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Guiding Social Security into the next 80 years: a conversation with Carolyn W. Colvin

In June 2014, the Obama administration nominated Carolyn W. Colvin to head the Social Security Administration (SSA). She has been serving as Acting Commissioner since February 2013, and, in August 2015, she will be on hand to observe the agency's 80th anniversary. Colvin came out of retirement in 2010 to be the SSA's Deputy Commissioner, and embodies so many of the characteristics and values older workers possess—she has formidable intelligence and experience, is calm under pressure and is thoroughly engaged in her work.

'Quite simply, people receiving Social Security benefits are targets.'

Robert Blancato, an ASA Board member who has previously worked with Colvin in Washington, D.C., interviewed her in late April about anti-fraud efforts, Social Security's solvency and more.

Robert Blancato (RB): You are aggressively pursuing fraud cases. What programs are in place to prevent financial elder abuse, and how common a problem is it?

Carolyn Colvin (CC): The Social Security Administration [SSA] serves some of the most vulnerable individuals, not just the aged, but children and disabled people. Protecting seniors is a top priority. Financial exploitation is now an epidemic, and we are approaching it as we would a health epidemic, by joining forces with multiple agencies (we're working with Kathy Greenlee at the Administration on Aging [AOA]) and finding ways to work collaboratively. SSA has always had zero tolerance for fraud, and [we] will tirelessly identify and prosecute, to the fullest extent of the law, anyone who commits fraud.

Quite simply, people receiving Social Security benefits are targets. When beneficiaries are incapable of managing their finances, SSA appoints a family member



Carolyn W. Colvin

or friend to manage their benefits for them. We conduct annual accounting reviews for those individuals to see if benefits are being properly used. We still find it's a critical issue [in that] we see some [benefits] misuse and fraud of our beneficiaries. We have two pilot projects to recruit and train representative payees so they have the skills and capacity to identify

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Advocating for aging—when the personal becomes professional

By **Barbara Meltzer**

After my father died in 2003, I moved my mother from Florida to an assisted living facility in Los Angeles, near where I live. As her primary caregiver, I spent a lot of time with Mom and watched helplessly as dementia slowly erased her mind. I went from being her beloved daughter to being the "nice lady" who came to visit, until one day, I reached out to embrace her and knew I had become a total stranger.

This particularly sad moment came toward the end of my often painful caregiving journey and ultimately propelled me, unwittingly at first, onto a path of advocacy for the aging and their families. I believe caregiving to be a silent epidemic with no "medicine" available to cure it. Now, I continually think of ways to make things easier for those who are caring for loved ones.

Finding My Passion and Purpose

I found a purpose that had not been in any life plan or on any list of goals, but one that evolved out of personal experience, research and passion: It was clear



Barbara Meltzer with her mother, Sara.

that the aging of the baby boomers was and is creating innumerable crises that need immediate attention—and I needed and wanted to be of service.

'I found a purpose that had not been in any life plan or on any list of goals.'

The aides where Mom lived told me that I was one of the few adult children who visited their parents; this made me

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Keeping up our spirits, honoring those who served

August 15, 2015, is the 70th anniversary of the end of World War II. With cooperation from our friends at the Keep the Spirit of '45 Alive! organization, we offer this short roundup of happenings as we approach this historic milestone.

When the Chancellor of the University of Richmond, E. Bruce Heilman, was 72 his wife gave him a Harley Davidson motorcycle to mark their 50th wedding anniversary. She told him it was about time he "had a little freedom." Heilman had ridden motorcycles when serving as a Marine in WWII, but left that pastime behind once he married and became the father of five children.

At age 81, he traded in that motorcycle for an upgrade, and on Memorial Day he served as Grand Marshall of the national parade in Washington, having just finished a 6,000-mile road trip from Richmond, Va., across the country and back—all to help publicize the 70th anniversary of the end of WWII. Heilman figures he'll trade in this bike when he turns 91 (he's now 89, and still serving as chancellor).

"As far as we can determine, I'm the only World War II veteran that [the Spirit



Bruce Heilman poses on his Harley at the start of his cross country trip.

of '45 staffers] could locate who could ride the motorcycle 34 days across the country, maybe 6,000 to 8,000 miles. So I got the job," he told the American Legion's social media manager Steven Brooks in an interview in April 2015.

