



# SHIFTING SANDS



## A Spiritual Message

### The (Seemingly) Endless Season

The run-up to our November presidential elections seems endless. Has it been exacerbated by the summer’s heat, or does it just seem as though this season of campaigning is more vitriolic — and boring — than those remembered in the past? Since this may be the last Shifting Sands before election day, I thought it would be worthwhile to reflect on our duty to vote as citizens of a democratic nation and on how we should bring our Faith to bear on the choices we make.

As with all our moral choices, it all comes down to our conscience, and that simply means that I vote for the man or woman who I think will best serve in the position at stake. That, in turn, depends on what theologians traditionally call a “well-formed conscience,” on a conscience that takes its cues from the law of God, from gospel values. Are the reasons I chose this or that candidate because I think he or she will make decisions according to those values?

From experience we know that it is not always an easy choice. Not easy, first of all, to find a candidate who shares our values, even more difficult to find one who shares them completely. More often, we have to go through a balancing act, sadly voting for the better of two not-so-good options.

As Alhambra and Porto Charities folks, our concerns naturally side with the disadvantaged; we would consider especially favorable a candidate who has the same heart as we for those who were especially dear to Jesus — the poor. Tempted as we may be to vote our own personal interests, as Christians we have to reach out in our political choices as well as our personal lifestyles to the common good. It is tempting to reject out of hand, for example, any candidate who threatens to raise taxes, but our Faith and our “Alahambraesque” hearts should remind us that “it’s not about us.” It’s always about those less fortunate. In election choices that means support for the poor, the immigrant, the unborn, the elderly. It means voting for the candidates who respect the disadvantaged and those who are dependent on others for the material and moral support they need to live up to their God-given potential. It means foregoing jingoism and respecting the brotherhood — and sisterhood — of all humankind as the children of God.

Let’s pray for the upcoming elections — for all the candidates, for the country, and for ourselves, that we may take the time to prayerfully discern what is right and have the courage to vote our Christian consciences, our Faith.

*Fr. Edwin Dill, ST*

## IN THIS ISSUE

A Spiritual Message	1
Porto Charities, Inc., President’s Message	1-2
Housing Committee Report	2
Grand Commander’s Message	3
Calendar	4
Disabilities and Social Security: You Don’t Know What You Don’t Know	5
Member Profile: Jenny Holden	6
Organizations Porto Supports: JP Options	7
New ‘Waivers’ for Disabled Care Fall Short of Need in Virginia, Locally	8
Chapman’s Send-off	9
JPMF Annual Family Picnic	10
Bishop Loverde’s Mass	11

## Please Pray for...

- ❖ Margie McMahon who is undergoing a procedure for kidney stone removal
- ❖ Don Christie who is in hospice care



Call PGC Rick Vranesh (703-241-9526) if you know of anyone in need of our prayers, comfort or support.

## Porto Charities, Inc., President’s Message: Happy Dance

I am certain you all have very fond and memorable occasions in the lives of your children. Each and every loving memory is precious. Recently, my daughter Christie left one of those indelible marks in my life. She had had a paying-job interview on a Tuesday arranged for her by the Best Buddies of Northern Virginia. The very next day she was called by the interviewing employer and told that they wanted to hire her. Needless to say, Christie was ecstatic. My wife told me that when Christie

hung up the phone, she did a “Happy Dance” while she screamed “I got a job”, “I got a real job”!

I can vividly visualize Christie’s “Happy Dance” as if I were there to see it. She had called me that day and told me about her good fortune and as soon as I walked in the door that night, she ran and hugged me while she was telling me again that she got a job. She said “I can relax now Dad, I have a job”. She also asked me to help her call her aunts, uncles, and cousins about her new paying job. Christie was, as they say, “Happy as a clam at high water”.

*(continued on p. 2)*

(continued from p. 1)

Experiencing Christie's elation is dramatic testament to GC Leo's emphatic plea in his remarks in this edition of the *Shifting Sands* that "we now need to band together and get jobs and housing". I therefore wholeheartedly endorse Leo's appeal to all of us to seek avenues through our contacts to enthusiastically gain charitable financial support for employment and housing as well as the overall life enhancement and independence of God's Special Angels as Bishop Loverde affectionately calls our special needs children. Furthermore, as Father Dill pointed out at our recent PCI Board of Director's meeting, we will be approaching the Holiday season over the next months, a time when people turn to charitable giving. Let's draw on his sage counsel and put forth our best efforts to attain our charitable goals. Let's make a determined effort to ensure that the Special Angels' dream of a Happy Dance becomes reality.

Speaking of Bishop Loverde and Father Dill, please plan to attend the Bishop's annual Disabilities Awareness Month Mass at the Cathedral of St. Thomas More in Arlington on Sunday September 30th at 5:00 p.m. Indeed, the Bishop's Mass will be a most fitting and encouraging head start for our Disabilities Awareness Month. I truly look forward to seeing you all there at this joyous occasion.

