

University of Pennsylvania

FALL 2004

THE IOA USHERS IN ITS NEXT QUARTER CENTURY

The Institute on Aging celebrated its 25th Anniversary during its annual Retreat held on May 25, 2004 at the University of Pennsylvania's Houston Hall. Joined by nearly 300 guests, IOA Director John Q. Trojanowski, MD, PhD cut the celebration cake, and ushered in the IOA's next quarter century. In attendance were many who were instrumental in forming the Center for the Study of Aging, the precursor to the IOA. Key among this founding group was Vincent J. Cristofalo, PhD, the first Director of the Center for the Study of Aging and current CEO and President of Lankenau Institute for Medical Research and Professor Emeritus at the University of Pennsylvania and at the Wistar Institute. Dr. Cristofalo was featured as the Sylvan M. Cohen Visiting Scholar and spoke to a standing room only audience on "Longevity, Senescence and Aging".

Following Dr. Cristofalo, was Sarah Kagan, PhD, RN, who addressed this audience as the PENN Presenter, on "The Scientific Import of Imbedded Social Constructions of Being Old and Having Cancer or How Bench Scientists Can Help Reconstruct Outmoded Social Icons of Aging". Dr. Kagan is Associate Professor of Gerontological Nursing and winner of the MacArthur "Genius Award".

After concluding their presentations Drs. Cristofalo and Kagan joined many others at the annual poster session. With categories incorporating Basic Science, Clinical Research, Educational Programs and Other Projects, and Pew Fund Elderly Program participants, this year's poster session featured 73 entries. The judges, after studied deliberation, awarded prizes to the following PENN entrants:



Message from the Director





John Q. Trojanowski, MD, PhD

foundation, I look ahead with promise and anticipation toward the IOA's next quarter-century as we continue our work toward helping all of us age successfully. Tipping our celebratory hat toward our first twenty-five years, the IOA hosted Vincent J. Cristofalo, PhD and Sarah Kagan, PhD, RN at its 25th Anniversary celebration held on May 25, 2004. Joining the celebration were 73 poster presenters, who offered work in Basic Science, Clinical Research and Educational and Other Programs, as described more fully in our cover story.

The IOA is already looking forward to another busy year that will be capped off by our 2005

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Director

John Q. Trojanowski, MD, PhD

Deputy Director

Kathryn Jedrziewski, PhD

MISSION:

The mission of the Institute on Aging (IOA) at the University of Pennsylvania is to improve the health of the elderly by increasing the quality and quantity of clinical and basic research as well as educational programs focusing on normal aging and age-related diseases at the University of Pennsylvania School of Medicine and across the entire PENN campus.

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THE MARIAN S. WARE ALZHEIMER PROGRAM BEGINS WITH A UNIQUE **BRAINSTORMING RETREAT**

in Partnership with the Commonwealth of Pennsylvania Department of Aging

On April 30, 2004 the Pennsylvania Department of Aging and The Institute on Aging co-hosted the Marian S. Ware Alzheimer Program Kickoff and Brainstorming Retreat on Alzheimer's Care. This all-day Retreat, held on the PENN campus, was designed to take the discourse on Alzheimer's Disease (AD) to a new level – integrating the often separate efforts of academics, government agencies, practitioners, policy makers, community service agencies, private industries, care providers and advocates.

The Retreat was facilitated by Nora Dowd Eisenhower, Secretary, Commonwealth of Pennsylvania Department of Aging and John Q. Trojanowski, MD, PhD, William Maul Measey – Truman G. Schnabel Jr., M.D. Professor of Geriatric Medicine and Gerontology and Director of the Institute on Aging. Both Secretary Eisenhower and Dr. Trojanowski had been hoping for the opportunity to host an open forum like this, to invite the public to think and plan together. They had several times discussed their shared views that Pennsylvania was facing a public health crisis, that work needed to be done to address the tremendous human and economic consequences of AD and that this work would require participation on every level.

The stage was set for the April 30 Retreat by several circumstances. With the National Alzheimer's Conference taking place in Philadelphia in July 2004, Philadelphia seemed the right place to begin the statewide conversation. This notion was solidified in January 2004, when The University of Pennsylvania announced the establishment of the Marian S. Ware Alzheimer Program, comprising a set of collaborative initiatives between PENN Medicine and the University of Pennsylvania School of Nursing to advance drug discovery, clinical research, and patient care related to Alzheimer's disease. The Program was created through a \$6 million gift from Marian S. Ware, a long-time supporter of the University and advocate for progress in medical research and treatment for Alzheimer's disease.

The formation of the Marian S. Ware Alzheimer Program underscored the value of the multi-disciplinary approach needed to find solutions. This message was emphasized by both Dr. Arthur H. Rubenstein, Executive Vice President of the University of Pennsylvania for the Health System and Dean of the School of Medicine, and Dr. Afaf Meleis, Dean of the School of Nursing, in their opening remarks for the April 30 Brainstorming Retreat.

Alzheimer's is a progressive, degenerative disease that attacks the brain and results in impaired memory, thinking, and behavior — drastically affecting the daily lives of patients and their families. Increased hospital stays, emergency room visits, re-hospitalizations and caregiver burdens are already placing strain on the healthcare system and on families in the Commonwealth.





