

Image

The Inglis Newsletter

Spring
2015

inglis.org



Making Our House
A Home

IN THIS ISSUE

MS Care Today with
Thomas P. Leist, MD, PhD

Making our
House a Home

Inglis Under
Construction

Carolyn Collins
Finds Poetic Voice



Ability &
Independence.
Redefined.

What is Multiple Sclerosis (MS)?

- **MS is a chronic disease of the brain and spinal cord.** There is no known cause or cure. It can cause fatigue, numbness, paralysis, and problems with vision, balance and cognition.
- **In MS, the immune cells attack myelin,** which insulates nerve fibers and helps them to conduct electrical impulses. Damaged nerve fibers cannot conduct messages to and from the brain effectively.
- **The progress, symptoms and severity of MS differ for each person.** Some live their lives with only minor problems; others are seriously affected. Most people experience a more moderate course. Treatment advances and disease-modifying medications have helped many over the past 30 years and current research holds more promise.
- **Multiple Sclerosis is thought to be an autoimmune disorder**—meaning that the immune system acts against normally-occurring antigens in the body as if they were foreign.

To learn more about MS, visit www.nationalmssociety.org.

*Because of our outstanding clinical care and adapted technology, recreational and social services programs for those with MS, Inglis has been named an **MS Center of Excellence** by the **National Multiple Sclerosis Society**.*

Inglis House residents by diagnosis:

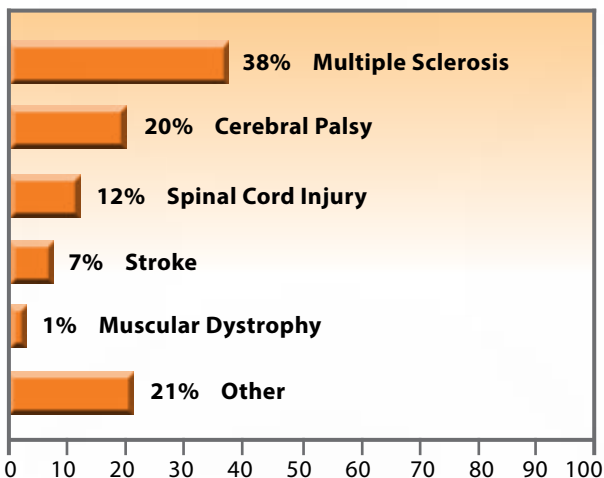


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2600 Belmont Avenue
Philadelphia, PA 19131
inglis.org

Main Number: 215-878-5600
TDD/TTY Number: 215-878-5337
Toll-Free Number: 866-2-INGLIS (866-246-4547)
info@inglis.org
admissions@inglis.org
community@inglis.org
development@inglis.org
drinkaide@inglis.org

On the Cover:

(l.) Mary Czyzyk, Inglis House resident and (r.) Dixie Wigton, Former Inglis Board Chair, in front of the architectural renderings and design plans for the renovations for the 3 South Neighborhood. Please see page 5.



“If you have MS, you couldn’t go to a better place than Inglis.”

When he made that statement, Len Brown was talking about his sister, Harriet Brown-Schlagle, who lived at Inglis for 29 years. Harriet and Len were the inspiration for us to devote this issue of *Image* to Inglis services for people with Multiple Sclerosis (MS). This neurologic disorder results in damage to the brain and spinal cord, and can cause significant disabilities for many years - just as Harriet experienced.

We enjoy a strong partnership with the **National Multiple Sclerosis Society (NMSS)** and are honored to have been designated a **Center of Excellence in the Care of People with Multiple Sclerosis**.



This is an exciting time at Inglis. Housing options for people with MS and other complex physical disabilities will be expanded with Inglis Gardens at Belmont, now under construction next door. Slated for completion in 2016, this affordable, accessible housing community will be the home of our new, innovative Inglis Community LIFE program.

Our Person Centered Care (PCC) initiative is also gaining momentum at Inglis House. We are now making physical transformations to support that culture change. The renovations to our first neighborhood, 3 South, were made possible through a generous gift from former Board Chair Dixie Wigton (see page 5). We have also designated a second unit, 2 South, as the next to make the transition to a PCC neighborhood. We hope to transform all of Inglis House into neighborhoods by the end of 2016.