In addition, I hope you all are making an enthusiastic and deliberate effort to find sponsors and participants for the annual Porto Charities Golf Tournament to be held on Friday, October 12 at the Regency at Dominion Valley Golf Club Haymarket, Virginia. The Golf Tournament is our preeminent charitable drive of the year. It is also a marvelous social gath-

ering to relax and have fun. As I have mentioned before, in order to make this fund raising event a triumph we positively appreciate your generous help in seeking sponsors to support our worthy cause. Along with this issue of *Shifting Sands*, attached to the e-mail message, you will find the flyer about the Golf Tournament as well as the Porto Charities Mission Statement that you can print out and use in your effort to find sponsors. As noted in the Golf Tournament Flyer, there is a wide array of sponsoring benefactors ranging from the Porto 104/PCI Family Sponsor at \$100 to the Corporate Hole Sponsor at \$300 and all the way to the Gold Sponsor at \$5,000. With your unrelenting support, I am sure we will achieve success in this charity fund raising endeavor. I would love to see as many of you as possible who can attend this pleasurable event.

I am very delighted to announce that the Special Kids/ Special Needs Collections from parishioners of local churches in the Arlington Diocese has wonderfully raised for us \$36,227.48 so far this year.

In closing, I must say that while writing this note, I was reminded of a quote from Henry Wadsworth Longfellow, a most popular American poet of the 19th Century, "The life of a man consists not in seeking visions and in dreaming dreams, but in active charity and in willing service". In the spirit of this quote, I firmly believe it clearly is apropos to what you all do for our Special Angels. I profoundly thank you all for your hard work.

*Carmen DiPlacido*

## Housing Committee Report

Our committee, with the assistance of various local entities serving individuals in the community with disabilities, surveyed the families of these individuals to determine their respective housing plans. With the context of the survey, we determined the timeline, budgetary elements, and service/support expectations. We received approximately 150 replies that provided the basis to prioritize PCI's housing initiative. Survey results may be viewed on the PCI website.

Additionally, the committee met with Debbie Fisher of the Jewish Foundation for Group Homes (JFGH), a well-respected and experienced service provider, to gain insight into the available levels of service and related costs. Debbie is a great resource as she and JFGH have "walked the walk" and thus provide bona fide guidance as to what works and what doesn't.

We have in excess of 30 families that have indicated the desire for housing within the 2012-2013 timeframe. It is abundantly clear that the demand outdistances the supply. Most families are hopeful of receiving a housing waiver from the State that would cover the majority of the housing costs, but the waivers are far and few between. Thus our mission is to

explore and implement housing models that are sustainable without the financial assistance associated with the waiver, a daunting task in Northern Virginia. Fortunately, many respondents have expressed the ability to personally contribute \$50,000 to \$75,000 toward the acquisition of a dwelling for their family member. By pooling together, we can likely tackle the acquisition piece. The ongoing service piece represents the biggest challenge, both in cost and in addressing the variable needs of the respective occupants; particularly as they age or their health situation changes.

As many Alhambrans are in or approach their twilight years we would be thankful if they considered donating toward our initiative. Donated dwellings are welcome!!! Food for thought!!!

Shortly, the committee will contact individual respondents in an effort to bring families with similar timelines and needs together, thus facilitating moving forward into actual housing accommodations.

Our motto: "If we don't do it, it won't get done".

*Ron Gutkowski, PCI Housing Chair*

## Grand Commander's Message

*"Believe there are no limits but the sky."*

*Cervantes*

My eldest daughter, Marisa, and her husband, Coach A.J., have the above quote on top of their fireplace mantel. Betty and I did not give this to her, but reading it gave me a sense of accomplishment as a father, knowing that we had strived as parents to instill this sense of expectation for her, Vivian, and through the years for my employees and Special Olympics athletes and coaches.

The quote ties in to Porto and PCI because through the years, as Porto members founded St. Coletta's and financially supported numerous groups and programs for our Special Angels, the members believed that there were no limits standing in the way of success for these programs. As time has demonstrated, they were right.

Most of our member families have instilled in our Special Angels this same sense of accomplishment and they have grown and been successful with our encouragement. As parents, we have fought with local and state governments, schools, teachers, doctors, hospitals, therapists and numerous other agencies. We convinced them that given the opportunity there would be no limit to the accomplishments of our now young adults.

When Vivian was born 28 years ago, we were told by the hospital delivery doctor to institutionalize her. How far we have come through all of our efforts! Life expectancy for our Special Angels has risen from the low to mid 30's to the high 60's. Our challenges continue as we now have to focus on JOBS and HOUSING for the next 30-40 years. This is our new frontier.

Porto and PCI have researched numerous successful programs throughout the country. Several members and groups have visited homes in California, Massachusetts, Missouri, and Virginia. We have also interviewed housing vendors and staff.