Nora Dowd Eisenhower Secretary, Commonwealth of Pennsylvania Department of Aging

Secretary Dowd Eisenhower explained in her opening remarks that legislators and policy makers need the input of doctors, nurses and caregivers to better under-stand the need for early non-invasive diagnosis, interventions, and treatment that are appropriate, affordable and effective.

Dr. Trojanowski further expressed the interdependence of all stakeholders in addressing AD, the need for models of care that support and complement research and clinical interventions. He began the Retreat on April 30 with an overview of the challenges confronting everyone working in AD from education and awareness to diagnosis, from develop-

ing interventions to delivering affordable and effective care. He reframed the severity of this disease as a public health issue. AD currently afflicts 4.5 million people in the United States and accounts for over 100,000 deaths every year at a cost of \$100 billion a year.

Dr. Trojanowski also put the demographics in realistic perspective: "Alzheimer's Disease is an 'equal opportunity' disease affecting people of all social strata, ethnic groups, men and women...and by 2050, there will be 14 million Alzheimer's patients in need of care." He also described the potential impact of working together at all levels in delaying the onset of Alzheimer's Disease in Pennsylvania. "If you can delay the onset of AD by 5 years, you can cut the prevalence in half...and we are very close to being within striking distance of that goal."

Wendy Campbell, President of the Alzheimer's Association Delaware Valley Chapter, further expressed how the prevalence of AD had the very real potential to devastate our communities. AD not only affects the close to 500,000 Pennsylvanians afflicted but also requires the financial and physical support of their families and communities. She presented the work that the Alzheimer's Association is doing in raising awareness, fostering research, caring for those living with AD and training caregivers. Ms. Campbell highlighted one of the most recent and far-reaching developments, the implementation of the national Contact Center/Helpline 1-800-272-3900, a free service provided by the Alzheimer's Association available 24 hours a day, seven days a week. She also described a new prevention initiative, Maintain Your Brain, encouraging healthy preventative lifestyles.

As the degenerative process related to AD begins years before the symptoms present themselves, it is important to make lifestyle changes early. Kathy Jedrziewski, PhD, Deputy Director of the Institute on Aging, expanded on the importance of lifestyle changes in the prevention of early onset AD. Dr. Jedrziewski presented recent research on healthy brain aging exploring the impact of leisure activities in the onset of AD and related dementias. While this area of inquiry is rather new, data has been collected establishing the importance of cognitive (music, reading, crossword puzzles) and physical (walking, dancing) as a possible means to prevent AD.

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Message from the Director

Retreat, which will be held on
June 8, 2005 at the University of
Pennsylvania. Presenting at the 2005
Retreat are PENN's Stuart L. Fine,
MD, Chair of the Department of
Ophthalmology and Joshua L.
Dunaief, MD, Assistant Professor of
Ophthalmology who will speak about
Macular Degeneration, while Majd
Alwan, PhD, University of Virginia,
will offer information about Robotics
and Eldercare Technologies.

We are also very excited about the Anti-Aging seminar we will host, along with PENN's Center for Human Appearance, on March 18-19, 2005 at PENN. Entitled "The Art & Science of Anti-Aging Therapies: Convergence of Theory and Practice" this two day agenda combines a wide array of approaches toward healthy aging of the body and mind and even features a session on Antioxidants and Aging in Dogs! (please see page ____).

Our Visiting Scholars program initiates its second year with a roster of distinguished speakers active in a number of capacities in the field of aging (see page _____). Kathy Parker, PhD, RN of Emory University was our first speaker and presented her findings in transitional research in nursing. Robert Storr, MFA, of New York University will offer an interesting presentation on "The Mind and the Hand" on December 2nd when he will discuss his perspective on the

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In fact, this concept of comprehensive palliative care is relatively modern. Now a nationally guaranteed benefit under both Medicare and Medicaid, hospice is only a 25- year-old institution in the United States. Currently, the benefit includes access to a



multidisciplinary team of professionals including a hospice physician (often the medical director of the program), nurses, home health aides, social workers, clergy or other counselors, trained volunteers, as well as speech, physical, and occupational therapists. Also included are medications, respite care, and bereavement counseling. Hospice care is provided in a variety of settings, including the home, hospice units, hospitals, and nursing homes.

"Despite these benefits," says Casarett, "hospice has remained underutilized. According to the National Hospice and Palliative Care Organization (NHPCO), more than 800,000 patients die in hospice every year. However, the median time spent in hospice care is only three weeks, with one third of patients in hospice for only a week. Ten percent are in hospice for only a day. "A day?" Casarett asks. "That's a little like a surgical patient receiving anesthesia for only the last few minutes of an operation. Surely we can do better than that."

But Casarett also points out that those patients are fortunate to receive hospice care at all, since most patients do not. In particular, Casarett notes that certain groups of patients — those with non-cancer diagnoses, African Americans, and nursing home residents — are significantly less likely to receive hospice care. Increasingly, Casarett's research is focusing on understanding and overcoming these disparities in access to hospice.

In one of Casarett's recent studies comparing nursing home residents with community-dwelling older patients, he wrote, "Indeed, it is becoming increasingly clear that the current health care system often fails to promote a good death, broadly defined as a safe and comfortable dying experience, self-determined life closure, and effective grieving." Casarett goes on to say that "data suggest that even basic needs for pain control may not be met for nursing home residents in general, and especially for those with cancer."