Construction is in the final stages on our new Wellness & Rehabilitation Center, scheduled to open in May. This new facility will offer the latest equipment and wellness programs to residents. The Center is also an outgrowth of PCC, and was designed with resident input. In the Center, therapists will collaborate with medical and adapted technology staff to provide residents with optimal care. Look for stories about this wonderful new resource in our next issue.



Harriet Brown-Schlagle and her brother Len Brown, as children.

The response to our first, revised edition of *Image* last fall has been overwhelmingly positive. You will notice that each issue will be built around a theme related to our residents, consumers, donors, staff, and partnerships. They will tell the story of Inglis—an evolving organization meeting the needs of our consumers. Without your support, our work could not continue. Do you have an Inglis story to share? If so, please contact me at the email address below. Thank you for helping us to improve the lives of nearly 1,000 people and their loved ones.

Sincerely,

A handwritten signature in blue ink that reads 'G. R. Kerr'.

Gavin Kerr
President and Chief Executive Officer

Gavin.Kerr@inglis.org

Ken Regan – Developing from the Heart

For real estate developers Ken and Larry Regan, creating affordable, accessible housing is really a family affair.

The brothers formed Regan Development Corporation in the late 80s, but they had seen the benefits of providing affordable housing thanks to their father who had been developing those properties since the 60s.

Because of what their father accomplished, they wanted to focus on the same industry. “Although we’re a for-profit company, we understood the social benefit also,” Ken said. “Housing costs are too high, people are paying 40-50% of their income. Though not an easy niche, it helps others.”

Although the brothers fully appreciated the demand for affordable housing, the need for accessible housing didn’t hit home until 2003 when Ken was diagnosed with Multiple Sclerosis (MS). “I was not prepared,” he said. “But I spent a lot of time researching MS and what it meant and would mean.”



That research brought him to his local MS Chapter. “They provided great support and through them I learned more about the great need for affordable housing that was also fully accessible,” he said. “I offered them our expertise to develop independent living opportunities for people with MS and other disabilities, and we built our first accessible housing community, Kershaw Commons in Freehold, NJ.”

Ken met Inglis President & CEO, Gavin Kerr, through his MS Society connection. They began discussions for Inglis Gardens at Belmont, a new model of housing combining units for those without disabilities

and those transitioning from nursing homes to independent living – a first focusing on this specific population.

“It’s very rewarding to build an environment that provides independent living with supportive services, along with affordable housing for people without disabilities,” says Ken. “We are fortunate to partner with an organization like Inglis.”

“Housing for people with disabilities is woefully inadequate, but it makes such a difference. My brother Larry and I feel so rewarded putting keys in people’s hands and seeing their joy.”

◀ **Meet Mary Czyzyk, PCC Champion & Inglis Resident**

Mary lives on 3 South, the first neighborhood renovated as part of our Person Centered Care (PCC) initiative thanks to Dixie’s generous donation. Mary is an active participant in implementing PCC at Inglis. She participates in the PCC Steering Team and is a Person First trainer, helping Inglis residents and staff to explore what it means to live and work in a “person centered” environment. Mary also co-chairs Inglis’ PEERS group, a mentoring group for residents.



The Inglis Community has been working tirelessly to move to a Person Centered model of care —

one that makes resident dignity, preferences and choices a priority—and away from the old institutional way of delivering care. We are also transitioning from a hospital-like environment to one that is more homelike.



Making our House a Home

A transformational gift with an enduring impact

The next steps towards creating this setting recently became a reality when former Inglis Board Chair Dixie Wigton made a generous gift to Inglis.

It will fund renovations to our 3 South Neighborhood, formerly known as a *nursing unit*, the first area in Inglis House to adopt Person Centered Care.



Dixie (holding shovel) at the ground breaking of our first independent living apartment complex in 1973.

This initiative is so very important to a person's quality of life," said Dixie. "I am pleased that Inglis is adopting this person centered approach and wanted to designate my gift to advance it. It is a wonderful way to make life even better for those living here now, as well as many others who will live here in the future."