Most recently, three of us spent a day in Wilmington, Delaware where we toured 12 homes, each with four adults as residents, and each with various levels of support. Every home was spotless; the rooms were neat and tidy and displayed the residents' own special touches and decorations. Every home was in a community and two were usually next to each other for management and staffing reasons. Most homes were built by Ryan Homes in conjunction with the Homes for Life Foundation. The interior plans were redesigned to meet the different level of needs. On the outside, they were colonials and looked like those in every other middle class neigh-

borhood. Ryan Homes also built for them the same homes in lots they purchased in other vicinities.

The person who spearheaded this effort since 1989, Micki Edelson, has a son with intellectual disabilities. She has raised funds to build, furnish and fully pay for 28 homes. They are then turned over to the ARC of Delaware to manage. The ARC is responsible for renting and providing maintenance and repairs to the homes. The State of Delaware Department of Human Resources provides staffing for each house through a hired vendor according to needs.

Along the way, Mrs. Edelson also helped create paid jobs through area companies, donors, business leaders, law offices, local banks, national banks, at parents' businesses and places of employment, retail stores, supermarkets, fast food and other restaurants, and in maintenance and landscaping fields. Many have now worked at their jobs for over 20 years.

I returned very impressed with her 23 years of success, but dejected as I realized we were so far behind in our housing and job efforts in northern Virginia.

- We live in the richest area of the country;
- We have the highest income levels in the country;
- We have the highest level of education in the country;
- We have best weathered the housing crisis in the country;
- We have the best and most thriving economic area in the country;
- Porto and PCI members are very dedicated, educated, professional, successful, well connected and of capable means.

I then realized we are each waiting for someone else to find the jobs and housing for our young adults, be it DHR or vendors from the State. We are waiting for a Wildflour to expand. We are waiting for Medicaid waivers to solve our future housing issues, even though at this time it looks like parents will have to be disabled, turn 70 or move on from this world in order to receive one. The recent Department of Justice settlement with Virginia will put over 2,000 institutionalized residents into the community. We will be last on the list!!

We fought the fight until the age of 22. **WE NOW NEED TO BAND TOGETHER AND GET JOBS AND HOUSING.** Call GC Leo or Email with any job opportunities or leads you may have about fundraising support. We will follow up. As members of Porto, we need to **BELIEVE THERE ARE NO LIMITS BUT THE SKY !!!**

*GC Leo Alonso*

# Calendar

## PORTO 104 / PORTO CHARITIES AND COMMUNITY EVENTS

Saturday, September 8 12:30 pm - 4:30 pm FREE	Retirement Send-off / Pot Luck Cookout for Sir Noble Zach, Don and Lynn Chapman. Bon voyage to Arizona! (See flyer on p. 9) Where: GC Leo & Betty Alonso's home, 3734 Center Way, Fairfax, VA
Sunday, September 9 2:00 pm - 5 pm FREE	Joey Pizzano Memorial Fund Family Fun Picnic. We will have the park for our private use. Food frolicking in the fountains, playground and tree house--fun for all! (See flyer on p. 11) Where: Our Special Harbor, Lee District Recreation Area, 6601 Telegraph Road, Alexandria, VA
Thursday, September 13 7:00 pm - 9:00 pm FREE RSVP to Carey Alford at (703) 279-6561 or calford@financialguide.com	Jewish Community Center/Washington Group Social & Recreational Opportunities Workshop Where: Jewish Community Center of Northern Virginia, 8900 Little River Turnpike, Fairfax, VA This workshop will focus on introducing many opportunities, many that you may not be familiar with. There will also be a social and recreational focused resource fair, with many participating vendors.
Sunday, September 16 8:00 am Pre-registration fees: \$15 students and faculty \$25 all others	RunFest 5K Where: Paul VI Catholic High School, 10675 Fairfax Blvd., Fairfax, VA Fundraiser for the Paul VI nationally-recognized Options Program and the Paul VI Cross Country Team. For more information and to register, visit <a href="http://pracing.racebx.com/events/register/4fc65cec-2488-4fa2-b51f-69bec0a8651f">http://pracing.racebx.com/events/register/4fc65cec-2488-4fa2-b51f-69bec0a8651f</a>
Monday, September 17 Noon Shotgun Start Golfers \$150 per person	Northern Virginia Auto Body/Porto Charities Golf Tournament (this group raised \$10,000 for Porto Charities in 2011) Where: Bull Run Golf Club, 3520 James Madison Highway, Haymarket, VA Contact Leo Alonso if interested.
Monday, September 24 6:30 pm doors open 8:00 pm performance \$50 for ArtStream students \$150 for public	ArtStream Gala: Performance, awards, appetizers, drinks Where: Round House Theater, Bethesda, MD ArtStream creates artistic opportunities for individuals in communities traditionally underserved by the arts.
Thursday, September 27	Arlington Catholic Diocese Disabilities Awareness Month Kick-off See double-page informational ad in <i>The Catholic Herald</i>
Sunday, September 30 5:00 pm	Bishop Loverde's 4th Annual Disabilities Awareness Mass. Private reception with Bishop will follow Mass Where: St. Thomas More Cathedral, 3901 Cathedral Lane, Arlington, VA We need to fill the Cathedral. Non-Catholics are welcome.
Friday, October 12 9:00 am Shotgun Start Golfers \$100 per person	Porto Charities Fifth Annual Golf Outing Where: Regency at Dominion Valley Golf Club, Haymarket, VA We need sponsors, prizes, raffle items, golfers. Ask everyone. Lunch will be available for non-golfers who wish to join us.
Saturday, October 13 7:00 pm - midnight \$275 per person	ARC Golden Anniversary Gala Where: Fairview Park Marriott, 3111 Fairview Park Drive, Falls Church, VA Contact ARC of NoVa by 9/18 at 703-532-3214
Saturday, October 27 6:00 pm - 10:00 pm	Porto Charities Oktoberfest (bingo) Where: Our Lady of Good Counsel De Sales room

