

**REMINDER:** AUGUST is a great time to meet with your U.S. Representative in his/her District office near your home to seek support for H.R. 3995. Call to make an appointment today.

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**VOR Weekly E-Mail Update**

**August 15, 2008**

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**STATE NEWS**

**REACHING THE MEDIA SUCCESS**

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**COMING UP:** More State News, including Oregon and California

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**1. IOWA: Mother sees compassionate care at Glenwood**

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**About the Author:** Sybil Finken is the First Vice President of VOR, national advocacy organization for people with developmental disabilities. Her son Seth is profoundly disabled and

resides at the Glenwood Resource Center. She is a veteran music teacher for the Glenwood Public Schools. She and her husband Russ reside with their daughter Carmen in Glenwood.

## **Mother sees compassionate care at Glenwood**

**Opinion Editorial by Sybil Finken, VOR First Vice President**

**August 2, 2008**

**Des Moines Register**

I am the mother of four children.

Son Zach lives near Chicago where he is the Executive News Editor of the Chicago Sun Times. Son Luke lives in Colorado where, following in his parents' footsteps, he is an educator.

My youngest, Carmen, will be a junior in high school this fall. She is an honor student, involved in many school and community activities. Carmen is well poised for a very bright future.

Son Seth's achievements are also remarkable. We've nurtured Seth and continue to provide all we can to ensure his continued happiness. Seth is severely disabled. He suffered meningitis when he was 7 months old. Seth is deaf, blind, has profound mental retardation, is wheelchair bound, and has a seizure disorder. His home is Glenwood Resource Center (GRC.)

No one ever questions our decisions on behalf of Zach, Luke and Carmen. My husband Russ and I are not shy about taking some credit for the amazing people they have become. Yet, we are increasingly challenged about our care choices for Seth, especially in light of recent news stories about care at Glenwood.

As a longtime national disability advocate, I'm familiar with the question of whether institutions such as GRC are ever appropriate. I

frequently talk with parents and advocates for the disabled in other states. And they have told me about the terrible problems their loved ones face when facilities like GRC are closed: long wait lists and seriously compromised care in community settings. I have responded that Iowans are sensible people. We know that a range of options is necessary. GRC isn't for every disabled person. A person with mild mental retardation who can take the bus to his/her job at HyVee can thrive and be happy in a community setting. But Seth will never be like that. GRC is the only place for him.

Common sense, however, doesn't always carry the day and the concerns I have heard from families in other states are suddenly very close to home.

Advocates who trumpet the "one size fits all" approach to disability services seem uncomfortably delighted by recent headlines which call into question the quality of care at GRC. These advocates are saying "I told you so" and calling for the closure of Glenwood and (for good measure) Woodward Resource Center, Iowa's other specialized mental retardation facility. These advocates - some of whom have never met me, Seth or visited Glenwood - are also saying, indirectly, "I am a bad mom."

Yes, I am offended.

The headlines are scary and alarming, and families have responded. We are the first in line to raise concern, get the full story and call for improvements. Families are not blindly supportive of Glenwood Resource Center. The protective reflex in parents is like none other; it is only magnified when your loved one is basically helpless and at the mercy of caregivers.

We support Glenwood Resource Center because we know Seth receives compassionate, state of the art care by people who have worked with him for years. We visit Seth regularly, dropping in unannounced. If Seth were being harmed, we'd know it.

So what is the full story? Much of the concern relates to paperwork, process and documentation. If, indeed, there are needed changes to

policies and procedures, then, yes, those changes must be made. The state and federal oversight of Glenwood - as opposed to the basically nonexistent oversight of scattered community homes - gives parents like me so much comfort. When people like my son are forced from a place where their superlative treatment is examined with microscopic intensity to a "free" environment in the "mainstream" community, they are too often ignored and the quality of their lives depreciates beyond belief. These failings don't often make front-page headlines. But they are all too real.

We call on Glenwood's administration and state officials to improve its documentation and reporting, recognizing this can only offer a degree of protection not available anywhere else. Meanwhile, visit Glenwood Resource Center for yourself. I think you will agree that the lack of paperwork is not worth closing a remarkably compassionate home for Iowa's most vulnerable citizens.