Heilman's open road adventure took him down to Atlanta, Shreveport, Dallas, El Paso and Tucson, and back up through Denver, Omaha, Chicago, Louisville and Charleston. Along the way, he swung by the American Legion headquarters in Indianapolis and also managed to squeeze in a visit with Iowa's governor. He wasn't

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IN FOCUS

Women's ways: caring, creative and fully engaged as they age

When we considered the rather broad theme of “women and aging” for this In Focus, caregiving, naturally, was on the topic list. As we worked with Guest Editor Barbara Meltzer on narrowing the theme, it soon became apparent that caregiving is a thread connecting most stories about women as they age.

Caregiving for her mother prompted Meltzer's interest in aging. Caring for children and parents kept many in the current generation of older women from embracing feminism more thoroughly, according to author Martha Holstein. Caregiving is a huge part of the challenge women face with Alzheimer's, as Maria Shriver says in our interview with her about



Photo: iStockphoto/annebaek

her advocacy work (also see Dr. Gary Small's sidebar on the latest research on Alzheimer's).

But we also realized that there are many women who, as they age, care so much about the larger world—as evidenced in two profiles of women doing amazing work late in life. And, lest we forget about self-care, we've included some bonus material online in ASA's AgeBlog: Joan Price's pragmatic look at why sexuality remains a key factor in women's happiness and well-being as they age (www.asaging.org/blog/late-life-sex).

Maria Shriver: Alzheimer's advocate and architect of change

Maria Shriver, and the perception of her, continues to evolve—from being known as Robert F. Kennedy's niece, to her role as an award-winning journalist and six-time *New York Times* best-selling author, to producing *The Shriver Report*, which chronicles shifts in American culture and society as they affect women. And she was California's first lady from 2003 to 2010, when she spearheaded The Women's Conference.

Shriver now sees herself as an Architect of Change—someone willing to step out of his or her comfort zone to create solutions to modern-day problems. One of those new roles for Shriver is as an advocate for families struggling with Alzheimer's. In 2003, her father, Sargent



Photo: Kwaku Alston

Maria Shriver

Shriver, was diagnosed with the disease and, since that time, she has been in-

involved in raising awareness and funds for Alzheimer's care and research.

Aging Today connected with Shriver via e-mail in April, to talk about why it's important that we understand not just Alzheimer's disease, but also its devastating effects upon women.

Every 67 seconds, another one of us [women] develops Alzheimer's.

Aging Today: Alzheimer's disease is in the forefront of the news today, largely a result of *Still Alice*. How are you helping women with Alzheimer's and women who are caring for someone with the disease? Why women? Why now?

Maria Shriver: Why women? Back in 2010, when we published *The Shriver Report: A Woman's Nation Takes on Alzheimer's* (<http://goo.gl/HYIE7Q>), we broke the news that women were more than half the individuals diagnosed with Alzheimer's and nearly two-thirds of the unpaid caregivers of those who had it. Now those numbers are far worse. Today, nearly two-thirds of those with Alzheimer's are women—that's more than 3.2 million women. And women are more than 70 percent of Alzheimer's caregivers, having to reduce their own workload or even drop out of the workforce altogether to care for loved ones. **AT: Please give Aging Today readers a quick rundown of the statistics about women and Alzheimer's?**

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Advocating for aging

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feel so sad about the people who never had visitors or company. There are many, many older adults put in homes and seemingly forgotten. Is that what must become of us when we age?

I am not married and have no children. I often think about what will happen to me and people like me, if and when we need help as we age. I have wonderful friends, but I think that ultimately it is family members who step up to the plate when personal, intimate and hard things must be done to help a loved one age safely and with dignity.

Thinking of the others in my mom's nursing home made the idea of solo aging something I contemplate regularly, spurring an advocacy interest in work on age-friendly cities.

The subject of aging women also is a very personal priority. That is why I am happy to be guest-editing this particular “In Focus” section on Women and Aging. I am an aging woman trying mightily to do all of the things we are told will assist us in remaining healthy or “aging well,” however one chooses to define that.

Which made it chilling to read the statistics about women and Alzheimer's disease in the interview with Maria Shriver, above. I know of no one who is older, man or woman, who has not expressed fear about the possibility of a future diagnosis.

This brings me to another priority—increased funding for Alzheimer's. Having become intimately familiar with the horrors and despair caused by the disease, I know we must advocate harder for more research dollars. The ripple effect for families who are caring for someone with dementia is heartbreaking—and a crisis, to be sure.