## Disabilities and Social Security: You Don't Know What You Don't Know

Porto Charities invited Mr. David Melton, Community Affairs Specialist, Social Security Administration (SSA), to speak to our community on August 28th at Our Lady of Good Counsel about the different issues surrounding social security for people with disabilities. Mr. Melton gave a presentation to an audience of



about 45 individuals who, for the most part, represented families who have a family member with a disability.

The need for the presentation on Social Security arose when PCI members investigated Social Security and related benefits for people with disabilities, particularly when the individual is a survivor after his/her parents passing. It was evident that most of us had little knowledge of what benefits were available beyond our own. Telephone calls to the Social Security Administration expanded the awareness beyond that level. Discussion led to confusion over the various programs: Social Security, SSI, SSDI, DAC, SGA, Spouse With Child in Care, Voluntary Suspension, Full Retirement Age, PIA, Earned Credits, etc. What are these? How do these interact with Medicaid and Medicare? How do these benefit Federal retirees? Can the individual with a disability retain assets without impacting benefits?

One thing is true: there are no prescribed paths to follow to maximize your family benefits, as each family circumstance varies. What may work best for one family may not work for you. For example, the age difference of spouses can have a significant variance in available options as well as if an individual with a disability is, or has been, employed and contributed to Social Security. A critical time is when the parent of an individual with a disability attains Full Retirement Age status (between the ages of 65 and 67) as many doors open up.

Usually a person begins receiving Social Security benefits when s/he retires: a person will receive a Primary Insurance Amount (PIA) which is the Social Security benefit payable at 100% of the amount at full retirement age. Each year the SSA sends individuals a mailer that contains their benefit.

The presentation's objective was to enlighten the attendees and expand their knowledge about social security and disabilities to facilitate more meaningful discussion if anyone desired to follow up with SSA in examining their family circumstance and options. The following is a general description of primary benefits and we strongly suggest you contact the SSA for in depth discussion relating to specific family concerns.

A person with a disability may qualify under three different types of benefits related to Social Security:

- Disabled Adult Child benefits
- Supplemental Security Income
- Social Security Disability Income

Each type of benefit has different requirements to qualify, but the first is meeting the definition of disability: lack of being able to perform "substantial gainful activity" for at least a year or longer. Substantial gainful activity refers to work for remuneration and in 2012 that referred to earnings of \$1,010 or less per month.

**Disabled Adult Children (DAC)** benefits are for individuals who became disabled before age 22, are not married, and have a parent who has filed for social security benefits. That individual will receive 50% of the PIA his parent receives, though families are subject to a maximum. For example, if a parent retires at age 66 and receives a full, unreduced amount of \$2,000 per month, the DAC benefit will be \$1,000, but if that amount would exceed the total family amount, it would be reduced accordingly. In addition, 24 months after DAC benefits are activated, the son or daughter with disabilities can start receiving Medicare; albeit they likely would lose Medicaid during that interim period. This benefit may be coupled with Spouse With Child in Care benefit and is also subject to the family maximum. It generally is 50% of the PIA of the individual filing for benefits at full retirement age.

**Supplemental Security Income (SSI)** is a Federal income supplement program funded by general tax revenues (not Social Security taxes). It is designed to help people with disabilities and those older than 65 who have little or no income by providing them with cash to meet basic needs for food, clothing, and shelter. SSI is determined by looking at the disability of the child and looking at the income, resources and living arrangements of the parents and child. When the child is a minor, the assets of parents affect a child's eligibility for SSI and if s/he qualifies, the benefits that s/he receives depend on the income of the parents. When the individual reaches age 18, s/he becomes an adult and parents' income is no longer taken into consideration. However, resources are considered and those include bank accounts, investments, etc. A person receiving SSI cannot have more than \$2,000 in his/her name (or \$3,000 if in a marriage). Resources like a house, car, personal belongings (e.g., jewelry) are not considered. Living arrangements (whether the individual lives alone, in someone else's household, in an institutional setting/group home) usually do not preclude the individual from receiving SSI. The individual receiving SSI is eligible for Medicaid though each state determines whether it is automatically provided to the individual or s/he has to apply for it. In Virginia, individuals have to apply for Medicaid once they begin receiving SSI.