The renovations to the 3 South Neighborhood include the installation of a kitchen and pantry for the dining solarium, which allows for in-neighborhood cooking and meal preparation. In the living areas, new furniture, flooring, molding and an attractive color scheme—all chosen with input from residents and staff — has been added. The physical barrier of the nurses' station has also been removed and converted to a more residential environment.

Dixie's association with Inglis is a family tradition. She was introduced to the organization by her mother-in-law, an Inglis Board member, whose own mother was also on the Board.

"I've seen how every succeeding generation makes this organization better," says Dixie. "I am thrilled to see the wonderful work that is continuing here."

Dixie served on the Board for over 20 years and was President from 1970-76. During her tenure, board members exhibited remarkable vision by breaking ground on Inglis' first affordable, accessible housing development, the Esther M. Klein Apartments, in 1973.

After her Board service, Dixie remained deeply connected to Inglis as a dedicated volunteer, donor and member of the Annie Inglis Society. She served on the Board and Steering Committee during Inglis' 125th Anniversary and continued to connect generations of volunteers to our mission as Honorary Co-Chair of the 135th Anniversary Celebration with Gordon Keen and Ann Schellenger.

"Inglis is ever-grateful to Dixie for her unwavering loyalty, support, and friendship," says Lauren DeBruicker, Chair of the Inglis Board of Directors. "Her engagement is critical to move forward with Person Centered Care, a key Inglis initiative, and one that will shape our future for many years to come."

MS Care Today with Thomas P. Leist, MD, PhD



Neurologist Thomas P. Leist is the Director of the Comprehensive Multiple Sclerosis Clinical Center at Thomas Jefferson University. He provides consultative neurological care to residents at Inglis House.

Why is Inglis so important to people with MS?

MS is the most common cause of non-traumatic disability in young people. A small percentage of those with MS may become care-dependent. Their needs are very different from the elderly people who enter nursing facilities. It's necessary to have support teams who understand this younger population's specific medical, social, and emotional needs.

Inglis House is a unique place for individuals who are greatly impacted by MS. Specialized physical therapy and rehabilitation medicine, subspecialty neurologic care, and psychosocial support are available on-premises. MS and caregiver support groups are open to residents and their families, and link Inglis House to the community it serves.

How do Inglis House services fit into the spectrum of care available for people with MS?

When a person has a more involved disability, more help may be needed than can be given in the community. Inglis House can be a good long-term solution or a shorter-term opportunity to "sort things out" and allow a safe transition back into the community. I tell patients that Inglis House is not necessarily an "end place."

According to Dr. Leist, these are some promising therapies for the treatment of progressive MS that are now in clinical trials:

** Ocrelizumab: In phase two, this drug showed a significant reduction in brain lesions among participants taking it, compared to those taking a placebo. It is now being studied in phase three trials.*

** New research into myelin repair: In MS, myelin, the protective sheath that surrounds nerves, becomes damaged, preventing the effective transmission of nerve impulses. Anti-LINGO-1 is a monoclonal antibody that scientists hope can help repair damaged myelin. This drug met the primary endpoint in an exploratory phase II proof-of-concept study.*

** Research to evaluate the safety and effectiveness of drugs to reduce spasticity or increased muscle tone in people with MS: Drugs under study include Sativex, a mouth spray which contains cannabis extracts called cannabinoids, and long-acting Baclofen, a muscle-relaxing agent.*

It can be a place for wheelchair fitting, gaining assistive technology skills, and then at some point, making a guided transition back into the community. Inglis also offers accessible, affordable housing in the community with support. So Inglis has integrated life care along the spectrum.

What's on the horizon in MS research and treatment?

At present, disease modifying MS therapies are available for relapsing forms of MS only. This is the most common form of the disease. Now, the MS Society and MS Coalition are pushing research to investigate treatments for progressive MS. Research has not yet yielded a medication shown to be effective, but there are several trials studying different agents. (See sidebar below)

Are there any other exciting advances that are improving quality of life for those with MS?