This multi-site case-control study, which compared the two patient groups' needs for palliative care and survival rate from the time of enrollment, raised further questions for Casarett. While the study concluded that the need for care in the two groups was similar, Casarett notes that the "hospice teams often identified at least one need that had not been addressed by the nursing home resident's care team." Further, nursing home residents in the study had a significantly shorter survival rate.

Casarett's findings illustrate that while nursing home residents had significant needs for care, they had fewer needs than do other hospice patients. While Casarett would like to feel optimistic about future partnerships between hospice organizations and nursing homes, he is well versed in the economic and regulatory barriers that hospices face. "A shorter survival

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genesis of these devastating disorders and their relationship to normal aging. We may now be on the cusp of developing new and more effective therapies. And with the IOA, the Alzheimer's disease center, and the Center for Neurodegenerative Disease Research, as well as a large number of investigators focusing on neurodegenerative disease, PENN is uniquely positioned to contribute to this research."

Virginia Lee Named Co-Vice Chair for Pathology Academics



Virginia M.Y. Lee, Ph.D. became Co-Vice Chair for Academics in the Pathology and Laboratory Medicine department, effective September 1, 2004. In

assuming this new leadership position, Dr. Lee will take on primary responsibility for overseeing faculty mentoring within this Department, building upon her contributions as a Co-Director of Faculty Mentoring. Dr. Lee's outstanding research accomplishments in the field of neurodegenerative diseases have been recognized by a number of major awards, including the Potamkin Prize for Medical Research in Alzheimer's Disease and the Bristol Myers Squibb Unrestricted Biomedical Research Grant in Neuroscience, as well as Penn's prestigious Stanley Cohen Biomedical Research Award. Dr. Lee is Director of the Center for Neurodegenerative Disease Research at Penn and the leader of an NIH T32 training program in aging brain diseases.

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Naylor Selected McCann Scholar



Mary Naylor, PhD, RN, FAAN, Professor of Nursing at the University of Pennsylvania School of Nursing and Director for the RAND/Hartford Center for Inter-

disciplinary Geriatric Health Care, has been made a 2004 McCann Scholar. The Joy McCann Foundation focuses on the development of future leaders in medicine and science by encouraging more doctors, nurses and scientists to become mentors. This honor awards \$150,000 to inspirational mentors to use at their own discretion.

Dr. Naylor garnered a national and international reputation as a geriatric scholar, combining her humanistic concern and respect for vulnerable elders with rigorous science to create innovative models to enhance the care and health outcomes of this population. She has also earned the respect of her students and peers as an outstanding teacher and mentor. Especially noteworthy is the leadership Dr. Naylor demonstrated in promoting educational and research collaborations among scholars and students from various disciplines.

Trojanowski Named Recipient of 2005 Rous-Whipple Award



The American Society of Investigative Pathology (ASIP) named John Q. Trojanowski, MD, PhD as the recipient of its 2005 Rous-Whipple

Award. The ASIP seeks to advance and disseminate knowledge concerning the pathogenesis of disease, knowledge

THE INSTITUTE ON AGING ANNOUNCES 2005 PILOT GRANT AWARDS FOR RESEARCH IN AGING

The IOA has awarded three grants supporting pilot projects in aging-related research.

The IOA Pilot Grant program, now in it's second year, is a highly valued component of the IOA serving to support new faculty entering the field of aging and to stimulate multi-disciplinary projects that focus the diverse expertise at the University of Pennsylvania toward aging research. In doing so, the IOA aims to foster the exploration of new directions in the field of aging on a broader scale.



"Osteopenia and osteoblast differentiation in mouse models of accelerated aging"

The aging of bone is characterized by the loss of mineral content which compromises bone strength and predisposes bone to damage. Dr. Robert Pignolo is leading a study examining the cellular mechanisms which link gene defects with the impaired bone density commonly associated with osteoporosis and bone

damage in old age. Dr. Pignolo's research focuses on the impaired capacity of to divide and differentiate bone-forming cells, osteoblasts, as we age.

A better understanding of the factors that contribute to osteoblast differentiation may provide new insights into the pathophysiology of bone loss leading to more effective treatment and prevention for the range of debilitating problems that affect millions of older individuals.

Robert J. Pignolo, M.D., Ph.D. Assistant Professor of Medicine, Division of Geriatric Medicine Staff Physician, Philadelphia Veterans Affairs Medical Center

Collaborative Faculty, McKay Laboratory of Orthopaedic Surgery Research Fellow of the Institute on Aging



"Sleep:wake cycles and oxidative stress in age: Drosophila"

Dr. Amita Sehgal will be heading a project that seeks to determine the cause of the fragmentation in sleep cycles that occurs with age. Many of the molecular components controlling the timing of sleep are now known – Dr. Sehgal and her team will focus on determining which of these components change with age. In addition, this project will test the hypothesis

that the fragmentation of the sleep cycle is due, in part, to the accumulation



Message from the Director

possible effects dementia may have played in the works of some distinguished artists. Patricia Archbold, DNSc, RN from Oregon Health & Science University will speak on February 3, 2005 about aspects of family care for elders, followed by Christine Cassel, MD, President & CEO of the American Board of Internal Medicine who will speak on April 7, 2005 about Medicare. The former Governor of Colorado, Richard Lamm will be our speaker on May 12, 2005 before rounding out our schedule with the Retreat in June.