**Social Security Disability Insurance (SSDI)** pays benefits to the individual who has become disabled and certain members of his/her family if the individual who has become disabled is "insured," meaning that s/he worked long enough and paid

*(continued on p. 7)*



## MEMBER PROFILE

### Jenny Holden

Like many children, Jenny Holden always knew what she wanted to be when she grew up. She wanted to “teach tiny kids.” Now 24 years old, Jenny is excited and happy because she is getting her chance. She recently started work as a full-time teachers’ aide at a Montessori preschool in Fairfax County. She assists several teachers there with everything that needs to be done, from serving lunch to helping children settle down for naps, from reading books at story time to supervising children in outdoor play.

Jenny loves being active and staying busy. While still in high school, Jenny started volunteering and then working for Fairfax County’s Therapeutic Recreation Services (TRS) summer day camp program for children with disabilities. Jenny found that she really enjoyed helping children with special needs. Jenny also worked as a volunteer and then as a teacher’s aide for her Sunday school. Later, while an intern in George Mason University’s Mason LIFE Program, Jenny worked at the Jewish Community Center of Northern Virginia’s preschool and after-school program for children. In these pursuits, Jenny was acting much like her siblings. Both Jenny’s older brother Michael and her younger sister Cindy have worked with children in Sunday school and summer camp programs. Jenny often asks them for advice about working with children.

Asked about her wildest dreams, Jenny would probably tell you she’d like to be famous. She loves everything

about the performing arts — going to the theater, taking dance classes, and acting. In 2007, Jenny graduated from the Paul VI Catholic High School’s Options Program, and her fondest memories include drama class as well as singing and dancing in two PVI musicals, *The Boyfriend* and *Anything Goes*. Jenny continued working on her academic and independence skills in the four-year George Mason University Mason LIFE Program and in the GMU LIFE internship program. At GMU, Jenny audited regular university classes in ballet and modern dance, and took ArtStream acting classes. Jenny acquired the “ham” gene naturally; her Dad performs in a band and Jenny often takes part in rehearsals.

Jenny also likes speaking in public and being a self-advocate. She is a Best Buddies Ambassador, and she really enjoyed going to the Best Buddies Leadership Conference in Indiana, where she learned to give speeches. Jenny used this training in 2010-2011, when she served as the Mason LIFE Program Liaison to the GMU Student Government and made short speeches about LIFE Program activities and the concerns of students with disabilities.

When she relaxes, Jenny enjoys hanging out with friends, going to movies and concerts, singing karaoke, and drawing women’s fashions. She also likes taking long walks with her Mom and sister. Jenny loves Special Olympics soccer, basketball, and track and field with

Coach Leo, and especially likes going to Special Olympics State Games. She looks forward to going to visit relatives in Rhode Island, New York, and New Jersey, and going to the beach on vacation. Her all-time favorite family vacation was a cruise to the Bahamas. ■





## ORGANIZATIONS PORTO SUPPORTS

### POPE JOHN PAUL THE GREAT CATHOLIC SCHOOL OPTIONS PROGRAM

JP Options is an innovative, inclusive Special education program at Pope John Paul the Great Catholic High School in Dumfries, VA. The program offers students with moderate intellectual or cognitive disabilities the opportunity to grow spiritually, socially, and academically alongside their peers in an inclusive Catholic environment.

It is with great joy that the entire JP community embraces the opportunity to provide this. In addition to the benefits the program provides each individual student with special needs, are the countless gifts and blessings these young men and women bestow upon our community. Weaving together the daily interactions of the students in the JP Options program with the entire student body and faculty, allows us all to better appreciate the many ways we are the same, and better experience the

unconditional love God has for each of his children.

Over the past 4 years, due in large part to the generosity of Porto Charities, JP Options has grown from 1 to 6 students, with our first student, Sean Reidt graduating in the Spring of 2012. When asked to describe their son's 4 years as a student in the JP Options Program, John and Mary Jo Reidt responded, "Sean loved his time at JP because of the faculty and his friends who included, supported, and loved him throughout his school day and extracurricular activities." Mr. and Mrs. Reidt added: "While he improved academically, he grew socially, he matured, his self-confidence increased — JP became his home. The culmination of his four years occurred at Baccalaureate Mass when Sean received the longest ovation of any student when he walked across the stage — we were brought to tears. That moment rein-

forced what we had known for four years: we made the right choice."