Entering the Path of Advocacy

The original crisis with my parents and my first hint of the challenges that faced our aging population in 2004 led me to a friend—an ardent activist who encouraged me to join the L.A. County Area Agency on Aging Advisory Council. Federally mandated by the Older Americans Act, the Council is a critical link between the Area Agency on Aging, Los Angeles County's senior community and local elected officials.

Topping my list of priorities is the creation of age-friendly communities.

In 2007, then L.A. County Supervisor Zev Yaroslavsky appointed me to the Los Angeles County Commission for Aging (now the L.A. County Commission for Older Adults) (LACCOA), which is the County's primary advocacy body for residents who are ages 60 and older. I

chaired the Communications Committee for several years and now serve as Chair of the Legislative-Advocacy Committee. Both are about communicating and educating. Over the years, I have written LACCOA's newsletter, created a LACCOA Speakers Bureau and an accompanying Tool Kit, worked on county-wide fairs for seniors, and midlife and older women. As head of my own public relations agency, it is an ideal fusion of my passion and profession.

A West Hollywood resident for many years, I was in 2013 appointed to its Human Services Commission, on which I represent the city's older population. Ours is a small, well-managed and progressive city that cares deeply about its residents and has the funds to provide many important and diverse programs and services. The Commission is a policy-making body that oversees a \$4.5 million budget used to provide these services for West Hollywood residents.

As I served on these commissions, I found myself homing in on certain issues that became (as mentioned above) priorities—caregiving, aging women, solo aging and Alzheimer's. But topping the list, because it's an endeavor that can be effective in ameliorating all these issues, is the creation of age-friendly communities—a fascinating, important and inclusive concept with complex and overarching goals.

I was thrilled when West Hollywood's leadership recently announced that the city will be launching an Aging in Place Initiative and that the Human Services Commission will be taking the lead.

The Path Ahead

I will continue my work in this vast and complex world of aging. As I reflect upon my “encore” career, my primary goal is to do exactly what I am doing now—serving on boards and commissions and building my business with clients and events that increase my involvement in aging issues. My ongoing advocacy for aging in place and family caregivers helped to set the West Hollywood initiative in motion. We will soon create a program for family caregivers because I have convinced city leaders of its importance. In addition, the LACCOA Speakers Bureau Tool Kit is being used by commissioners at speaking engagements throughout the County. It is exciting and fulfilling to make a difference in tackling the issues, challenges and possibilities of our aging population. ■

ASA member Barbara Meltzer is the founder and principal of the Los Angeles-based public relations and marketing agency, Barbara Meltzer & Associates. She can be reached at barbara@meltzerpr.com or by visiting www.meltzerpr.com. Meltzer also serves on the Aging Today Editorial Advisory Committee.

Gender matters: on battling late-life inequalities, and building a new feminist wave

By **Martha Holstein**

I am 74 years old and so I—and other women in their 70s—have not been a focus of current feminist work. We are not trying to “lean in” or juggle family and career or prove our competence in the male-dominated workplace. But even if “traditional” feminism doesn’t pay direct attention to women like me, its work matters.

Older women in the future will benefit from feminist efforts made now to disrupt norms that contribute to the accumulating income and health inequalities in late life. Feminist gerontologists are analyzing and calling attention to the structural and cultural genesis of these late-life inequalities, which undermine assumptions that equal opportunities to age well exist. And, feminist gerontologists critically examine “new aging” (e.g., the need to be “young,” successful, engaged, sexy, productive), revealing its unintended but consequential darker side.

Working because of necessity is a far cry from creating a second career.

Feminist work disrupts generalizations to remind us that we are not all living longer and in good health. Feminist gerontologists invite multiple narratives, which unsettle conventional assumptions that young is categorically good and old is categorically bad. Feminists disrupt the elite framings of public issues and demonstrate how different the world looks from the broom closet than from the corner office.

Feminism Exposes Gender Norms

Feminists remind us that to understand the situation of older women today means understanding how gender norms have shaped our lives from the beginning. While we women in our 70s came of age at the cusp of second-wave feminism, we (except for the rebels) accepted the dominant maternalistic norms, often setting aside our careers and education to fulfill them. Even if we wanted to reject them, without available, affordable childcare and eldercare, we couldn’t.