Yes. Adapted technology is an area in which Inglis is very active, and is helping people with MS and other disabilities to live more independently. An array of devices can help people operate a computer, use a telephone, open a door, turn on the lights and do many other things. This is important because even if there is a "cure" for MS someday, with the aging of society, many people will need support.



Dr. Leist assesses resident Shelley Van Scoyoc in Inglis' in-house clinic.

Consumer Profile

Carolyn Collins finds her poetic voice and helps others living with MS

“I’ve been through so much,” laughs Carolyn Collins, “I have to stay positive.”

Sharing that positive attitude is at her core. Carolyn, a published poet and tenant at Inglis Gardens at Germantown, encourages others by being open about her experiences living with Multiple Sclerosis through her online MS Support Group.



Prior to being formally diagnosed with MS in 2007 at age 36, she suffered many years before the MS was identified. “It was so bad that I’d only be able to work for an hour or two before needing to go the hospital,” recalls Carolyn, a former security supervisor at the Springfield Mall.

“Now, I’m positive for everybody,” she says, referring to her online support group. “Sometimes, those who’ve just been diagnosed with MS think that they’re dying.

I tell them, ‘You can manage this. With the right doctor, team and treatment you can live—and live happily.’

“If you have a dream, don’t let anyone talk you out of pursuing it.”

Smile

*(an Excerpt from “Smile,” a poem from **Seeing the World Through My Eyes**, by Carolyn Collins)*

The lights go out around the world and the day comes to an end.

*You lay still, thinking of all
The beautiful things you saw
and*

*The wonderful things you heard.
You close your eyes and dream
joyful thoughts that
make you smile.*

Following her diagnosis, Carolyn was referred to Inglis Care Management Services. Due to a shortage of affordable, accessible housing, she waited four-and-a-half years to move into Inglis Gardens at Germantown. “Being able to just roll into my apartment has been a blessing,” says Carolyn, who is a wheelchair user.

Carolyn says that courage and determination are traits that she learned from her mom, who battled breast cancer and passed away in 1992, and through her faith.

I also advise them not to let anyone tell them how they should feel. People can’t see the effects of MS the way they can see a broken leg and can have a hard time believing you’re ill.”

Writing poetry is a source of joy for Carolyn. She recently published a book of poems, *Seeing the World through My Eyes*. “For years, people told me that I didn’t have a voice,” she says. “But these poems represent my emotions and experiences. If you have a dream, don’t let anyone talk you out of pursuing it.”

Inglis Care Management Services

Reaching into the community to support people with MS

Multiple Sclerosis (MS), can be an overwhelming diagnosis for individuals and their families. The Inglis Care Management team offers a full spectrum of support services for people living with MS, during all stages of the disease process.

Because MS has the potential to affect one's physical and cognitive functions, relationships, career and recreational activities, treatment focusing on medical symptoms alone is inadequate. Emotional support and access to resources that meet an individual's needs are equally important. Care Management services provide this support through partnerships with the National Multiple Sclerosis

Society - Greater Delaware Valley Chapter, Thomas Jefferson University Comprehensive Multiple Sclerosis Center, and Inglis Housing Corporation.

At Jefferson's Comprehensive MS Center, Inglis Care Manager Jennifer Schwartz, MSW, LSW, offers patients support and referral to vital services in the community. Some may need employment counseling to navigate workplace issues, some require home modifications to make their environment safer and more accessible. Mobility devices or assistive technology can enhance independence and function. Those who need assistance with self-care and household chores may be eligible for participation in Medicaid programs.



Jacqueline Smith (at left) and Jennifer Schwartz are care managers who support people with MS living in Philadelphia, and throughout Southeastern Pennsylvania and Southern New Jersey.

Care Management referrals from the MS Society also allow Jennifer and her colleague Jacqueline Smith, MHA, CMC, to travel throughout Southeastern PA and Southern New Jersey, providing one-on-one support to people with MS. Jennifer, Jackie and Tim Peterson, a social services associate, also provide support and referral services for tenants in the Inglis Housing Corporation's eight housing communities.



(back, l. to r.) New Board Members, Kenn Penn, Anita Weinberg and Jamie O'Neil join (front, l. to r.) Ashley Murphy-Moore, resident; Lauren DeBruicker, Chair, Inglis Board; and Ty Klug, resident, during their Board orientation at Inglis.