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## **2. IOWA: More about Sybil -- Glenwood citizen to serve as national disability organization's First Vice President**

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### **Glenwood Opinion Tribune**

**April 30, 2008**

A local and national leader in disability advocacy has been nominated to serve as First Vice President for the national organization, VOR. Sybil Finken of Glenwood will begin her term on July 1. Finken has served on the national organization's board of directors for since 2003.

VOR, which is celebrating its 25th anniversary in 2008, is well-known for its advocacy in support of people with profound developmental disabilities.

"Sybil has served VOR as an advocate and leader for many years," said Mary O'Riordan, Chairman of the VOR Nominating Committee that selected Finken to serve as the organization's next vice president. "She's known by her peers as a level-headed thinker who is willing to roll up her sleeves to help get the job done."

"She is very service oriented," agrees Tamie Hopp, VOR's Director of Government Relations and Advocacy. "When VOR asks its members contact their Members of Congress, Sybil is always among the first - if not the very first - to report she's followed through."

"This sort of 'drop everything' responsiveness contributes significantly to VOR's success as a grassroots organization," added Hopp.

Finken's motivation for involvement is personal. Her son Seth, age 29, suffered meningitis when he was just 7 months old. The resulting disabilities were profound. He is deaf, blind, has profound mental retardation, is wheel-chair bound, and has a seizure disorder.

Yet, he's content. "Seth has been blessed with receiving compassionate state of the art care at Glenwood Resource Center for much of his life," says Finken.

Nationally, the trend has been away from large facility care for people like Seth, favoring instead community-based care.

"There is a 'big is bad' philosophy around this country," said Finken. "Fortunately for Seth and his peers, Iowans are sensible people. We recognize that people with developmental disabilities are not all alike. There is a tremendous range of needs. People should have choices to meet those needs."

In Iowa, funding for community based long term care for people with developmental disabilities is nearly equal to what is spent to provide care at the two state facilities, and a smattering of smaller licensed facilities throughout Iowa.

That's the way it should be, says Finken. "For most people with developmental disabilities community placement is most appropriate - Iowa should be supporting people in the community equally."

It is the principle of choice that drew Finken to VOR several years ago. VOR is known for its support of a full array of residential services for people with developmental disabilities. It carries out its mission by tracking and responding to trends across the country that are threatening the facility option.

VOR is the only organization that supports families like the Finkens, who feel strongly facility based care best meets their family members' intense and specialized needs.

"I credit VOR for the fact that we still have two facilities with experienced staff providing compassionate support to more than 500 Iowans with significant developmental disabilities," says Finken.

She bristles at the suggestion that Glenwood Resource Center is somehow segregated.

"The Glenwood Community School District, serving school children from pre-school through high school, shares the same campus as Glenwood Resource Center. There is also a workforce development center, a domestic violence shelter, offices for the Department of Natural Resources Conservation and Forestry, a variety of University training and research programs, and much more on the Glenwood campus," shares Finken.

"If that's not integrated, I don't know what is."

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### **3. KENTUCKY: Oakwood ICF/MR - Reality better than perception**

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**By Chris Harris, CJ Staff Writer**

**Commonwealth Journal**

**August 11, 2008**

Children running, laughing, playing. Big colorful inflatables. People singing, dancing, having fun. It's a joyous scene, to be sure.

In fact, it was the scene at Oakwood Saturday - not a place with a reputation for happy times, necessarily, but one where many employees and family members of residents will tell you things are much better than the public perception indicates.

"Family Day" has become a tradition at Oakwood over the year - it's been going on for a long time, but this is only the second such event held under the leadership of the Bluegrass Mental Health-Mental Retardation Board, which took over management of the besieged mental health facility in November of 2006.

Gayle Rees, both a parent of an Oakwood client and president-elect of the advocacy group P.R.O.O.F. (Parents and Relatives Of Oakwood Facility), said that this is possibly the largest event in terms of scale and number of fun attractions offered - indeed, spread out across Oakwood's lush green campus was a sea of carnival game stands, umbrella-shaded tables, inflatable slides and giant alligator-shaped structures that brought to mind some place like King's Island more than the troubled Oakwood that makes the headlines.

