



# The Communities of Don Guanella and Divine Providence

Programs of Catholic Social Services  
Archdiocese of Philadelphia

## A JOURNEY TOGETHER Counting Our Blessings Along The Way

Mimi Schwerdtfeger and her son Denis have traveled a long and loving journey together. The fourth of five children, Denis was born with Down Syndrome in 1969. The unique bond of mother and son was shaped as they navigated an uncertain future together. For years Denis enjoyed living at home with his parents and siblings. He began work at the Cardinal Krol Center (CKC) Work Activity Center in 1994, and then moved to the residential program on Don Guanella Village (DGV) campus in 2004, where he flourished.

Sadly, Denis had begun to show signs of dementia-like reduced skills while still at home. At age 31, testing revealed clear indications of dementia and he was diagnosed with early onset of Alzheimer's dementia (AD).

Amid the DGV campus closing and many of its residents moving to community-based group homes, staff and family concurred that another campus setting, offering more comprehensive services and staffing, would be a better fit to meet Denis' increasing medical



needs caused by the growing dementia. So in 2014 Denis moved to Divine Providence Village (DPV), where he was joined by 15 peers to become the first class of men to live at the formerly all-female campus.

A critical component in treating a resident with dementia is the active involvement of and partnership with families. The family's input into the person-centered plan and welcoming families into the treatment process are

absolutely essential. For example, Mimi works collaboratively with medical professionals and the DPV residential and Day Program teams. She visits Denis several times a week, and arranges for him to come home every other weekend, where he remains an integral part of his extended family that includes Mimi's other children and grandchildren.

As Mimi travels this journey with Denis, her steadfast devotion to him is exemplary and inspiring. In addition to providing special care to Denis, she also gives back to the DGV and DPV communities in so many ways.



## FROM THE DIRECTOR'S DESK

### An Aging Population and the Challenges of Dementia

I wish to begin by gratefully acknowledging the interest of our attentive readership, particularly those who took time to send us their comments on our first Newsletter published last summer. We appreciated your remarks as to the timeliness and appearance of the Newsletter, and were especially encouraged by your recognition of our diligent efforts to offer a variety of services in a caring and individualized manner. Indeed, your kind words serve as an added inspiration for us to heed the call of our mission statement to “transform the lives of people with intellectual disabilities.”

While the prior Newsletter described the dramatic changes accomplished over a relatively short period of the last few years, this edition explores an evolutionary change occurring at DPV and DGV, which will have a significant cumulative impact of its own. Specifically, I am referring to our comprehensive response to the challenge of dementia and its related illnesses. With the blessing that people are living longer over the last twenty-five years, dementia has emerged as a major public health problem in society. The impact of dementia on the individuals we serve, as well as their families and caregivers, is far-reaching.

While dementia's effects on the intellectually disabled are generally similar to the population at large, there are very profound differences for people with *Down Syndrome*. According to the *National Task Force on Dementia*, these individuals are more at risk for dementia,

experience earlier onset, more rapid decline, and briefer longevity after diagnosis. Within the DPV and DGV communities, where approximately 40 percent of our residents live with Down Syndrome, there are significant medical and program implications.

In this issue, you will read several stories which highlight how we have progressively evolved in our treatment of dementia. Our protocol now involves: **1)** anticipating and routinely screening for the illness; **2)** adjusting programs and individual treatment plans accordingly; **3)** enlisting the active support of families; and **4)** employing outside resources for training and consultation.

As we respond to the formidable challenge of dementia care, we never lose sight of our commitment to person-centered treatment and our obligation to provide the highest quality of life possible in light of the particular diagnosis of each resident.

Amid these programmatic changes, we are consistently guided by our Catholic identity and core values. I hope you find this Newsletter on our dementia care initiatives informative and instructive, and that our efforts on behalf of the intellectually and physically disabled continue to be worthy of your support. May you and your family be blessed in the New Year.