Also entering its second year is the IOA Pilot Grant program, which awards grants in support of aging-related research. With the objective of supporting new faculty entering the field of aging and encouraging multi-disciplinary research, the IOA awarded one year grants to Robert J. Pignola, MD, PhD, Amita Sehgal, PhD and Jennifer Tjia, MD, MSCE, as described more fully on page _____.

Please refer to our website
www.uphs.upenn.edu/aging for
current information about all of our
activities. We thank you for your
continued interest in Aging and hope
to see you at one of our many events
this academic year.



of oxidative damage. In the long term, the goal is to establish treatments, either genetically or by changing environmental conditions, to improve the quality of our sleep cycles and assess the effect upon lifespan and quality of life.

Amita Sehgal, Ph.D.
Associate Professor
Howard Hughes Medical Institute
Department of Neuroscience, School of Medicine



"Comparing pharmacy refill records to PACE administrative claims to measure medication adherence"

Dr. Jennifer Tjia will be collecting data to establish an alternative method for measuring medication use among the elderly in order to evaluate the impact of the Medicare Modernization Act of 2003 and help inform more effective public policy in the future. Her primary research focus is to develop methods to optimize the uptake and utilization of emerging pharmaceutical ther-

apies by older adults. She is specifically interested in understanding the effect of state and federal prescription drug policies on elder health outcomes and health service utilization, and understanding the predictors of medication uptake and adherence among older adults.

Jennifer Tjia, M.D., M.S.C.E. Instructor of Medicine, Division of Geriatric Medicine Fellow of the Institute on Aging



The IOA Pilot Grant program provides initial support in both basic science and clinical areas in aging for investigators engaged in biomedical, epidemiological, behavioral or health services research. A salient goal is to assist PENN faculty in obtaining preliminary data to serve as the basis for grant applications to the NIH or other public or private agencies concerned with aging. A pilot grant recipient from last year, Dr. Daniel Polsky, recently received multi-year federal

funding to continue his research on the impact of the lack of health insurance on health outcomes in old age focusing on the influence of Medicare on elderly health both overall and for subgroups of the population based on health insurance status.

Daniel Polsky, Ph.D. Assistant Professor of Medicine General Internal Medicine

More information on the IOA Pilot Grant Program and the current grants can be found on the Institute on Aging website: http://www.uphs.upenn.edu/aging.

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that is derived from diverse experimental approaches including genetic, immunologic, molecular, pharmacologic, physiologic and structural investigations. Named for two Nobel laureates and pioneers in American pathology, the Rous-Whipple Award is given annually to a distinguished mid-career investigator with a longstanding and ongoing research program. Dr. Trojanowski will be honored at the ASIP Awards Presentation and Reception in early April 2005 and will speak on "The Alzheimer Brain: Finding Out What's Broken Tells us How to Fix It". Dr. Trojanowski is Professor of Pathology and Laboratory Medicine, Associate Director of the Center for Neurodegenerative Disease Research, and Director of the IOA

Visiting Scholars Series

The IOA Visiting Scholars series presents valuable educational lectures by experts in the areas of aging research, policy, and clinical care. Sessions are open to the public, free of charge and are designed to promote interdisciplinary dialogue, discussion and debate. For more information on the following sessions, please visit our website at www.uphs.upenn.edu/aging or call the IOA at (215) 898-3163. The remaining scholars for the 2004-2005 season are:

December 2, 2004

Robert Storr, MFA

Rosalie Solow Professor of Modern Art New York University "The Mind in the Hand" Place: University of Pennsylvania John Morgan Building Class of '62 Hall

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International Frontotemporal Disorder Forum:

A SHARED OPPORTUNITY FOR SCIENTISTS AND CAREGIVERS

Frontotemporal Disorder (FTD) is a degenerative condition of the front (anterior) part of the brain, affecting the areas of the mind that control reasoning, personality and social comportment, and speech and language. Because of its symptoms, FTD is often initially misdiagnosed (and subsequently mistreated) as a psychiatric problem, Alzheimer's disease, or Parkinson's disease. However, FTD differs significantly in pathology and progression from more common forms of dementia such as Alzheimer's disease.

On July 15 and 16, 2004 the University of Pennsylvania hosted a forum that convened the world's most prominent researchers who are currently working to identify the distinguishing factors of and subsequent interventions for FTD. Held as a satellite meeting to the 9th International Conference on Alzheimer 's Disease and Related Disorders, the forum attracted over 450 attendees from all over the world including scientists, physicians and professionals in the field of aging. Also among this large audience were caregivers of people living with this rare and misunderstood disorder.

FTD is progressive and over time (usually only a few years) the patient's ability to live and function independently is severely diminished. Most FTD patients become completely dependent on others for the most basic activities of daily living. Because the burdens of caregiving are so great, the organizers for this event, Drs. Murray Grossman, Virginia M.-Y. Lee, John Van Swieten, John Q. Trojanowski and Bruce Miller, were committed to not only providing caregivers access to the latest research and but also to creating caregiver specific sessions responsive to their needs.