Rees is clearly proud of what has been done at Oakwood over the last two years, as Bluegrass inherited a facility teetering in the brink of oblivion after a string of citations for incidents of abuse and neglect. Under Bluegrass and CEO Joseph Toy, Oakwood has virtually erased the problem trends while steering the home for developmentally disabled residents back toward Medicaid certification.

"If I was the Inspector General, I would approve this place," said Rees, referring to the need for an upcoming survey to determine whether the facility will be able to regain its federal funding and thus retain its future.

Few people wouldn't approve on a day like Saturday. With warm weather and the smell of grilled food in the air to mix with the sound of residents and family members belting out karaoke tunes, smiles were plentiful on the faces of those in attendance.

Dr. Claude Farley of Lexington sat in the shade at a picnic bench with several members of his family, including his son Scott - a developmentally disabled resident of Oakwood. He found inspiration in the day's event, reminding him of "how much a part of the human family we all are," and was clearly enjoying time with his son rather than feeling concern for his safety.

"It's wonderful (home for Scott)," said Farley of Oakwood. "It provides not only safety and security for him but the kind of activity he can't get at home. He has a job here that's very meaningful to him. He's able to earn a little money, which makes him proud and gives him a reason for being. They need a reason to belong. Oakwood is now giving them that reason."

Farley is impressed by the job done by Bluegrass since the non-profit Lexington-based organization took over, doing away with the state's merit system employees, an employment loophole which Bluegrass felt protected individuals who didn't take the safety and well-being of Oakwood's residents to heart.

"It's getting back to where it was originally - it's an organization that cares about the residents," said Farley. "We were down a long, lonely road there for a while, but (Bluegrass has) done a marvelous job in bringing it back and making it a place we can be proud of."

Dorothy Stevens knows that long and lonely road well - she has been employed by Oakwood for 19 years. In that time, she has seen a remarkable amount of growth and development, and hasn't seen much happier times than exist currently.

"We've undergone dramatic differences (in the last 19 years)," said Stevens. "We used to take clients from their home and go to the classroom for two-and-a-half hours a day. We had a mock room that had shelves set up and empty cardboard containers and we would sit in there letting them choose empty containers off the shelf.

"Now we have a community living room where (the residents) can do the cooking, they can go out and do the grocery shopping, write down grocery lists, find out what value of money is," she continued. "You can see a major difference."

Stevens said that the tone of her own voice was an indication of progress - in 2006, under the previous management, you wouldn't have heard such enthusiasm, she noted.

"It's much better under Bluegrass than it even was under the state," she said. "(It used to be that) you had to wait three months to even get a stapler for the classroom. It's a major overhaul - staff morale is so much better."

P.R.O.O.F. held an annual meeting in the Oakwood gym in the midst of the festivities, which featured special words from Somerset Mayor Eddie Girdler and key Kentucky lawmaker Sen. Julie Denton.

Girdler said Oakwood is part of the Somerset "family" and stressed the importance to this city of keeping the facility viable.

"I have elevated Oakwood to same status as any department (or) any activity in Somerset," said the mayor. "The large industries, the hospital - Oakwood will get the same attention. We have started a number of contingency items to ensure that Oakwood is successful, that it does remain open, and that we are committed to the quality of life of every (individual) that lives here."

Denton, a Republican and chairperson of the state's Health and Welfare Committee, said she has been to a number of similar family day events at other facilities and Oakwood's ranks among the very best. She expressed a desire to see the facility succeed and encouraged anyone else concerned about Oakwood's future to contact her, whether they live in her district or not.

"It's really just a village. This is not an institution ... the staff is just fabulous," she said. " I think you have a lot of support in the legislature. It's so crucial for you to keep lobbying your legislators.

"Whether it's a community or a home, a facility or a village, I think you have to all options open," she added. "I do believe that it's the right thing to do."

A large number of families were in attendance throughout the course of the day, with the event lasting from the morning to late afternoon. Most of the families are already familiar with the campus, said facility director David Phelps, but are able to see it in a whole new light under these conditions.

"We have some families here with as many as 15-20 family members here for one person," said Phelps. "That doesn't happen on a regular basis, except for 'Family Day'.

"It looks like everyone is having wonderful time," he added. "People come up and say this (event) gets better every year. The staff enjoying themselves, and the people live here are enjoying themselves."

In order for Oakwood to survive, the observation that the residents are enjoying their time there cannot be emphasized enough.