*Fran Swiacki*

Fran Swiacki  
Executive Director

## SPECIALIZED DAY PROGRAMMING

### Older Adults Daily Living Center

The *Day Programs at Fatima* offer services to individuals living in Don Guanella Homes, at Divine Providence Village, and in various community settings. One of the programs offered there is the Adult Training Facility (ATF). The ATF provides a specialized Aging Program designed for older individuals and those diagnosed with dementia. Core services of the Aging Program include assistance with personal needs and basic daily living activities, as well as engaging participants in simple exercise movements, cooking, music and pet therapy. Nursing services, physical and occupational therapy, nutritional oversight, and promoting overall social wellness are all regular components of the daily schedule for participants.



Individual and social activities are provided throughout the day, including sensory exercises, table top and interactive games, basic arts and crafts, and puzzles. A higher staff-to-client ratio is maintained for those needing more individually focused care. Horticulture activities have recently expanded with the opening of the Sean Casey Memorial Greenhouse. Individuals with dementia benefit from a regular routine that combines horticultural

objectives with sensory input such as garden smells, sounds, and textures, as well as movements like reaching for water or scooping dirt, standing, communicating with others and observation skills.



Sadly, dementia takes a toll on an individual as his/her cognition and functioning steadily decline over time. In the words of ATF Director Candi Foell, her staff are able *“to identify the slightest change which allows us to develop strategies as issues arise.”* For example, when it was noticed that Denis needed a different environment, he was able to switch program rooms.

Relationships are the heart of each individual’s day program, anchored by committed employees who have consistently supported and befriended these individuals for many years. This dependable and dedicated workforce helps keep individuals with dementia engaged in meaningful activities and assists us in identifying any cognitive regression or increased medical issues. The day program staff, family members, and residential teams work collaboratively to ensure that individuals age in place with dignity.



Mimi was a CSS Board Committee member for 10 years, has been active in the family group, and has volunteered her time for weekly bingo and fundraisers like the annual golf outing. A devout Catholic and faithful member of St. Denis parish, Mimi often attends mass there with Denis.

Several specific aspects of treatment now available to Denis, due to his dementia-related needs, include:

- Careful coordination of medical services by a team of doctors, nurses, and specialists.
- Direct care staff added to his individualized care program to enhance daily supervision, given his steady decline in functions, which include hallucinations.
- A full-time nurse solely dedicated to serving the more complex needs of residents in the campus building where Denis lives, complemented by other nursing supports as needed.
- A change to his Day Program routine, where he is now active in a smaller group along with other individuals with dementia who receive increased attention and supervision.

- Increased outreach and social work intervention to educate and elicit support from families, in an effort to reduce any sense of guilt, lessen stress, and address confused emotions.

Reflecting on having a son with Down Syndrome who is also beset with the added complications of dementia, Mimi is genuinely grateful and spiritually strong. She calls the staff who care for Denis “outstanding” and offered this inspirational insight: *“I believe all of the special needs individuals are saints. Denis is the best gift”* we could ever have. All those who know him echo that sentiment with a resounding “Amen.”



## DEMENTIA FACTS EVERYONE SHOULD KNOW

- The main thing to remember is that life doesn't end when dementia begins.
- Dementia is progressive, with worsening symptoms like memory loss and difficulties with other cognitive functions, and is typically accompanied by disturbances of mood, behavior and personality.
- Factors that play a role in the development of dementia include: age, genetic history, heart disease, stroke, high blood pressure, history of severe head injury, as well as conditions such as diabetes and obesity.
- Though there is currently no cure for dementia, things like regular physical exercise, staying cognitively active, eating a healthy diet, and cutting out smoking all reduce the chances of developing the condition.
- There are medications to slow symptoms down for a while; with their assistance, it is possible to live well with dementia for years.
- The earlier one seeks medical advice the better. Early diagnosis increases the opportunities available to help overcome problems and find the best coping methods.

## FINDING THE RIGHT HOME

### Compassionate Continuum of Care

Our commitment to providing a compassionate continuum of care for individuals with intellectual disabilities is clearly manifested in the recent construction of the *Cardinal Krol Homes* mini-campus. Beginning in 2012, as part of the plan for residential services beyond the Don Guanella campus, most of the men moved to smaller community-based group homes where they enjoy more independent living. Yet there was an ongoing need for increased support and special sensitivity for aging residents and those experiencing dementia. In response, these most medically fragile men were the last to leave the Don Guanella campus, moving literally “next door” into Cardinal Krol Homes in the fall of 2015.