If we worked outside the home, it was in a genderized workplace that paid us less than men and viewed us as less competent. Considering recent reports and litigation, I wonder how different it is

now. In the long term, living by the era’s normative standards meant that we now have modest Social Security benefits, few pensions and little savings. Thus, we often are neither safe nor secure in old age.

Working because of necessity is a far cry from creating a second career that earns us recognition and respect. While much has changed for women, gender still is a dominant force in how we experience our lives.

Political, Social Forces Stoke the Gender Fire

As those of us in our 70s moved from middle age to old age, the near simultaneous emergence of the new conservatism and new narratives of late life reinforced and added to gender expectations. The ideology of neoliberalism, dominated by a commitment to small government, the marketplace and individualism, partnered with images of sexy, slim and tanned women enjoying moonlit dinners by the sea or starting new companies at age 69. Phrases such as “productive” or “successful” aging, the Third Age and “70 is the new 50” proliferated.

While the relationship between these political, cultural and representational shifts is complex, the results are clear: if one ignores the effects of gender and class, it is possible and, to some, desirable to assume that we all have the ability and the will to age in good health, remain productively engaged and retain beautiful bodies.

But in our neoliberal society, these goals also serve a political agenda. The leap from the new Third Age to undermining the justifications for a stronger Social Security program or to blaming the person who failed to measure up is not so large.

Gender and Ageism

As women age, ageism intersects with gender norms. If women need to work, jobs are particularly hard to find, and it becomes increasingly familiar to feel invisible. We may narrow our worlds to avoid situations in which we feel marginalized, thereby limiting risk-taking and seeking new opportunities, while being judged if we don’t do so. Or we may try to manage our identities through hair dye, makeup or cosmetic surgery to come closer to a normatively sanctioned (that is, young-looking) appearance. Insisting we are “not old” may temporarily exempt us from ageist stereotypes, but it does nothing to erase ageism. We become unwilling collaborators.

kindness. It’s a particularly telling part of horse psychology, according to Hayes, that humans are drawn to horses that mirror their personalities, strengths and weaknesses.

“I really understood what made me *me*, and working on the painful parts allowed me to share that with others, to show how healing through horses was so beneficial. Horses draw out compassion—they are the masters of compassion,” says Hayes.

For more information, visit www.hayesisforhorses.com. ■



Photo: iStockphoto/FotograficaBasica

Gender, age and class shape our lives, influencing the choices we have, how others do or do not respect us and our self-esteem. How we are when old is inseparable from the impact of the gender norms that shaped our lives. To make our lives better, we need to keep fighting for changes in social structures (i.e., the workplace, the family) that disadvantage women. We need to embrace, rather than reject, our aging selves as growing into a time that is neither all good nor all bad, but open to developmental possibilities. We need to reject today’s ways of being old that emphasize how “young” we are.

If we devalue old age why should anyone else value it? If we can (and should) avoid old age by “right action” and flee from the label of old, will we have the resources to embrace ourselves when we can no longer be “not old?” We can’t mitigate ageism and its effects by claiming personal exceptionalism or by demonstrating that some great grandmothers can jump hurdles. Instead we have to probe deeply for its causes and rupture it at its roots.

Needed: A New Feminist Wave

A new feminist wave might begin with small groups of women honoring rather than fleeing their age. We probably have more to offer as comfortable 70-year-olds than ersatz 50-year-olds. Coming together, preferably in intergenerational groups, women can explore issues of identity, goals, values, sadness and happiness. We older women can demonstrate that our puckered upper arms

don’t translate into a generalized incompetence or even unattractiveness.

Collectively we can reject normative views that suit some women some of the time and most women none of the time. We need to be trusted with our freedom to find our voices about how to live. We must also be alert to faulty assumptions couched in the voices of dominant elites. We need to have a ready response to the current conventional wisdom that “entitlement reform,” i.e., benefit reductions or other policy changes, is not a problem. Resting on assumptions that apply to the more affluent, they will disadvantage women and many lower wage workers.

‘If we devalue old age why should anyone else value it?’

These are only some of the suggestions for building a new feminist wave that can carry us toward a milestone that Tish Sommers, cofounder of the Older Women’s League, described many years ago—the day of the older woman will have come when women go to the beauty counter and ask for brown spots. We’ll then be partly there. ■

Martha Holstein has worked in the field of aging for more than 40 years. The ideas in this article are addressed more fully in her new book, Women in Late Life: Critical Perspectives on Gender and Age (Lanham, MD: Rowan & Littlefield, 2015; <https://goo.gl/6ENeii>, or on Amazon, <http://goo.gl/oYs7eG>).