Gayle Joseph, who directed all the forum planning, worked closely with Helen Ann Comstock, Board Chair of the Association for Frontotemporal Disorders, a not-for-profit organization created in 2002 to advocate for the people who live and work with FTD. The sessions designed for caregivers included specialized lectures, support groups and even a dramatic presentation. In addition, every effort was made to ensure that anyone interested in attending could be present. Some families were offered small grants for travel, specials accommodations were arranged and, as a result, the forum was host to caregivers from California, Michigan, North Dakota, Wisconsin and Texas.

Caregiver feedback was exceedingly positive, as was the feedback from physicians and scientists who were quite pleased to have had the opportunity to meet people living with FTD. Caregivers have historically been included in FTD conferences and FTD research has benefited a great deal from first-hand information caregivers can provide regarding the varied and unique progression of this degenerative disorder.



THE IOA AND THE OFFICE OF HUMAN RESEARCH CONVENE SYMPOSIUM TO ADDRESS ISSUES OF INFORMED CONSENT

for Research on Human Subjects with Cognitive Impairment

Enrolling human subjects in research must be justified on scientific, clinical, and ethical grounds. According to the American Gerontological Society, over the last fifty years, informed consent of cognitively impaired individuals has been the most critical element in the ethical conduct of research involving human subjects. Ethicists, legal scholars, policy makers, researchers, and affected patients and families have debated how research can proceed in an ethical fashion when potential subjects are either in the process of losing or have lost the capacity to provide informed consent.

On Tuesday, September 14, over 100 members of the PENN community as well as researchers and policy makers from centers throughout the region participated in **Cognitively Impaired Research Subjects: Issues in Informed Consent,** a symposium co-hosted by the IOA and the Office of Human Research designed to address the most current concerns, protocols and effective methods in engaging cognitively impaired subjects in research.

Beginning with a case study, symposium presenters worked within a panel format to discuss the following topics: Assessing Decision-Making Capacity, Strategies and Tools for Assessing Capacity, Deciding With Others: When And How To Talk With Someone Other Than The Subject, and Public Policy and Legal Aspects.

All symposium presenters were from the University Of Pennsylvania and all dedicated a significant amount of time in preparation for the day. They were: Jason Karlawish, MD (Institute on Aging, Alzheimer's Disease Center, Marian S. Ware Alzheimer Program), Jennifer Farmer, MS, CGC (Center for Neurodegenerative Disease Research) Agnieshka Baumritter, MA (Clinical Trials Coordinating Center Preventive Ophthalmology & Biostatistics), Aliza Schwartzman (Associate General Counsel University of Pennsylvania and University of Pennsylvania Health System) and Yvonne K. Higgins, CIP (Human Subjects Research Office of Regulatory Affairs).

One of the first of its kind to be hosted in recent years at PENN, the symposium was an important step in addressing a dynamic and critical issue not only in the field of aging but for all medical research. The IOA and the Office of Human Research are committed to continuing the dialog and look forward to working together in the future.

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February 3, 2005

Patricia G. Archbold, RN, DNSc, FAAN

Elenora E. Thomson Distinguished
Professor and Director, John A.
Hartford Center of Excellence in
Geriatric Nursing
Oregon Health & Science University
Place: University of Pennsylvania

March 18-19, 2005

The Art & Science of Anti-Aging

Therapies: Convergence of Theory and Practice

Place: University of Pennsylvania Biomedical Research Building Auditorium

April 7, 2005

Christine Cassel, MD

President and CEO

American Board of Internal Medicine "Medicare Matters: Healthcare, Aging and the Social Contract"

Place: University of Pennsylvania

May 12, 2005

Fmr. Gov. Richard D. Lamm

Do-Director Institute for Public Policy Studies University of Denver

Place: University of Pennsylvania

June 8, 2005

Majd Alwan, PhD, University of Virginia, Director Robotics and Eldercare Technologies

Stuart L. Fine, MD, PENN Chair, Department of Ophthalmology and Executive Director

Scheie Eye Institute

Joshua S. Dunaief, MD, PhD, PENN Assistant Professor of Ophthalmology Institute on Aging Annual Retreat with

Poster Session

Place: University of Pennsylvania

Houston Hall

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IOA Project Coordinators Forum Schedule

Project Coordinators and Managers who are involved in projects on aging are invited to attend these informal monthly discussions. Projects at any stage, from planning and development through final analysis are welcome. The remaining schedule of presenters for 2004-2005 is:

November 9, 2004:

Jennine Groce-Martin – The EXPORT Program report on Health: Community Outreach for Obesity and Related Illnesses

December 14:

Jill Idan – The LIFE Center

January 11, 2005:

Kara Krissel – Alzheimer's Disease Center Education Core

February 8:

Martha Trudeau – VA Research Matters: An Overview of the Veterans Health Administration and Veterans Health Research.

March 15:

Susan Buidenstein – FITness on the GO!

