The Tree Unites the Branches; The Branches Bear the Fruit

The ORANJ TREE

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President's Message

Have you noticed an increase in the number of mobility devices being used by Independent Living (IL) residents? People are living longer. Some IL residents are choosing to hire an aide, sometimes full time, rather than moving to Assisted Living (AL). Some residents attracted to Continuing Care Retirement Communities (CCRCs) are now opting to "age in place." Visit our website at oranjccrc.org/research/ to view "Report on Opinion Survey" based on data from the ORANJ Plenary Meeting, Cedar Crest, October 21, 2015.

The ORANJ Health Committee has chosen to address these trends in their recent committee meetings at Seabrook and at Fellowship Village. The growth in mobility devices has resulted in crowded hallways and dining rooms. It is not clear whether all private duty aides that are hired directly by residents (not by the CCRC) meet state-required quality, safety and care standards. Are these issues going to be corrected by the IL residents or should CCRC providers be required to fix them? Most likely, residents and management will work together to navigate these evolving situations. Regulation of mobility devices and private duty aides varies greatly by CCRC.

Some IL residents say these are urgent issues needing immediate strong action. Others wonder "what can be done?"

Fellowship Senior Living (FSL) has embarked on a construction project to change Assisted Living and Skilled Nursing facilities to a new "household model." The person-directed quality of life should attract more IL residents to move from the "age in place" model.

FSL has formed the Home Community Based Services business unit which includes Fellowship Helping Hands. This service provides trained and certified aides to CCRC residents, "Senior Living at Home" clients, and other New Jersey residents. New Jersey Organizations and individuals must conform to "Best Practices for Health Care Service Firms (April 15, 2014)," a document which is published on the NJ Division of Consumer Affairs website. Private aides hired by residents of Fellowship Village must conform to those same standards. The management enforces this policy.

At the latest meeting of the ORANJ Health Committee, Elizabeth Fandel, VP of Fellowship Home and Community Based Services, gave a complete description of the best practices covering aides. She stressed that private duty Home Health Aides must be W-2 employees of a NJ Licensed Health Services Firm. njconsumeraffairs.gov/nur/Documents/Best-Practices-for-Health-Care-Service-Firms.pdf contains the full document.

I want to thank Alice Crozier for her excellent leadership of the ORANJ Health Committee. In July, she will be moving to Pennswood Village, a CCRC in Newtown, PA. We wish Alice the best fortune and happiness as she moves into a new dimension in her life.

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ALZHEIMER'S DISEASE DIAGNOSIS AND INTERVENTION
A Personal Experience with Memory Screening

On April 19 Dr. Michelle Papka, Director of the Cognitive and Research Center of New Jersey (CRCNJ) spoke at the semiannual ORANJ Plenary Meeting on "Current thinking regarding Alzheimer's disease diagnosis and intervention."

THE COGNITIVE AND RESEARCH CENTER OF NEW JERSEY, LLC

thecrcnj.com

Clearly my thinking was way outdated. Until the plenary meeting I still thought that the plaques and tangles that distinguish Alzheimer's from other types of dementia were only visible on autopsy. Not so. Now amyloid PET scans can identify Amyloid plaques 10-20 years before symptoms occur. In 2011 new criteria and guidelines for the diagnosis of Alzheimer's disease were established. These guidelines establish three diagnostic groups:

- Presymptomatic,
- Symptomatic predementia,
- Alzheimer's disease (AD).

Changes in the brain start decades before symptoms arise. As Dr. Papka stressed, "Early diagnosis is very important. Many people deny and ignore early symptoms, thinking that it is normal aging or that there isn't anything they can do about it anyway. On the contrary, if we want cures, we need clinical trials aimed at this population and there are many resources available to help these individuals and their families."

I was curious and wanted to learn more, so I went to the Internet.