New Members Join Inglis Board

Inglis is pleased to welcome three new members of the Board of Directors.

R. James "Jamie" O'Neil, CFA

Jamie O'Neil is a partner and analyst/portfolio manager at Cooke & Bieler. Prior to joining Cooke & Bieler, he was an Investment Officer at Mellon Bank. He currently serves as an Overseer for Colby College, and has been a member of the Inglis Investment Committee since 2011. Jamie is a graduate of Colby College in Waterville, ME and received his MBA from Harvard Business School.

Kenneth D. Penn, CPM®, CCIM®

Kenneth D. Penn, President of Community Property Management, Inc. (CPM), has more than 25 years in the real estate and property management consulting services industry. Prior to becoming President of CPM, Ken was with a regional property management company, CoreStates/First Pennsylvania Bank in Philadelphia and Bank of America in Miami, Florida. He holds an MBA in Finance from Boston College and serves on the board of the African-American Chamber of Commerce in Pennsylvania.

Anita Weinberg

Anita Weinberg is Area Director of Government Affairs for BAYADA Home Health Care, Inc., representing BAYADA to government officials and advocating for legislation supporting home care services. Anita is the former Director of Government Affairs for BAYADA and Executive Director of Visiting Health Services of Union County. She received her Master's and Doctorate in Social Work from Columbia University.



Wellness & Rehabilitation Center The new Inglis Wellness & Rehabilitation Center will open this Spring, providing new equipment and technology for rehab therapies and a variety of programs offering a more holistic approach to wellness including stress management, nutrition and positive thinking groups.

Inglis under construction

It's an exciting time at Inglis: we're creating new facilities, upgrading resident living spaces and building a new apartment complex for those with disabilities.

Inglis Gardens at Belmont

Inglis Gardens at Belmont is under construction next door to Inglis' campus on Belmont Avenue. The 80-unit development will provide affordable housing for wheelchair users and other qualified tenants.



FY14 Annual Financial Highlights

Inglis is grateful to be able to provide our extensive services to nearly 1,000 people every day, thanks to generous donors, loyal volunteers and a strong endowment.

Selected Financial Highlights Inglis and Controlled Entities

	Fiscal 2014
Operating Revenue	
Resident Service Revenue	\$ 45,041,736
Other Operating Revenue	\$ 1,635,748
	<u>\$ 46,677,484</u>
Unrestricted Investment Income-Net of Expenses	
Investment Income-Net of Expenses	\$ 26,151,803
Gifts, Bequests & Assets Released from Restriction	\$ 2,815,617
	<u>\$ 28,967,420</u>
Total Unrestricted Revenue & Gains	\$ 75,644,904
Expenses and Losses	
Programs and Services	\$ 36,585,125
Administration and Support	\$ 10,520,160
Maintenance of Facilities	\$ 6,706,538
Depreciation	\$ 3,226,265
Interest	\$ 1,256,175
Strategic	\$ 1,115,071
Total Expenses and Losses	\$ 59,409,334
Operating Revenue and Support in excess of Expenses and Losses	\$ 16,235,570
Costs in Excess of Reimbursements	
Inglis House Medicaid Reimbursements	\$ 8,571,503
Care Management Services	\$ 170,205
Total Charity Care Provided to Community	\$ 8,741,708
Volunteer Hours Provided	19,271

A dedicated philanthropic community and a strong investment portfolio enabled us to extend more than 8 million dollars in charitable care to our Inglis Community and build towards a strong future. We are thankful and conscientious stewards of both. These resources allow Inglis to enable people with physical disabilities – and those who care for them – to achieve their goals and live life to the fullest.

A Special Synergy: Inglis and the Multiple Sclerosis Society



Tami Caesar, President, NMSS -
Greater Delaware Valley Chapter

Throughout its history, Inglis has partnered with various organizations to provide care and train generations of health care providers. One of the most productive of these partnerships is our collaboration with the Greater Delaware Valley Chapter of the National Multiple Sclerosis Society. Our organizations work together in various ways to meet the particular needs of people living with MS.