Women-owned businesses can generate an economic boom

There are about 9 million U.S.-based enterprises owned by women, which employ almost 8 million employees and generate \$1.4 trillion in revenue, according to *The State of 2014 Women-Owned Businesses Report* (<http://goo.gl/Ja9lvr>), commissioned by American Express. And women entrepreneurs usually are at least 40 years old or older.

Yet only 4.2 percent of the 542 partner-level positions in venture capital firms are filled by women, and businesses run by women receive only 7 percent of venture capital funds. This is despite the fact that women-led tech companies achieve a 35 percent higher ROI and, when backed by venture capital, make 12 percent higher revenue than similar male-

owned companies, according to the Small Business Administration.

If women entrepreneurs began their businesses with the same capital as do men, they could add 6 million jobs to the economy in five years, 2 million in the first year, says a 2009 report from Ernst and Young (<http://goo.gl/AWmtQ9>).

This past spring, the National Older Women’s League launched a campaign to increase women’s access to venture capital funding to foster the growth of investment in women’s businesses from 7 percent to 20 percent by 2020. This initiative involves communicating directly to the venture capital community and institutional investors, plus a nationwide grassroots effort. For more information, visit <http://goo.gl/LT1IGQ>. ■

The Engaged Age

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feel about their experiences in combat. Even recalcitrant and addicted teens find solace and hope.

Riding Home also relates Hayes’ own healing story. The son of an alcoholic father, he spent years working through his demons, but finally really reached a new level of joy through his work with horses. He has a valued relationship with one particular horse, Austin, that Hayes says reflected his personality traits—heightened awareness, approachability and

Tending gardens, tending to troubled souls

By **Barbara Meltzer**

Working as a costume designer for more than 30 years—the latter half of that for “Late Night with Conan O’Brien”—Deborah Shaw decided to leave the show when in 2009 it moved from New York to Los Angeles. Her husband’s job was in New York and she was ready for a change. After taking a year to decide what to do, Shaw soon focused on volunteering in a prison.

“I’d long been interested in the criminal justice system,” says Shaw, 61. “It started several years ago when I read a book titled *Random Family*, the true story of a large extended family in the Bronx, most of whose male members had been incarcerated. I realized then that we have a correctional system with little or no correction.”

Shaw contacted Rikers Island to explore volunteer opportunities. Rikers is the second largest prison complex in the United States, housing about 12,000 inmates, most of whom are there awaiting trial. Also an avid gardener, when Shaw discovered that Rikers had a highly regarded horticultural therapy program for

inmates, she knew that was where she wanted to volunteer.

“I come from a family of community activists,” she says, “and the Rikers program provided a way for me to be of service to others, in addition to pursuing a passion.”

I realized we have a correctional system with little or no correction.

The program director required visitors take a course in horticultural therapy before visiting the prison garden. Based upon an ancient practice that uses live plants and the growing environment to heal and rehabilitate people, the course Shaw took was offered at the New York Botanical Garden.

When she was finally able to visit the Rikers garden, she was amazed at its beauty. “It’s a 2-acre oasis of vegetables, flowers, trees and a pond with fish, inside a desolate 400-acre prison complex,” she says. The therapy program hadn’t traditionally used volunteers, but Shaw “pestered” the director to take her on. Now there is at least one volunteer working per day.



Deborah Shaw

Prison inmates are referred to as “students,” and assigned to the program by the Department of Corrections. They are allowed to use only small plastic knives and pruning shears. They grow salad greens and other easier to cut vegetables, and they tend apricot and cherry trees. Flower arranging is taught in the summer, as well as seed-starting in the spring and seed-saving in the fall.

Shaw says she has never been afraid inside the garden, but notes that getting to it is another story. “We have a long walk through a very tough jail and I have been afraid when there’s a lockdown or an alarm.”

“I really enjoy the work I am doing. It’s exciting to see how the students react to the program, both to the gardening and to those of us who work there.” Shaw finds the students to be smart, respectful and inquisitive. Many have endured terrible hardships as children and as adults.

I’m older than almost all the students and I bring a lot of life experience to the table.

“They appreciate the program very much,” she adds, “and each person takes something different away from the experience.”

“I’m older than almost all the students and I bring a lot of life experience to the table, in addition to the gardening. When they are about to be released, we talk about their plans, where they’ll be living and how to keep themselves from coming back.”