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#### **4. PENNSYLVANIA: 348 residents need Selingsgrove Center**

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Note: This article focuses on the excellent care received by current residents of Selingsgrove Center. The article features Bert and Leni Springstead's son, Craig. Bert recently retired from VOR's Board of Directors after serving six years. Although this article features the needs and preferences of current Selingsgrove Center residents, the next article, which describes the plight of 21,000 people in Pennsylvania waiting for MR/DD services begs the question just how many of these people would benefit from Selingsgrove Center services.

**By Amanda O'Rourke**

**The Daily Item**

**August 03, 2008**

**SELINGSGROVE** -- The Springsteads park their minivan out of sight of their son, Craig, who upon seeing it becomes too excited to get his work done.

"You happy?" Leni Springstead asks Craig as he crawls into the back seat.

"Yeah," is his quiet reply.

It's a routine between this mother and her 49-year-old son, who has lived at the Selingsgrove Center for nearly 30 years.

Craig, who is developmentally disabled, functions at the mentality level of a 5-year-old, said his father, Bert. Craig walks slowly, with a subtle tick of his right arm.

The Selinsgrove Center, now nearly 80 years old, exists to help people like Craig, who call the sprawling 254-acre institution home.

The closing of the Laurelton Center in 1998, the Western Center of Canonsburg in 2000 and the Altoona Center in 2005 makes clear the state's desire to reduce its reliance on institutional care and improve access to home and community-based services for Pennsylvanians living with mental retardation.

Yearly assessments have determined that the Selinsgrove Center is meeting a need for Craig and the 347 other residents there, state Department of Public Welfare press secretary Stacey Witalec said. Therefore, operations continue at the Selinsgrove Center with no plans to close.

Craig's living quarters at Selinsgrove are similar to a college dormitory. In addition to furniture, Craig's bedroom is outfitted with a flatscreen TV and mini refrigerator, compliments of his parents. He has surrounded himself with family photos, as well as photos of himself, like the one of his standing in front of the ocean.

"I went to the beach last year," Craig said. "I swam in the ocean."

Craig, the middle of the Springsteads' three children, also is an avid collector of accessories -- rings, sunglasses and watches. He has dozens, but he doesn't show them to just anyone.

Craig leads a very active life at the center and because of it, his father said.

"He has a social life that's as good as mine ever was or better," said Springstead, of Newville, Cumberland County.

Because of the center, Craig has had the opportunity to go to the beach, county fairs, sporting events, dances, even ride a helicopter.

A typical day has him rising for breakfast and then heading off to work at the center's recycling center.

"We sit around and watch TV, put garbage out and we mop the floors here," Craig said of his household activities. "That's it."

### ***Center began as colony for epileptics***

The Selinsgrove Center of today and the Selinsgrove Center of yesterday are two very different places, documented in a single hallway in the institution's central building.

Behind glass showcases, hand-written ledgers dating to the early part of the 20th century put names to the institution's first function, which was as a colony for epileptics.

In cursive writing the names are entered, along with arrival dates, followed by death dates and causes, many listed as seizure or pneumonia. The development of penicillin in the 1940s is obvious in the book; the death rate plummets.

Farther down the hallway, the photos begin.

In one black-and-white shot, dozens of babies lie strewn about the floor, two, maybe three nurses watch over the lot of them. A subsequent photo reveals the cost of the time they spent in recline as infants -- flattened heads.

"We do this to remember how far we've come," said Ellen Wagner, program project director at the Office of Development Programs.

It's not a past the center or its employees are ashamed of. Though the public's perceptions of institutional living have changed over the decades, the fact is the Selinsgrove Center, first known as the Selinsgrove State Colony for Epileptics, was considered state of the art in the 1940s and 1950s, years during which the center saw many of its admissions, its high-tide population reaching 2,141 residents in 1964.

"It probably wasn't the most pleasing environment to live in," interim facility director Fred Lokuta admits.

When the center opened in 1929, 180 epileptics -- all men -- lived there in three buildings. As part of their treatment, they farmed the center's property, more than 1,300 acres at the time. They were not paid for their work.

"The ideal country setting, the peace and quiet and the rest -- that was all part of the treatment at that time," Wagner said.