With the 2012 grant from Porto Charities, JP Options purchased and implemented the use of iPads for the students in the program. Using the iPads in class has enabled the students to achieve greater success, and therefore grow in self-confidence, and self-worth. Students are currently making use of the iPads by participating with their peers in Anatomy and Physiology, Government, Speech and Debate, Graphic Design, English Literature, Bioethics, Religion and more. We are blessed to have Porto Charities as a partner in furthering our school's mission to provide an environment in which the dignity of every student is affirmed.

*For more information on JP Options, please contact Megan Battle at 703-445-0235 or [megan.battle@jpthegreat.org](mailto:megan.battle@jpthegreat.org). ■*

*(continued from p. 5)*

Social Security taxes. In essence, if you worked and contributed to Social Security it applies.

Families can gather additional information from the SSA website, by visiting a SSA office or by calling them directly. Whenever you contact SSA, make sure to inform them that you are calling about a child with a disability and the related survivor benefits.

Porto Charities would like to thank Mr. Melton for an incredibly enriching talk and for answering numerous questions from the audience present.

#### Useful Social Security links

*Disability Planner: Benefits for A Disabled Child:*

<http://www.socialsecurity.gov/dibplan/dqualify10.htm#age22>

*Disability Benefits:*

<http://www.socialsecurity.gov/pubs/10029.html>

*Adult Disability Starter Kit:*

[http://www.socialsecurity.gov/disability/disability\\_starter\\_kits\\_adult\\_eng.htm](http://www.socialsecurity.gov/disability/disability_starter_kits_adult_eng.htm)

*Child Disability Starter Kit:*

[http://www.socialsecurity.gov/disability/disability\\_starter\\_kits\\_child\\_eng.htm](http://www.socialsecurity.gov/disability/disability_starter_kits_child_eng.htm)

*Apply for Disability:* <http://ssa.gov/pgm/disability.htm>

*Supplemental Security Income:*

<http://www.socialsecurity.gov/pgm/ssi.htm>

*Apply for Supplemental Security Income:*

[http://ssa-custhelp.ssa.gov/app/answers/detail/a\\_id/270](http://ssa-custhelp.ssa.gov/app/answers/detail/a_id/270)

*Disability Publications:*

<http://ssa.gov/pubs/index.html?topic=Disability>

*Benefit Eligibility Screening Tool (BEST):*

<http://www.benefits.gov/ssa> ■

## New 'waivers' for disabled care fall short of need in Virginia, locally

*From Down Syndrome Daily posted on 12 Jul 2012 04:00 AM PDT  
By Paul Salasky from the Daily Press*

More than 3,600 Virginians with intellectual disabilities are on an "urgent" needs waiting list for a coveted ID/MR Medicaid waiver which would provide them the range of services and support they need. They have cerebral palsy and autism, Down Syndrome, spina bifida and schizophrenia, mild mental retardation and extreme intellectual disability. All require round-the-clock, nonstop care and supervision.

Death of a loved one, divorce or deployment can wreak havoc in any family. Add in loss of employment or illness, and for those with disabilities, such situations amount to a crisis.

On the Peninsula alone, more than 120 such families are on the "urgent" waiting list for an ID waiver. (Waiting in the wings are many, many more whose needs are deemed non-urgent.)

Typically, Medicaid waiver slots become available at the rate of perhaps one or two a month as recipients die or move into a nursing home.

On July 1, as the state's annual budget kicked in, 300 additional ID waivers, the gold standard for care for those with disabilities, became available.

### How waivers are allotted

Ten days before, nine employees of the Hampton-Newport News Community Services Board, including nurses, supervisors, day services personnel, those involved with children and adolescents, and a parent representative hunkered around a table. They spent the next five hours in conference to determine who would receive the 10 new slots the board snagged from the state's 300 — plus another three recently released.

For the 13 waivers, they consider the situations of 28 of the 127 families in their catchment area with the most urgent needs. The Department of Behavioral Health and Human Services has a formula for the number of cases to be considered — roughly double the number of slots available — and a couple of years ago it established a standardized, anonymous Tier 2 review system. "We're all working from the same framework now. It's much better," says Natale Ward, senior director, intellectual disabilities services, for the community services board. "It's much more objective."

The meeting kicks off with Carol McCarthy, adult case management clinical administrator, reminding staff about the anonymity of the process, with clients identified only by a seven-digit number. She goes over the scoring process and assigns tabulators. Each participant has had a week to review information packets on each person.

In a measured, steady stream, 19 case managers, some representing more than one person, then take turns to present their client's case and answer questions.

Scorers want to know medical details and what type of help, if any, they're receiving currently. And what type of services

they are seeking, whether residential housing, employment, day services or a combination. Many times they pitch in with suggestions — in the event the client doesn't obtain a waiver — for alternative piecemeal support. They note follow-up actions to take, and suggest other resources. If asking for group home placement, they want to know how the client would fit in, particularly in cases of aggressive behavior.