"Inglis has a very special role in the care of those with progressive forms of MS," says Tami Caesar, President of the Chapter. "Their ability to care for this population at Inglis House is a model throughout the country. But we also partner with them to support individuals living in the community."

Inglis Security Staff Rescue Resident in Distress



Inglis Security Officers Jamal Griffin and Monica Phillips were honored for their heroic rescue of a resident in need.

Inglis' Security Department was a shining example of courage last summer when two officers aided a resident attacked by wasps.

Officer Monica Phillips stepped into the courtyard and discovered the situation. She defended the resident while calling for help on her radio. Officer Jamal Griffin immediately responded. Both officers sustained dozens of stings. However, the severely stung resident made a full recovery.

"There's no doubt you saved a life," said Inglis President and CEO Gavin Kerr. "You are both remarkable examples of courage and compassion." "They put someone else's safety ahead of their own," added Manager of Security and Communications, Leonard Johnson.

The entire Inglis Community extends its gratitude to Monica and Jamal for their heroism.

Continued on page 11

MS Nursing Home Alliance

The Alliance includes nursing homes that have chosen to adapt their communities to more effectively meet the unique needs of younger people living with MS. These organizations work closely with their Society chapter and offer specialized MS educational opportunities for staff.



Inglis was proud to host the two-day annual conference of the Nursing Home Alliance of the National Multiple Sclerosis Society last fall. The event attracted 50 attendees from across the country with programming on new models of care, MS immunology, adapted technology for persons with disabilities and other topics of interest to providers.

Left to right: Event hosts Gavin Kerr, Inglis President and CEO; Debra Frankel, VP of Programs, Services and Clinical Care, National MS Society; Kathy Ardekani, Inglis Director of Admissions, Bill Grim, Co-Executive Director and Administrator, Inglis House and Marjorie Harding, Co-Executive Director and Director of Nursing, Inglis House.

A Special Synergy: Inglis and the Multiple Sclerosis Society *Continued from page 10*

In addition to the one-on-one professional support provided by the Inglis Care Management program through an MS Society grant, Inglis and the MS Society provide self-help groups for families, residents and participants in the Inglis Day Program. According to Tami, these groups provide a forum for vital connections. "Unlike online groups, they facilitate the person-to-person contact that people with an unpredictable chronic illness really need," she says. "There's no replacement for the shared connections made in a meeting."

Now, with the construction of Inglis Gardens at Belmont, the partnership will again be leveraged to provide tenants with MS programming, psychosocial support and education.

The Greater Delaware Valley Chapter is a 2013 Inglis ACE Award Winner, which honors the outstanding performance of not-for-profit organizations in the Philadelphia region, providing direct services, products, and/or advocacy for people with physical disabilities. In addition to self-help groups and care management services, the Society helps

professionals with MS gain employment, and provides eligibility-based home modification grants, and counseling and advocacy that keeps legislators informed of constituent needs.

"Our partnership with Inglis grew from our mutual goal to do the very best for those we serve," says Tami. "It's characterized by a free exchange of ideas. It's a great working relationship."



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2015 Inglis Golf Outing tees off Monday, June 8

Join us at the
White Manor Country Club
in Malvern, PA for the
14th Annual Inglis Golf Outing

Since 2001, the Outing has raised nearly \$1.3 million to enhance care and quality of life for people with complex physical disabilities. Proceeds from this year's event will update the technology providing free Wi-Fi access to Inglis residents.

This year's presenting sponsor is Reliant Senior Care. Consider maximizing your support with one of our multi-level sponsorships.



2014 Golf Outing Committee members:
(front row l. to r.) Mark A. Cooper, James G. Logue, Esq., Mary Ann Flanigan, Marie T. Logue, Co-Chair, George C. Brady, III and Kevin Kelly. (back row l. to r.) Nathan Niles, David Strange, Gavin Kerr, Anthony J. Ferrante and Matthew O'Mara.

Visit www.inglis.org/golfouting for details.

For more information, please contact Meredith Quirin Waldron, Director of Development, at meredith.waldron@inglis.org or 215-581-0703.

Please let us know your thoughts and/or story suggestions for **Image** at info@inglis.org