### ***Remaining centers won't close, official says***

It wasn't until the 1940s that women and children were admitted. The increased population led to expansion. In the 1950s a law was passed that made the Selinsgrove State Colony for Epileptics a facility for the study, care, treatment, education and training for the mentally retarded and the name of the facility was changed to the Selinsgrove State School and Hospital.

In the 1970s, the state began an initiative that continues today to place residents of its state centers into community group homes, leading to a slow decrease in population.

"We look forward to be able to afford a community option to them when it's appropriate," said Witalec, the Department of Public Welfare press secretary. "It's our hope that we can help people continue to move into the community if that's what they wish to do and many of them, they want to be able to live at home or in a home-like setting."

It could stand to reason that the state's push to move its mentally retarded clients into community settings would eventually lead to the closure of all state centers like Selinsgrove, but Witalec was adamant that will not happen.

"I think there will always be that level of need," Witalec said. "There will always be some individuals who have such a unique situation or a high level of care that's needed that it may not be appropriate for them to move into the community. There will always be a need."

Today the center cares for 348 residents, all older than 22, with an average resident age of 58. As its residents age, Lokuta said, the center must consider their changing needs, which include Alzheimer's care and care for advancing physical disabilities.

Nearly 900 employees provide medical and mental health care, physical and speech therapy, nutritional care and pastoral services. A vocational department provides work opportunities to center residents.

### ***Father: Center provides needed care***

Springstead said he believes that the level of care provided at the Selinsgrove Center is one his son will always need, and prefers his son not be moved into a group home, believing it would actually limit Craig's freedom.

"He's had pretty free reins at this place," Springstead said. At another place, "He'd have someone hovering over him. Craig doesn't want to be hovered over. Nor do I.

Being the father of a developmentally disabled child is a life of ups and downs, Springstead said, from the frustration of getting Craig placed into a facility that could address his needs to the guilt, however unreasonable, of having a son who has special needs to begin with.

Springstead, a retired Army man, never realized the full potential of a career in the military.

There will be no retirement to Florida for him and Leni Springstead.

"It kind of keeps your foot nailed to the floor," Springstead said.

"But I wouldn't pull my foot loose from the floor if I could. I won't leave him."

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## **5. PENNSYLVANIA: Mentally handicapped in Pa. await more help**

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**Summary:** More than 21,000 Pennsylvanians were awaiting services through the mental retardation system as of June.

**By Craig Smith**

**Pittsburg Tribune-Review**

**Monday, August 11, 2008**

Lisa and Doug Kosanovich hope a Pittsburgh charity can do for their daughter what the state can't.

They're seeking \$5,000 from Variety, the Children's Charity, to help cover the cost of building a wheelchair ramp for Lainey, 13, who is mentally retarded and has a disease that's causing her hip to crumble.

"It's frustrating. There's a huge paper trail, but then you don't get anywhere," said Lisa Kosanovich, 40, of Daugherty in Beaver County.

Lainey Kosanovich is one of the more than 21,000 Pennsylvanians on a waiting list for services, including more than 4,500 who were classified as having "emergency" needs and more than 9,500 listed as having "critical" needs.

She has been on the emergency waiting list for five years.

State money could be used to build the ramp, administrators said. But in the days of tight budgets, it often comes down to choosing among emergencies.

"So many people have emergencies, but what's the worst emergency? There's money, but there's not enough of it," said Nancy Murray, president of The Arc of Greater Pittsburgh.

The Arc of Pennsylvania said the state's new budget fails to adequately address the needs of those with intellectual disabilities. Although the budget includes a previously planned 1 percent "cost-of-living" increase -- which officials said doesn't cover

inflation -- the state also calls for a 1.3 percent spending reduction.

"This is not a good way to run a railroad," said Steve Suroviec, executive director of the state organization.

## **WHAT WILL BECOME OF THEM?**

Helen Waite, 75, of Irwin has different concerns for her mentally retarded son. She worries how he'll manage when she no longer can care for him.

Waite would like to see her son, Harry, 46, live with a roommate and a full-time caregiver, but she knows there's no money for that in the mental retardation system. Still, she holds out hope.

"Our needs right now are covered. But I know the time is coming when he is going to need help," said Waite, whose husband, Raymond, 79, has Parkinson's disease.