Shaw will receive her certificate in Horticultural Therapy from the New York Botanical Garden next year, and has recently started a horticultural program at Brooklyn Community Housing Services, a residence for formerly homeless people with mental illness. The residents have planted and tend a 70-foot garden of colorful annuals in front of the building, plus a container garden of herbs and vegetables. ■

Positive aging advocates champion the rich promise of life’s second half

By **Barbara Meltzer**

Many factors, including added longevity, financial insecurity and budget cuts in programs for seniors, make it vital that we invent how to live this new phase of life beginning at age 50-plus,” says Jan Hively, co-creator, with Moira Allan, of the Pass It On Network (PION; www.passitonnetwork.org).

Founded in 2013, PION is a global program exchange for positive aging that acts as a grassroots network of older adult thought leaders—innovators who are blending more traditional ways of outreach with new technologies and applying this mix to deal with issues of aging via mutual support networks.

We wanted to harness and nurture the active involvement and self-advocacy skills of older adults.

Both Hively and Allan believe that important elements of positive healthy aging involve meaningful work, creative expression and social interaction. “So rich in promise and challenges, the second half of life calls for us to be bold, imaginative and caring,” says Hively. They also champion the dissemination of stories about vital aging and intergenerational activities, as well as engagement in mutual support networks.

A Cape Cod resident, Hively, 83, and Paris-based Allan, 69, met in 2007 at the first Positive Aging Conference in St. Petersburg Fla. “Our network has grown out of our friendship and common passion for “meaningful work, paid or unpaid, through the last breath,” says Allan. “Jan and I both believe very strongly in empha-



Moira Allan, left, and Jan Hively in 2013 at the Encore Summit in San Francisco.

sizing the capacity of older adults to self-organize and help themselves and others find or create what’s needed to thrive.”

Long interested in raising awareness about new opportunities and challenges for older adults, based on 21st century trends and research, Hively’s early career was in city and school planning and administration. She earned her doctorate in 2001 and is cofounder of several thriving networks supporting lifework planning and positive aging, including the Vital Aging Network; ArtSage, Minnesota; and the SHIFT Network. An Encore Purpose Prize Fellow, Hively is an internationally recognized presenter and consultant for programs that engage older adult leadership and support positive and productive aging.

Originally from South Africa, Moira Allan has been living and working in Paris for the last 35 years with careers in journalism, public relations, training and

managing an occupational health organization. Her work in the positive aging movement has included coordinating the 2young2retire network in Europe with its French counterpart Le Cercle des Seniors Actifs, the association that conceived the Pass It On Network.

Hively and Allan created PION as an online aggregate site to help shift people’s deeply ingrained expectations for retirement and dependency in later life, and empower older adults to plan for meaningful work and self-determination. PION is a “meeting place” for innovative minds from all countries to explore, discover, compare, document and spread creative ideas that can forge a new way of talking and being as world populations adapt to longer lifespans.

PION hosts a directory of programs—like Age-Friendly Tuymazy, the first member of the World Health Organization’s Age-Friendly Cities Network from

Russia—that encourage lifelong learning and self-sufficiency and can be accessed in several languages. The website also includes links to like-minded networks—like SHIFT, a peer network geared toward helping older adults navigate work/life transitions—plus educational opportunities for teaching and learning, and guides for organizing self-help groups such as the Caring Collaborative developed by The Transition Network in New York City. In development are international peer-to-peer circles and training in organizing leadership for positive aging.

“We wanted to harness and nurture the active involvement and self-advocacy skills of older adults who will then share their strengths to help themselves, each other and their communities,” says Hively.

One recent networking success occurred when Allan mentioned Ashton Applewhite’s anti-ageism blog, “This Chair Rocks,” on the PION website, and PION’s Swedish liaison in Stockholm developed a “This Chair Rocks” consciousness-raising group. Applewhite is now working on discussion guidelines that PION will help disseminate this year.

Because of Allan’s outreach through PION’s South Africa liaison, a group of mid-life professionals in Johannesburg has drafted organizing documents for “Encore South Africa.” Encore.org has granted permission to use the name and Encore’s Betsy Werley offered guidance to its organizing process.