Each of the three homes on the mini-campus provides specialized services and support to 10 men. More than half of the men living at the Immaculate Heart of Mary Home (IHM) are of advanced age and diagnosed with dementia; many also have Down Syndrome. The staff-intensive programming offers a quality of life while supporting these individuals as they age in place. There is a nurse stationed at the IHM home and two nurses on campus at all times. In addition to nursing care, there is a house manager and typically one staff person for every three residents to provide support, supervision and integration of all aspects of each individual’s care plan.



Don Guanella Homes and Divine Providence Village have also established a relationship with *Crossroads Hospice and Palliative Care*. Over years of working together,

the Crossroads commitment to quality patient care for terminally ill residents has been proven time and again. Crossroads plays an integral part in the network of professionals, family members, residential and day program staff focused on quality end-of-life care. The palliative care and hospice teams provide pre and post training, volunteer visits (pet companionship is enjoyed by all), bedside care, nursing support on every shift, journaling, and Gift of a Day<sup>®</sup>.



Robbie’s situation represents compassionate continuum of care at its best. He was a vibrant person whose decline due to dementia indicated a need to move to the IHM Home at the Cardinal Krol mini-campus in December of 2015. Multiple entities were contacted for advice, guidance and support, and Crossroads provided compassionate hospice care. The ultimate goal was achieved; Robbie received quality care and support right there in his own home and peacefully passed away on June 24, 2016, surrounded by loving family and friends.



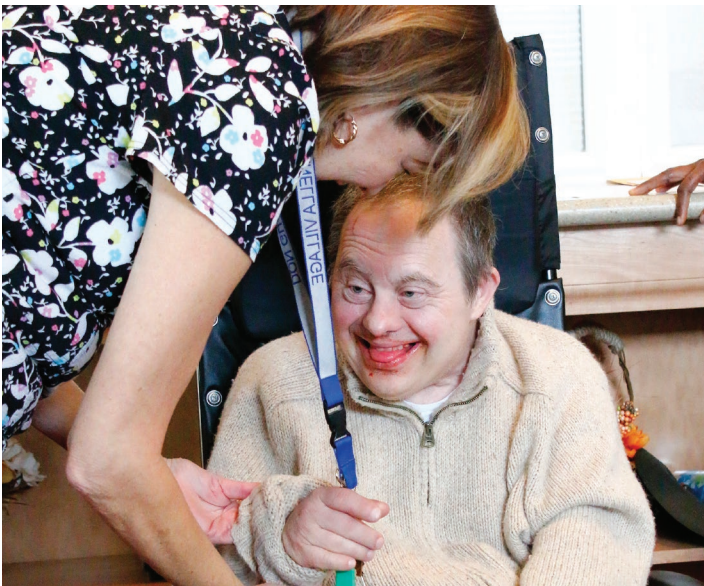
Peter and his housemates enjoyed a visit from the Philly Phanatic, a Crossroads Gift of a Day<sup>®</sup>.



# RESEARCH WITH RESULTS

## Cutting Edge Connections

As the emergence of dementia among our residents became increasingly apparent, DGV and DPV approached outside resources for information, education, training and research. Among our most valuable contacts has been our work with the New York State Institute for Basic Research (IBR). In 2005, 18 residents from Don Guanella Village, with the consent of their families, became part of a study conducted by IBR. Due to the high incidence of Alzheimer's dementia (AD) among our Down Syndrome (DS) individuals, the men chosen for this study were individuals with DS, but who had not yet been diagnosed with AD.



The research team, in conjunction with program staff, collected information on study members' abilities and physical condition, conducted a review of their medical and clinical records, and administered a series of short cognitive, language and blood tests. In addition, interviews with caregivers from both residential and day programs were conducted. The research has been ongoing ever since, with other individuals being added to the cohort from Don Guanella and Divine Providence Village, and procedures repeated periodically in 18 month intervals.

Research generally shows a greater incidence and early onset of AD among persons with DS, occurring in 25%

of individuals over the age of 40 and 66% of individuals over the age of 60, as compared with 3% over the age of 40 and 6% over the age of 60 in persons with other intellectual disabilities. In addition, research shows that AD among persons with DS progresses at a more rapid rate of 4 to 6 years, compared to the progression rate of 8 to 12 years in the general population.