April-June: Open

Meetings are held the second Tuesday of the month at Ralston House, 3615 Chestnut Street – Conference Room 241 from 2:00-3:00 pm. If you are interested in presenting your research or project in aging or would like more information, please contact the IOA by email at: aging@mail.med.upenn.edu or by phone at (215) 898-3163

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THE IOA USHERS IN ITS NEXT QUARTER CENTURY

Basic Science:

First Prize: Methionine Oxidation in the Nervous System as a Modulator of Lifespan in Drosophila presented by David Ramez Wassef

Second Prize: Selective Suppression of NF-kB by Indomethatcin

Modulates Abeta levels and Deposition but not Metabolism in a Model of Alzheimer's Disease presented by Hengxuan Yang

Clinical Research:

First Prize: The Clinical Efficacy of Passive Monitoring Technology in Identifying the Risk of Adverse Outcomes in Alzheimer's Patients presented by Nancy A. Hodgson

Second Prize: A tie between Are We Really Referring Patients to Hospice Too Soon? presented by Jennifer Kapo and The Efficacy of Visual Cues to Treat Patients with Parkinson's Disease Experiencing Freezing of Gait (FOG) Episodes: A Pilot Study presented by Lisette Bunting-Perry

Educational Programs and Other Projects:

First Prize: Speech and Swallowing Disturbances: The Silent Complications of Parkinson's Disease presented by Julia Howard and Rebecca Martine Second Prize: What Does It Take? Training Direct Care Service Workers in Community Settings presented by Kathleen Egan and Rebecca Snyder Phillips.

Enjoying a toast of congratulations over cake and wine, the poster winners joined others in sampling an array of snacks and beverages while they surveyed their colleagues' posters. After acknowledging the IOA's distinguished history, Dr. Trojanowski set his sights forward, anticipating 25 more years of the IOA working toward improving the health of the elderly.





THE MARIAN S. WARE ALZHEIMER PROGRAM BEGINS WITH A UNIQUE BRAINSTORMING RETREAT

Virginia M.-Y. Lee, PhD, MBA, the John H. Ware 3rd Professor in Alzheimer's Research and Research Director for the Center for Neurodegenerative Disease Research, framed the issues and recent research in identifying potential targets of therapy for Alzheimer's disease, describing in detail her goals to better translate and apply research, to move interventions safely and affordably into the hands of the people who need them. Indeed, a promising new example of pre-clinical success in treating Alzheimer's disease pathology in rodent models of this was presented by Dr. Lee based on studies of drugs that already are in use for therapy of cancer patients.

In order to prove the efficacy of any intervention, Dr. Lee and her colleagues rely on the participation of hundreds of subjects who must be followed over long periods of time. Jason Karlawish, MD, Virginia Brown Fellow for Aging and Stroke Research, is devoting a portion of his research to address the serious shortage of subjects in clinical AD studies. Dr. Karlawish presented the barriers to recruiting subjects, the complex decisions caregivers and patients face in participating in treatment studies and the methods he and his staff have been developing in confronting the problems researchers face in recruitment. His work has been establishing the importance of connecting with people where they live to better educate them about clinical studies. He also shared his recent documentation of the effectiveness of researchers working with subjects directly in their communities.

The need to work more directly in the community was echoed by Dr. Christopher Clark, whose work is aimed at re-engineering the diagnosis and treatment evaluation of AD, moving away from research centers and into the community where patients and their families reside. Dr. Clark's work as a clinician in the Department of Neurology and the Penn Alzheimer's Disease Center/Memory Disorders Clinic is focused on developing and validating efficient and reliable methods that can be implemented at the community level to identify individuals with early dementia, mark changes over time and provide evidence of treatment efficacy.

Drs. Karlawish and Clark both described the statewide and nationwide potential in establishing community-based research, treatment and evaluation networks. Mary D. Naylor, PhD, RN, the Marian S. Ware Professor in Gerontology at the University of Pennsylvania School of Nursing, presented more data to support the value of an integrated network of partners as related to her work to implement and evaluate a research based model of transitional care. Dr. Naylor's research addresses the challenges to delivering care and she has demonstrated the potential of an innovative, evidence-based model of coordinated care management for high-risk elders and their caregivers, which is implemented by advanced practice nurses in collaboration with patients' physicians and other health team members. Dr. Naylor stressed that public education is critical, that a collaborative effort is imperative and that there must

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Virgina Lee Receives AAUW Distinguished Senior Scholar Award

The American Association of University Women (AAUW) sponsors its Founders Distinguished Senior Scholar Award to honor a woman scholar at the pinnacle of her academic career for a lifetime of outstanding research, teaching, publications, and impact on women in her profession and community. Open to women in all disciplines, the AAUW named Virginia M.-Y.Lee, PhD as its 2004 Honoree. The John H. Ware III Professor of Pathology and Laboratory Medicine at the University of Pennsylvania School of Medicine, Dr. Lee focuses her research on the pathogenesis of Alzheimer's disease, Parkinson's disease, frontotemporal dementia, and other related neurodegenerative disorders of aging.