Hively and Allan truly believe in older adults’ capacity to help themselves and others find or create richness in late life. As Hively says, “There is a line from a poem that is attributed to the Hopi Elder, Chief Dan Evehema, that says, ‘We are the ones we have been waiting for.’ That is the core value of the Pass It On Network.” ■

Maria Shriver, Alzheimer's advocate

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MS: Every 67 seconds, another one of us develops Alzheimer's. Women in their 60s are about twice as likely to develop Alzheimer's as breast cancer. With 10,000 baby boomers turning 65 every day, there will be 13.5 million of us with Alzheimer's by 2050.

AT: Yet, with all of the exposure, the funding for the disease doesn't seem to increase. Why is that?

MS: Because it has long been thought of as a natural part of aging. For so long, people thought Alzheimer's disease happened only to folks in their 80s and 90s. *Still Alice* shows us that is just not true. Alzheimer's is a disease that kills. The truth is, we're right in the middle of an epidemic, but we, as a nation, are in denial. An Oscar for *Still Alice* is shining the brightest light yet on Alzheimer's, but light isn't enough anymore. Attention isn't enough. It's time to get serious. Alzheimer's is exerting a powerful impact on American families—on our health, our finances and our futures. And women are disproportionately impacted.

AT: There is a terrible stigma attached to the disease. How much of an impact does this have on funding? And what can be done about getting rid of the stigma?

MS: We have to make it mainstream. We have to talk about it. We have to fund this

research ourselves, because for some reason, it's not a priority for the government. In 2015, Washington will spend an estimated \$6 billion on cancer research and \$3 billion on HIV/AIDS research, but only \$586 million on Alzheimer's. Yet, this disease is costing our federal government \$226 billion every year. I don't get it, but I'm not going to wait anymore.

We have to fund this research ourselves because it's not a priority for the government.

It's time for the narrative around Alzheimer's to change. I remember when an HIV/AIDS diagnosis was a death sentence. I remember when cancer was a dirty word and the prognosis was always grim. But AIDS and cancer activists are helping to take these diseases from terrifying to treatable, from hopeless to hopeful. We want to do the same with Alzheimer's. We want to understand it, prevent it, treat it and beat it. Wipe Out Alzheimer's (wipeoutalzheimers.org) is creating a global community of women activists, agitators and agents of change to do just that.

AT: Your personal story about your father, who had Alzheimer's disease, is well known. What do you remember most about watching the disease advance in him?

Update on Alzheimer's prevention and treatment

By Gary Small

During the past two decades, medicines that help treat the symptoms of Alzheimer's disease have become available, but they offer only temporary benefits. No cure exists. Scientists have focused their recent research on disease-modifying interventions—treatments for slowing or halting the disease and offering sustained effects even if the medicine is discontinued. These investigations have targeted the abnormal protein deposits—amyloid plaques and tau tangles—first described by Alois Alzheimer in 1906.

Medications offer only temporary benefits against Alzheimer's.

Other medical interventions work on specific disease mechanisms. Because of research showing a link between diabetes and Alzheimer's risk, clinical trials using insulin nasal spray are in progress. Additional trials have tested medicines that dampen inflammation, boost cellular energy, promote brain cell messengers like serotonin or target other disease processes. Although many ongoing trials show promise, to date, all completed disease-modifying studies have failed because of drug toxicity, lack of efficacy or both.

Prevention May Prove Promising

One reason for the drug development impasse is that most previous clinical trials have included patients who already suffer from dementia—a cognitive decline that makes them dependent upon

others. Because evidence of the disease is apparent years before patients reach that stage, many new studies aim to prevent or delay dementia onset in people who are at risk. The Anti-Amyloid Treatment in Asymptomatic Alzheimer's Disease (A4) study is testing an antibody that targets amyloid plaques in normal people with brain-scan evidence of amyloid. The DIAN (Dominantly Inherited Alzheimer Network) trial is testing anti-amyloid drugs in asymptomatic people who have a rare genetic mutation that causes Alzheimer's disease.

And because healthy lifestyle habits appear to protect the brain and improve cognitive abilities, investigators are studying whether exercise and other behaviors can slow cognitive decline. The Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability (FINGER Study) recently demonstrated that physical activity, nutritional guidance, cognitive training, social activities and management of heart health risk factors improved cognitive performance in 1,260 older adults at risk for Alzheimer's disease. At UCLA, we have begun an Alzheimer's Risk Reduction Initiative that will recruit volunteers from the health system and offer an exercise, nutrition, stress management and memory training program to determine its effectiveness in improving cognitive performance and containing healthcare costs.