The website of the UCSF Department of Radiology and Biomedical Imaging explains, with images, the use of amyloid PET scans for Alzheimer's Disease assessment. **https://radiology.ucsf.edu/patient-care/services/specialty-imaging/alzheimer**

THE MEMORY SCREENING PROCESS

Then I made an appointment to have a free memory screening at the CRCNJ. A memory screening is the first step in determining eligibility for one of the research programs that provide free amyloid PET scans. These scans can cost $3000 or more and they are not covered by insurance but they are available through various research programs. My appointment was on May 3. Finding my way from the Garden State Parkway to 195 Mountain Ave. Springfield, NJ was far more difficult than the memory screening. Happily, Dr. Papka is opening a new office off the Somerville circle, much easier for those of us in South Jersey. My reason for driving 1½ hours for a memory screening was not because I think my memory is out of normal range for an 80-year-old. Heck, I mixed up my kids' names when I was thirty. Actually, I made the 1½ hour trip as a journalist, to write about the CRCNJ in this issue of *The ORANJ Tree.*

After being reassured that my memory is normal for my age, I asked the clinical research coordinator who did the screening what the next steps would be for someone who might be a candidate for a PET scan and what would be required of someone who was accepted into a research trial. Next steps would include getting medical records and other personal and medical information. Most requirements are different for different clinical trials, but one requirement is true for any trial: participants must have a "buddy" who accompanies them on visits to the office and also checks in with the participant several times a week to see how they are doing and makes sure they are adhering to the protocol. It seemed to me that both the participant and the buddy should live within a 30-45 minute drive to the office. Transportation can be arranged for subjects enrolled in a clinical trial.

SOME INTERNET LINKS RE AMYLOID PET SCANS

While amyloid PET scans were just one part of Dr. Papka's talk, it was this technology that most fascinated me. At the Internet I was able to learn more and to understand better the value of PET scans both in diagnosis and intervention.

THE RAMP REGISTRY

There are dozens of clinical trials which provide amyloid PET scans to participants. RAMP - the **R**egistry for **AM**yloid **P**ositive patients is used to identify patients who might be eligible for Eli Lilly clinical trials. **rampregistry.com**. Trials offered at Dr. Pakpka's research center are listed at this page. **thecrcnj.com/currently-enrolling-clinical-studies/**

ALZHEIMER'S DIAGNOSIS AND INTERVENTION (cont'd)

THE IDEAS REGISTRY

Imaging Dementia—Evidence for Amyloid Scanning is a registry focusing on whether there is an advantage to early establishment, or ruling out, of the diagnosis. As it says on the NIH National Institute on Aging website:

"Imaging Dementia—Evidence for Amyloid Scanning (IDEAS) Study - Brief Description: This study will assess the impact of amyloid positron emission tomography (PET) imaging on outcomes in patients with mild cognitive impairment or dementia of uncertain origin. Researchers seek to demonstrate that amyloid PET can help clinicians diagnose the cause of cognitive impairment, provide the most appropriate treatments and recommendations, and improve health outcomes."
nia.nih.gov/alzheimers/clinical-trials/imaging-dementia-evidence-amyloid-scanning-ideas-study

OTHER REFLECTIONS AND ARTICLES

There is a November 2016 article on the Internet called "Amyloid PET Scans: Are They a Game-Changer?" in which a physician describes a case that exemplifies improved health outcome due to an amyloid PET that was negative, ruling out the disease.

brightfocus.org/alzheimers/article/amyloid-pet-scans-are-they-game-changer

Quoting from the brightfocus.org website:
"The patient had been told that his troubling forgetfulness was due to Alzheimer's disease (AD), and that this condition would likely progress to disability. He was advised to consider his approaching decline as he and his dear family planned for their future. He began to plan an exit from his thriving business. At age 62, in what he had considered his prime, this was terrifying news.

"The patient wanted a second opinion and paid for an Amyloid PET himself. It was negative, thus Alzheimer's was ruled out, which showed that it was important to look for other causes of cognitive difficulty."

The article goes on to state, "Further medical assessment … identified issues that were treated aggressively. [The patient's] cognition improved and stabilized, and several years after these events he continues to enjoy an independent and active life."
What I've quoted is just a story on the Internet, not from a peer-reviewed journal or a website I'm familiar with. Whether or not it's accurate, the story does give an illustration of the value of the IDEAS study.

MORE DETAIL ABOUT IDEAS

Imaging Dementia—Evidence for Amyloid Scanning

nia.nih.gov/alzheimers/clinical-trials/imaging-dementia-evidence-amyloid-scanning-ideas-study

From the NIH website: "The main hypothesis is that, in diagnostically uncertain cases, knowledge of amyloid status, as determined by amyloid PET imaging, will lead to significant changes in patient management, which will translate into improved long-term outcomes. Investigators will evaluate the impact of amyloid PET on short-term patient management by comparing pre-PET intended management to post-PET actual management 90 days after the scan. The primary objective is to test whether amyloid PET leads to a 30 percent or more change between intended and actual patient management, including drug therapy, other therapy, and counseling about safety and future planning.