Mark Forman, MD, PhD Joins Department of Pathology and Laboratory Medicine



By joining the University of Pennsylvania as Assistant Professor in the Department of Pathology and Laboratory Medicine,

Mark S. Forman, MD, PhD, became the second new IOA faculty appointment. "It is quite an honor," says Dr. Forman, "to join the faculty of the IOA, particularly in this its 25th anniversary". Dr. Forman received his BS from Yale University in 1985 where he studied molecular biophysics and biochemistry. He then traveled up and down the east coast earning a PhD in Immunology

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from Rockefeller University in 1994 and an MD from Duke University School of Medicine in 1995. Upon completing his Medical Degree, Dr. Forman continued his clinical training in Anatomic Pathology and Neuropathology at PENN in the Department of Pathology and Laboratory Medicine. He also worked as a Postdoctoral Fellow with Dr. Virginia Lee in the Center for Neurodegenerative Disease Research where he studied the cellular processing of the amyloid precursor protein, the source of the beta-amyloid, the major component of senile plaques that are abundant in the brains of Alzheimer's Disease patients. Dr. Forman continued on as a Research Associate in the Department of Pathology and Laboratory Medicine. Dr. Forman was the recipient of the Experimental Pathologist in Training Award from the American Society of Investigative Pathology in 2003.

Assuming his new position in July 2004, Dr. Forman will build upon his earlier work by focusing on elucidating the contribution of non-neuronal cells to the neurodegenerative process and in particular the "tauopathies". "In the field of neurodegenerative disease research there is a strong bias towards the role of the neuron in disease pathogenesis. However, in many of the disorders, there is robust pathology in the glial cells and the contribution of this pathology to the neurodegenerative process is completely unknown", says Dr. Forman. "These are very exciting times to be studying neurodegenerative diseases. In the past ten years tremendous advances have been made in understanding the patho-

STUDYING HOSPICE CARE: LEARNING TO DIE WELL

By Dina Greenberg

If we were to break down academic medicine along the lines of research and clinical practice, David Casarett, M.D., like many physician/researchers, would have to describe his work as a hybrid of both disciplines. For Casarett, though, there is a significant twist; as a palliative medicine physician, his practice focuses on those patients who are near the end of life. Therefore, he would expand the definition of clinical practice which often emphasizes life-prolonging therapy — to include symptom management, improved quality of life, and psychological and spiritual well-being. He is indeed describing the rapidly growing field of palliative care. Casarett, assistant professor in the Division of Geriatrics at PENN Medicine and a core investigator and staff physician at Philadelphia VAMC, is asking a difficult question pertaining to this patient population: "When would our efforts be better spent helping patients to 'die well,' to maximize the quality of life throughout those last days, weeks, or months of their lives?" Casarett believes that there is an urgent need for improving end-of-life care for Americans and he also believes that this question deserves close attention.

A prolific investigator, Casarett has focused his efforts on studying the decision-making processes of people with serious, fatal illness. In his work, he has investigated a range of difficult choices faced by patients and families: decisions about medications and other treatments, research participation, and hospice enrollment. He is interested in determining why some seriously ill patients choose to continue life-sustaining treatments, while others choose hospice, relinquishing such therapies for palliative care only. And he is interested in the important role family members play in making what are frequently very difficult choices. Many patients involved in Casarett's studies have advanced cancer, but most have other diagnoses. "We think of cancer as the typical 'terminal illness,'" Casarett says, "but in fact, most people die from other diseases: heart disease, emphysema, stroke, and dementia." Many are suffering with multiple side effects of treatment in addition to the symptoms of their illness. According to Casarett, quality of life for these patients is severely diminished.

"To date, most research has aimed to improve survival," says Casarett. "That's where funding has been, on the biological basis of disease, and on finding cures. Instead, a new area of research — palliative medicine — focuses on symptoms, quality of life, and psychological and spiritual wellbeing." Historically, medical school curricula and health care practices have focused almost exclusively on more traditional goals of prolonging life. Casarett, however, feels that with an aging population, "it is just as important to teach future physicians how to relieve symptoms, how to enhance a patient's functional independence and dignity, how to support families, and how to help patients and families through difficult decisions."

A SHARED OPPORTUNITY FOR SCIENTISTS AND CAREGIVERS

With all of the success and good will experienced at the forum, Gayle Joseph is even more impressed with the far-reaching impact the forum continues to have in the months afterwards. She receives calls every week from individuals and clinicians who have been referred to her for information and has also received reports from attendees who returned home and created FTD support groups linking together people who would have otherwise never met. For Gayle Joseph, there could be no greater mark of success: "Bringing the caregivers and families together with the experts in the field was a primary goal."

For more information on FTD, visit www.FTD-Picks.org For audio of the presentations from the July 15 & 16 Forum, visit www.uphs. upenn.edu/cndr/retreat.html

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STUDYING HOSPICE CARE: LEARNING TO DIE WELL

among nursing home residents may provide a substantial disincentive to hospices to enroll these patients," says Casarett. Hospices currently receive a fixed per diem payment of \$110 and require longer lengths of stay to recoup the initial costs of intake, needs assessment, and care planning.

This study led to an ongoing randomized controlled trial, funded by a National Paul Beeson Faculty Scholars Award, which is evaluating an intervention to encourage nursing home residents and their families and physicians to think about hospice sooner. This study uses a decision aide that helps residents and their families to think through the treatment options and to make their own decisions about whether and when hospice is right for the resident. "Most important," says Casarett, "the study ensures that those decisions are communicated to the resident's physician."