The safety of the client and caregiver are recurring topics. Many cases involve the aging or terminal illness of primary caretakers, others the aging out of the school system by clients. Many involve inadequate living arrangements and the economic fallout from family members having to quit work in order to take on the role of caretaker.

### New waiver slots

Those around the table are buoyed by the unusual number of waivers to assign, but somber about the parade of need and the small dent they will make in the urgent waiting list. "They all have such dire needs," says Ward, a veteran of the process, after reviewing the first handful of cases.

The relative bonanza is fueled by a Department of Justice settlement with the state charging Virginia with changing the way it cares for residents with mental disabilities. Accordingly, over the next 10 years, the state must fund 4,170 new waivers for community care. This year, the settlement calls for 225 and the legislature sprang for another 75; in 2013, it must fund another 225, with similar numbers for subsequent years.

"I'm not sure I'll ever be satisfied with the number of waiver slots by the settlement or General Assembly. Those waiting have needs," says Chuck Hall, executive director of the Hampton-Newport News Community Services Board. "You are truly out of luck if you're in the community without a waiver."

The waivers are divided among the state's 40 community services boards according to the numbers on their "urgent" waiting list. Case managers conduct a standardized Tier 1 survey that takes into consideration homelessness, the age of the caregiver, and behavioral issues, among other factors, to establish a hierarchy of need.

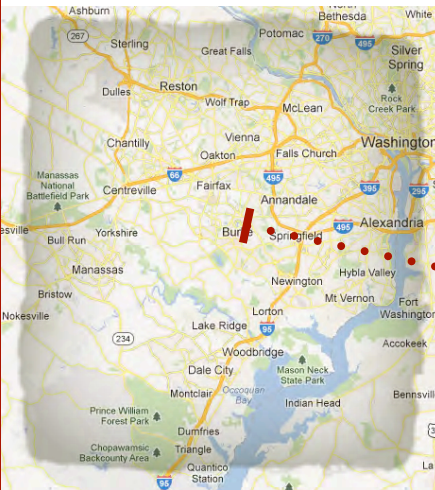
### Overwhelming needs

The only pattern in these 28 cases is the need. The clients are young, middle-aged and old, African-American and white, men, women and children, and the caretakers likewise range from mid-20s to decades past Social Security eligibility.

No simple solutions are at the ready as the professionals bemoan the cutback in respite hours — from 720 to 480 per year — that has put many families in a bind. Or that the EDCD waiver, Elderly or Disabled with Consumer Direction, often used as a stopgap, doesn't include vital transportation, and that its medical requirement also excludes many who could benefit from its services.

Two years ago the General Assembly reduced state general grant funds that the Hampton-Newport News board used to support 100 individuals waiting for waivers to fund a Day Support Voucher program in partnership with the Arc of the Pen-





# SN ZACH, DON & LYNN CHAPMAN

## ARIZONA RETIREMENT SEND-OFF

**SATURDAY, SEPTEMBER 8, 2012**

**12:30 – 5:30 PM**

(After GMU Soccer Practice)

G.C. & Coach Leo & Betty's House

3734 Center Way

Fairfax, Virginia 22033

Please RSVP to Leo Alonso at

[bettyleo@aol.com](mailto:bettyleo@aol.com) or (703) 626-2051

### POT LUCK COOKOUT

- A – E Water/Sodas/Juices
- F – K Chips / Appetizers / Salads
- M – P Side Dishes
- Q – Z Cookies/Brownies/Desserts
- Porto Hamburgers/Hot Dogs/  
Rolls/ Ice



Join us for the  
**Joey Pizzano Memorial Fund's**  
**Annual Family Fun Picnic**  
**Sunday, September 9<sup>th</sup>!**  
**1:00 p.m. - 4:00 p.m.**

at



**JPMF**, along with **K.E.E.N.** and **Porto Charities**, invite you to JPMF's Annual Family Fun Picnic at **Our Special Harbor**. We will celebrate **Special Kids - Special Families** and commemorate the **20th anniversary of K.E.E.N.** (Kids Enjoy Exercise Now) of Greater DC!

**Our Special Harbor**  
**Lee District Family Recreation Area**  
**6601 Telegraph Road**  
**Alexandria, VA 22310**

**Free - Food - Games - Fun**

Rain Date will be Sunday, Sept. 16<sup>th</sup> - check [www.JPMF.org](http://www.JPMF.org) for details



Special Kids - Special Families



(continued from p. 7)

insula; it had to pass on the cuts. "It was a double whammy for those in the community," says Hall.

Only immediate need, rather than length of time on the waiting list, factors into the scoring process. One case manager says softly of her client, "I've been trying for years to get him a waiver slot." This time she's successful.

Nearing the end, and knowing that more than half those considered will not receive an ID/MR waiver, McCarthy says, "It's tugging at me a little bit." In an ideal world, she'd like to see a voucher system to help everyone get their needs met.