Researchers believe that the high incidence of AD among persons with DS has to do with certain chromosomal abnormalities which produce overly high levels of proteins. These particular proteins cause build-up of plaque deposits which shrink parts of the brain related to memory and cognitive functioning. The research study thus far has concluded that greater incidence of early onset of Alzheimer's dementia has occurred among the DS population at DGV and DPV, which was a contributing factor in 25 deaths since 2005.

By participating in this research project we seek to continue to learn about the individuals we serve, and we highly value being a learning organization. In so doing, we have enhanced comprehension of this damaging illness and, as a result, have adopted diagnostic tools and treatment interventions for our clients who are challenged by dementia in general and Alzheimer's in particular.

We have been associated with *Philadelphia Coordinated Health Care (PCHC)*, *The American Academy of Developmental Medicine and Dentistry (AADMD/AAIDD)* and *The National Task Group on Intellectual Disabilities and Dementia Practices (NTG)*. The **NTG Online Support Group** is available to family or caregivers of individuals with Down Syndrome or other intellectual disabilities and Alzheimer's or other types of dementia.

For more information, go to:  
<https://aadmd.org/ntg/online-support-group>  
24/7 Helpline at: 1 800-272-3900  
[www.alz.org](http://www.alz.org)

## LEGACIES OF LOVE

### Don Guanella Day Celebration

The word legacy is often used to describe something that is handed down from one generation to the next. The Communities of Don Guanella and Divine Providence have a faith-filled *spiritual legacy* that was handed down to us by our founder, Saint Luigi Guanella.



Our staff, families, residents and community participants gather yearly on October 24<sup>th</sup> to celebrate Don Guanella's feast day. Monsignor Richard Bolger presided at this year's Mass, and his homily spoke of the *legacy of love and family spirit* that Don Guanella passed on to each of us. He pointed to everyone in the congregation, reminding us that we are all members of this beautiful mission of love because of the faith and vision of this one man!

## Communities of Don Guanella and Divine Providence

### MEMORIAL SERVICE

The first Memorial Prayer Service for our Don Guanella and Divine Providence families was held on Sunday, November 6<sup>th</sup> at the Divine Providence Village chapel. Through prayer and song, we remembered and honored the residents, parents of residents, and staff who had passed away since January 1, 2015. Candles were brought to the altar for each of the nearly 40 persons remembered that day. The candles reminded us of the unique beauty, light and love of those who have touched our lives in a special way. This Memorial Prayer Service will now become an annual gathering for our beloved Don Guanella and Divine Providence families.



## PLANNED GIVING

### The Saint Luigi Guanella Legacy Society

The stories in this newsletter remind us that a vibrant family spirit and an inspiring *"legacy of love"* exist in every mission-centered program within The Communities of Don Guanella and Divine Providence. That strong, enduring family spirit will be even more critical in the future if our Communities are to continue to provide the complex range of services that *"God's Good Children"* (an affectionate term of our founder, Don Guanella) require. Current funding sources will not suffice to sustain our Mission in the years ahead, so planned or deferred gifts are critical for our legacy of love to continue. For that reason, we are in the initial stages of rolling out

"The Saint Luigi Guanella Legacy Society." The life of our founder Don Guanella was marked by a deep, abiding trust in Divine Providence. We now trust that many members of our extended Guanellian family will choose to leave a *"legacy of love"* through their participation in this inspiring society.

For more information, contact:  
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**"LIVE, LOVE, LAUGH,  
LEAVE A LEGACY."**  
- Stephen Covey





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Rodney is all smiles at  
the annual Day Program  
Christmas party.



"THE WORKS OF PROVIDENCE ARE  
MAINTAINED BY CHARITY -  
AND TRUST." - Saint Luigi Guanella

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Staff from our  
Norwood office  
brought gifts and  
donations and  
enjoyed a visit with  
the "Coffee Club"  
at the CSS Delaware  
County Family  
Service Center in  
Chester.

**SAVE THE DATE:**  
**Family Town Hall Meetings**  
January 18, 2017  
April 5, 2017  
7:00 p.m.

Divine Providence Village  
Multi-Purpose Building



DPV and DGV Family Christmas Party at Springfield Country Club