say could not receive the care they need anywhere else if the state moves to “evict” them from the place most have called home for decades. In a related effort, VOR Board Member, Mary O’Riordan, initiated a petition that garnered more than 2,300 signatures and was been presented to local legislators.

“SDC is home to some of California’s most vulnerable and challenging residents,” said Kathleen Miller, President of the family association of Sonoma. Her autistic son has failed several attempts at living outside the facility.

Miller also sits on a 19-member state task force which includes various stakeholder including families. The Task Force has discussed the “future of developmental centers,” citing a continuing need for a stable quality array of services, especially for individuals with medical needs and challenging behaviors, and DD individuals involved in the criminal justice system. Several Task Force participants recognize and support the role developmental centers already play.

The Task Force must complete its work by November 15 and produce a written Master Plan that addresses: (1) The effective and efficient delivery of integrated services to meet the specialty needs of developmental center residents; and (2) The fiscal implications of developmental center operations, including the cost of resident care and services, maintenance of aging infrastructure, and utilization of existing resources.

*When Equitable Does Not Mean Equal: Respecting Diversity and Choice continued from page 6...*

People with disabilities should not have to endure a different standard of community than other populations and society in general. Rights should be individualized, respectful of diverse conditions, and inclusive of the entire disability population. In this spirit, VOR released its **Key Principles in Support of Ensuring the Rights and Opportunities for All People with Disabilities**, available on vor.net. We call on the broader community of advocates to support and promote these principles.

*By VOR (Excerpts). For copy of full article, as published in EP (Exceptional Parent) Magazine, October 2013, visit <http://www.vor.net/images/stories/pdf/EPRespectingDiversity10-13.pdf>*

*To read VOR’s Key Principles in Support of Ensuring the Rights and Opportunities for all People with Disabilities, visit: <http://vor.net/images/VORPrinciplesSept2013.pdf>*

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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.

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VOR is offering complimentary, electronic subscriptions to its *Weekly E-News Update* and *The Voice*, its tri-annual newsletter, through June, 2015. To give as gifts, just send VOR the names and email addresses of those on your list to [jhuso@vor.net](mailto:jhuso@vor.net), and reference "Complimentary Subscription," in the subject line. We'll send a special holiday e-greeting to your list and get the subscriptions started right away. This information will never be shared or sold.

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A large, faint, light gray version of the VOR logo's curved lines graphic is positioned in the background behind the central text.

**The VOR Board of Directors thanks each and every member  
for their advocacy and financial contributions.**

*“How lovely to think that no one need wait a moment; we can start now,  
start slowly changing the world!”*

— Anne Frank (diary entry, 1944)