More aging parents are losing the ability to care for adult children, mental retardation program officials said. Some mentally retarded people aren't attending day programs because they are staying home to care for aging parents.

The money shortfall makes it difficult to move people off the waiting list, said officials of the mental retardation system, which receives money from two primary sources -- the federal and state governments through the Medicaid program.

Pennsylvania moved 3,500 people off its waiting list in 2007 and planned to help 1,800 on the list this year. The Department of Public Welfare said the reduction in the approved state budget likely will reduce that number.

The kind of care Helen Waite hopes for could cost more than \$70,000 a year, depending on an individual's needs and the state where they live, according to the National Organization to End the Waitlists.

## **SYSTEM IN DISARRAY**

"We tend to be treading water. The system has never been able to support everybody who is in need," said Donald Clark, deputy director of the Allegheny County Office of Mental Retardation and Developmental Disabilities.

It's a national trend.

"There are problems all around the country," said Peter V. Berns, executive director of The Arc of the U.S.

The New Freedom Commission on Mental Health reported to President Bush in 2003 that the mental health system was in disarray, with unmet needs and many barriers to people needing services.

The Arc of the U.S. has started a "Stop The Wait" campaign to draw attention to the growing numbers on waiting lists. More than 285,000 people on waiting lists in 21 states are included in the campaign's database. About 716,000 people might be living with a caregiver who is 60 or older, Berns said.

"Something's got to give, sometime," said Deborah Neifert, deputy director of the Mental Health/Mental Retardation Administrators Association of Pennsylvania, which has called the mental retardation system in the state "unstable."

The system evolved from one focused on providing services in large institutions to one based on providing services in or near the home

and community. In 1966, more than 13,000 people lived in state-funded institutions. Just 1,300 people live in state institutions today.

A recent study by the Joint State Government Commission of the General Assembly made five recommendations to improve Pennsylvania's mental retardation system. Among them: making the elimination of the waiting list a priority; dedicating funding to ensure services for mentally retarded students to transition to adult life; and establishing consistent annual funding increases.

Those recommendations, if instituted, won't address people who need services but are not registered with any agency. There is no official estimate of the number of people on what mental health officials call the "shadow list."

"Some have said it could be double the waiting list," Suroviec said.

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**Tamie Hopp**

**REFERRAL/MEMBERSHIP/CONTRIBUTION FORM**

**THREE EASY WAYS TO SUPPORT VOR > REFER, CONTRIBUTE OR JOIN**

**THANK YOU FOR YOUR SUPPORT!**

**TO JOIN OR CONTRIBUTE:** \$25 per individual, \$150 per family organization, or \$200 per provider/professional organization. Extra donations are welcome!

You may pay by credit card or check.

**TO REFER SOMEONE TO VOR:** Use the form below, including the additional sections for referrals.

Mail the completed form (if joining or contributing) with payment to:

Voice of the Retarded  
836 S. Arlington Heights Rd., #351  
Elk Grove Village, IL 60007  
605-399-1631 fax (for referrals or credit card payments)  
[Tamie327@hotmail.com](mailto:Tamie327@hotmail.com) (for referrals or credit card payments)

**FOR REFERRALS:** \_\_\_\_\_ The contact information provided is for someone I think would consider membership with VOR.

**FOR REFERRALS:** \_\_\_\_\_ You may use my name in any correspondence with this individual. My name is

\_\_\_\_\_.

\_\_\_\_\_  
Name

\_\_\_\_\_  
Address (if paying by credit card, use billing address). All forms must include complete address including zip code)

\_\_\_\_\_  
City St Zip

\_\_\_\_\_  
Phone Fax

\_\_\_\_\_  
E-Mail

\_\_\_\_\_  
Family/Professional Organization Affiliation (if applicable)

VOR accepts Master Card and Visa. If paying by credit card, please provide the following information:

Amount to charge to card:

\_\_\_\$1,000 \_\_\_\$500 \_\_\_\$250 \_\_\_\$150 \_\_\_\$50 \_\_\_\$25 \$\_\_\_\_\_ Other  
amount

\_\_\_\_\_ Mastercard

\_\_\_\_\_ Visa

Card Number: \_\_\_\_\_

Expiration Date: \_\_\_\_\_

Cardholder's Signature: \_\_\_\_\_

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