"Researchers will also assess the impact of amyloid PET results on clinical diagnosis and prevention of unnecessary diagnostic procedures and treatments. They will use Medicare claims data to compare medical outcomes at 12 months for patients with known amyloid PET to control patients who have never undergone amyloid PET. The primary objective is to determine if amyloid PET in the "known" group is associated with a 10 percent or more reduction in hospitalizations and emergency room visits compared to the controls.

"The evidence obtained by the IDEAS study may support reimbursement of amyloid imaging by Medicare and other third-party payers."

Maggie Heineman

Save the Date

ORANJ Plenary Meeting

October 18, 2017

Stonebridge at Montgomery

National Continuing Care Residents Association (NaCCRA)

ORANJ is a state member of NaCCRA ($500 dues). The resident associations of Medford Leas and The House of the Good Shepherd are community members ($200 dues). There are forty individual members in New Jersey ($20). NaCCRA is financed mostly by individual dues ($20/year, $200/lifetime). Most individual members are from eight states and the District of Columbia. The numbers are: FL-601, WA-531, VA-175, CT-146, NC-115, DC-91, NY-44, PA-42, NJ-40.

Message from the NaCCRA President

*Basil Pflumm's message is in the **spring issue of NaCCRA LIFE LINE** which is available at naccra.com*

It is not lightly that I take up the assignment to lead NaCCRA as your President. NaCCRA works to ensure that essential services are there for you today and that they will be there for you when, and if, you grow infirm and dependent on others. That requires carefully managed, soundly capitalized CCRC organizations. I have served our country as a military officer and have served the cause of business integrity through The Institute of Internal Auditors (the inspector general function for private organizations). Accepting NaCCRA's leadership is an important and humbling task. I need you. I need your support. So far within NaCCRA I have experienced dedicated and knowledgeable leaders ready to engage on behalf of seniors who rely on their CCRC for living services in their most vulnerable time. Please join with us so that, together, we can address these challenges.

Resident citizenship is NaCCRA's challenge. Many residents believe, or hope, that all will turn out for the best. We hope so, too, but anyone who retires from their citizenship duties at the national, state, or CCRC level becomes vulnerable to abuse. Qualified residents ought to serve on provider boards. The voice of entrance fee investors and customers will strengthen the providers and better serve their mission. NaCCRA facilitates resident representation both as advocate and as trainer.

Our role of educator for our fellow residents leads to membership. We need individual members (target 50,000) and the associated revenues to deliver greater strength through greater numbers. I simply cannot see why any member of a state resident association would not want to be a national member. In taking up this calling, I want you to know that we in NaCCRA are neither complacent nor wasteful.

We need membership development representatives in all 50 states promoting membership at the CCRC, state, and national levels. A first step will be to acquire an understanding of the capabilities of our membership so that all can have the opportunity to serve fellow residents in line with their talent and experience. We will initiate a database of member talents and experiences.

Within NaCCRA, I am also encouraged by the strength of many state CCRC resident associations. I anticipate even closer relationships and joint processes with this very effective leadership. What I hope NaCCRA can do is to complement the state leadership efforts and help assure that they have the support they need at the national level. Further, we can hope for even more state organizations to be formed and join ranks as CCRC residents not now known to us learn of all that NaCCRA is doing for them.

NaCCRA's treasury is dangerously low, but even here our constituency has members who can assist by funding some of their efforts and can employ technology to replace travel expenses. We need to build sufficient financial resources to be effective. To that end, a supportive membership base is required.

NaCCRA also needs to maintain an executive presence among people who count in the industry among for-profit and not-for-profit providers, and with related organizations of seniors. By "executive presence" I mean knowledgeable, respected advocates who win adherents to NaCCRA's vision of resident security. NaCCRA will be a friend of all who foster dignity and well-being for seniors. Our members have provided for their own aging, and that is an acceptance of responsibility that deserves to be fostered and honored.

We are taking NaCCRA in a new direction, one of action beyond aspiration. You came to a CCRC seeking peace of mind. We want to make sure that your trust is well placed. We will be frugal and energetic and I look forward to working with all of you as our membership grows, and CCRC residents everywhere become a force.

Basil Pflumm, President

To join NaCCRA ($20 first individual, $15 second individual) send your check and name(s), address, phone number, email, and name of community to

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