### ID/MR Waiver

The services included with this Medicaid waiver include residential support services, day support, employment, personal assistance, respite and companion services, assistive technology, environmental modifications, skilled nursing, crisis stabilization, and support coordination.

*Eligibility:* Person must qualify for placement in an ICF, intermediate care facility, based on a "level of functioning" survey.

For information on the number of waiver slots assigned by the Department of Justice settlement, go here:

<http://www.dbhds.virginia.gov/settlement/factsheet.pdf> ■

## PORTO CHARITIES/PORTO 104 EVENT

SUNDAY, SEPTEMBER 30, 2012  
5:00 PM

BISHOP LOVERDE  
DISABILITIES AWARENESS MASS

St. Thomas More Cathedral  
3901 Cathedral Lane, Arlington, Va.  
(reception with Bishop to follow)

Kick-off for October 2012 Diocese of Arlington  
Disabilities Awareness Month

Let's fill the Cathedral with our Special Angels  
and Supporters of Porto and PCI

## GRAND DIVAN 2011-2012

### Porto Caravan no. 104

**REV. EDWIN DILL, S.T.**  
Chaplain

**LEO ALONSO**  
Grand Commander

**BILL MUNDY**  
Vice Grand Commander

**CHRIS WNUK**  
Grand Scribe

**PAT CROSS**  
Scribe of the Exchequer

**RICK VRANESH**  
Grand Chamberlain and  
Past Grand Commander

**BILL HINGSTON**  
Master of the Oasis

**TOM BRITTON**  
Master of the Wardrobe

**TOM RYAN**  
Captain of the Bodyguard

**WILLIAM HINGSTON III**  
Sentinel of the Tower

**PAUL TIERNEY**  
Sentinel of the Desert

**RONALD GUTKOWSKI**  
Grand Advocate

### Porto Charities, Inc.

**CARMEN DIPLACIDO**  
President

**BILL MUNDY**  
Vice President

**CHARLIE SULLIVAN**  
Treasurer

**PAT HAMMEKE**  
Secretary

**LEO ALONSO** (Grand Com-  
mander)

**PAT CROSS**  
**MICHAEL EISENBERG**

Directors

**SARA ADKINS-BLANCH**  
*Shifting Sands* Editor

## The International Order of Alhambra and Porto Caravan 104

The International Order of Alhambra is a fraternal organization of Catholic men dedicated to assisting persons with intellectual disabilities. The Order's mission is to:

- ❖ Provide assistance, education and residences for persons developmentally disabled;
- ❖ Identify, mark, preserve, and commemorate Catholic historical places, events and persons of international or regional importance;
- ❖ Promote fraternalism and sociability among its members and their families.

Porto Caravan No. 104 was chartered in 1956 and is an active Caravan in the International Order of Alhambra with a membership of about 100. Porto Caravan No. 104 is located in the Commonwealth of Virginia environs of the Nation's Capital. Any male practicing Catholic who is 18 years of age or older is eligible to apply for membership.

### Contact Information:

Porto Caravan #104 | Order of Alhambra

Post Office Box 7266 | Arlington, VA 22207

Telephone: 703.626.2051 | Email: bettyleo@aol.com

### Porto Charities Inc.

Porto Charities, Inc. is an I.R.C. 501(c) (3) charitable organization dedicated to actively assisting people with developmental or intellectual disabilities; their community and their environment. Our mission is to:

- ❖ Raise and provide funds, resources, assistance, education, residences and overall improved quality of life for people with developmental or intellectual disabilities; and
- ❖ Promote education, awareness, friendship and social forums among members, their families and the community.

Our vision is to:

- ❖ Focus our efforts on providing assistance and resources to people with developmental or intellectual disabilities and their environment through our charitable programs and projects while also emphasizing friendship, mutual support and social events for its members.

Organizations awarded charitable donations for this year include: ARC of Northern Virginia, ArtStream, Inc., Arlington Diocese "Keyboard for Kids" program, Autism Society of No. VA, Best Buddies Virginia, Central Fairfax Services, Inc., Down Syndrome Association of No. VA, Gabriel Homes, Inc., GMU Life Program, Joey Pizzano Memorial Fund, Paul VI HS Options Program, Pope John Paul the Great HS Options Program, S. John Davis Career Center, Special Olympics of No. VA Area 26, St. Louis Parish Special Education Program, St. Mark Catholic School Evangelist Program, Still Meadows Enrichment Center and Camp, Villa Maria Work Study Center, and Wild-flour Catering.

### Contact Information:

Carmen A. DiPlacido, President | Porto Charities, Inc.

Post Office Box 7266 | Arlington, VA 22207

Telephone: 703.746.0101 | Email: cd.cadco@att.net

**If you would like to submit a story, article, or  
news piece to *Shifting Sands*, please email  
sadkinsblanch@portocharities.org.**