Research Needs to Target Women

One area that needs greater focus is the brain health of women. Despite earlier efforts to unravel the impact of estrogen on Alzheimer's risk, few recent studies have

MS: My father's mind had always been a finely tuned instrument that left people in awe and inspired. But my family and I watched Alzheimer's erase that brain—slowly, inexorably, completely. It was terrifying, too, because back then, the disease was surrounded by shame and silence.

AT: You have been working to combat Alzheimer's disease since 2003 when your father was diagnosed. And you started Wipe Out Alzheimer's. What steps are you taking to combat the disease?

MS: We're asking women to put together their own "My Brain Trusts" in their communities—groups that will go out and do some muscular fundraising. But equally important, these Brain Trusts will gather to discuss and disseminate information about what the disease is—and isn't. What are the warning signs we should look for in ourselves and our parents? What's the difference between normal forgetfulness, dementia and Alzheimer's disease? Can brain games or meditation slow cognitive decline? Do dietary supplements help?

Local Brain Trust groups also will learn about the devastatingly high cost of Alzheimer's—how neither Medicare nor the Affordable Care Act cover long-term care, and private nursing homes average more than \$80,000 a year. They'll reach out to help and encourage women whose loved ones have Alzheimer's. They will

be politically engaged and encourage political candidates who support increased funding for Alzheimer's research. They'll push their doctors to get better educated about cognitive health.

AT: Education seems key. Beyond movies like *Still Alice*, how might we bring the reality of Alzheimer's to the general public more effectively?

MS: That's why we launched the Wipe Out Alzheimer's Challenge (wipeoutalzheimers.org/share.html), a multi-pronged campaign powered by women's brains. Our mission is to enlist women of all ages to get educated, engaged and empowered to instigate change. Women around the country will go out and raise the alarm, raise awareness, raise the stakes and raise millions of dollars to fund serious research into women's brains.

AT: How can others who want to help or are interested in more information about Wipe Out Alzheimer's get in touch?

MS: They can take the pledge (wipeoutalzheimers.org/share.html) on the website, they can share their stories for the Alzheimer's & Caregiving section on Maria Shriver.com (<http://goo.gl/aEanVP>) and they can start their brain clubs in their own towns to raise awareness and money for funding and they can apply to be on our Big Wall of Empowerment (<http://goo.gl/RQjR71>) to highlight the work they're doing for Alzheimer's. ■



Photo: iStockphoto/ Ira Schwartz

genetic risk has a greater impact on women than men, and women have a higher susceptibility to depression, which further increases dementia risk.

I am optimistic that effective treatments will soon emerge, but how soon will depend upon available funding. The current focus on protecting a healthy brain and including a range of treatment approaches is certainly encouraging. As we wait for results of the latest research, the scientific evidence is compelling that living a healthy lifestyle will not only protect the heart, but also the brain. ■

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targeted women with dementia, yet they comprise two-thirds of Alzheimer's victims. Women, on average, live longer than

Genetic risk has a greater impact on women than men.

men, and age is the greatest risk factor for Alzheimer's, but other factors are at play:

Caregivers—put on your traveling shoes!

Road Scholar (formerly Elderhostel), the travel company specializing in lifelong learning, offers worldwide adventures curated by experts at reasonable rates. Now, they're responding to older adult caregivers in need of respite by establishing caregiver grants allowing older adults who serve as family caregivers for sick or disabled relatives to apply for travel scholarships.

Their site states: "We're committed to helping you offset the costs of arranging substitute care while you attend a Road Scholar learning adventure." Applicants are required to write a statement enumerating why their selected trip inspires them, and how their caregiving responsibilities might make it difficult to attend without caregiver grant support.

Programs selected must be in the United States, and cost no more than \$1,400. Some potential adventures include "Monadnock Birding and Mammals" and "Treasures of Conservancy" (New Hampshire), or "Kayaking the Eastern Shore: The Chesapeake and the Atlantic" (Virginia) and "Intergenerational: Exploring Woods and Waters of the Northwoods", which is designed to be enjoyed with grandkids (Minnesota).

Post trip, applicants are asked to write a "thank you" note to the grant's donor, and post an online review and photos and blog about the trip. The company wants to publicize these grants via avenues such as online discussion forums, senior centers, support groups and faith communities; contact www.roadscholar.org/grant. ■