Casarett is particularly enthusiastic about the involvement of residents and their families. His previous research has shown that the family "has a significant, and often dominant, role in decision-making." He also points to the way that the study assesses goals and preferences, rather than trying to change them. "In the real world, data suggests that a lot of people — from 25 to 75 percent — really want to focus on comfort care, but those preferences never get incorporated into the care plan, because no one asks the patient or his or her family, and the patient and family are often too overwhelmed or intimidated to speak up."

Most important, Casarett points to the need for good communication between the "triad" of patient, family, and health care provider about goals for care, options for treatment, and hospice. "Often," says Casarett, "we [physicians] don't stop to have the conversation." He points out, however, that this is not necessarily because doctors choose not to present the option of hospice. "It may simply not cross a physician's mind to consider hospice until it's too late." In a recently completed national study of the hospice enrollment process, Casarett and colleagues found that as many as half of hospice discussions are initiated by the patient or the family.

"Physicians generally do not say much about it because they don't know a great deal about it, or what they do know is in broad terms. A lot of physicians will say that they allow the hospice care provider to explain the details to patients, and our data are certainly consistent with that."

Moreover, Casarett says, there is usually very little time for detailed discussions because hospice is not considered as an option until very late. "The hospice decision usually happens quickly," he adds. Casarett suggests, "Having this conversation at the last possible moment is part of the problem," a problem he defines as "systemic."

Acknowledging the sensitive and complex nature of this discussion, Casarett believes that an ideal time for physicians to offer hospice care as an option is during a discussion with the patient to determine what his or



her "goals for care" are. "A patient's goals may be to remain as comfortable as possible and to enjoy, to the best of his/her ability, remaining time with family. If you explain hospice in relation to this goal, many patients are open to the idea," says Casarett.

To illustrate this point, Casarett refers to a recent pilot program for a palliative care clinic, conducted at the Philadelphia VAMC. In this study, the options for care were delivered to patients in "a very scripted way," says Casarett. "The way that we talked about it in the study was to first establish the patient's goals for care, their needs for care — whether they would require a home health aide, durable medical equipment, medication, etc. — we were able to present hospice in a very tailored way. That is, we presented hospice not as a free-floating option, but instead as a suggestion that was clearly linked to patients' needs for care."

Casarett notes that these discussions are still difficult, no matter how much practice a physician has. "After every hospice discussion, even ones that go extremely well, I still think of things I should have said, or cues that I missed, or times that I should have stopped talking and listened instead." One of the most common challenges he faces, according to Casarett, is dealing with misconceptions about hospice. He offers some particularly frequent examples: "Hospice is a place you go to die, hospice is only for patients with cancer, hospice is only for the last days of life — None of these are true, but all are things that people strongly believe," says Casarett.

Still, in part because of these misconceptions, Casarett understands why many patients and families are conflicted when faced with making the choice. Many people refuse hospice because they do not want to give up life-sustaining treatment. Casarett gives as an example a patient with cancer who has a life expectancy of only three or four months. "In the course of his illness, the patient might develop pneumonia," says Casarett. "Intravenous antibiotics might be the therapy of choice, and might prolong survival for several months, but would not be available through the hospice. More than likely, this patient would die of the infection without the help of antibiotics. If he knows that he could potentially live another three or four months with the treatment, is it really fair to ask him to give that up? I'm obviously a fan of hospice, but I'm not such a big fan of the Medicare benefit for hospice. The challenge is figuring out a way to make it more inclusive."

Hospice has evolved slowly, but Casarett says re-evaluation is long overdue. "The current system of care that forces patients to choose high quality palliative care or life-sustaining treatment is laughable," says Casarett. "Does a patient with a broken leg have to choose between pain relief and good orthopaedic care?" Further, Casarett stresses, the requirement that hospice patients must have a prognosis of six months or less creates "needless barriers" to hospice access. "Prognosis is notoriously difficult for physicians, and even when we predict death accurately, it's difficult to explain to patients and their families."

SAVE THE DATE!

The Sylvan M. Cohen Institute on Aging Annual Retreat for 2005 will be June 8, 2005 from 1:00 to 6:00 pm in Houston Hall at the University of Pennsylvania.

Featured in the program will be Sylvan Cohen Visiting Scholar, **Majd Alwan, PhD,** Assistant Professor and Director of Robotics and Eldercare Technologies, Medical Automation Research Center, University of Virginia offering a presentation entitled "Technology as a tool in hightouch care."

The IOA is also honored to have secured as PENN presenters **Stuart L. Fine, MD,** Professor and Chair, Department of Ophthalmology and Executive Director, Scheie Eye Institute and **Joshua L. Dunaief, MD, PhD,** Assistant Professor, Ophthalmology. Dr. Fine will present "Treatment for age-related macular degeneration 2005" and Dr. Dunaief will present "Similarities between age-related macular degeneration and Alzheimer's disease: Accumulation of iron and amyloid beta."

THE MARIAN S. Ware alzheimer Program...

continue to be a balance in the investments made in finding the cure and providing patient care.

Early in the day, Dr. Trojanowski expressed the hope that the audience would not only listen but also participate in the conversation. He was pleased to see the over 75 person audience actively involved in discussion at every stage of the day adding a range of perspectives from policy makers, pharmaceutical companies, statisticians, geriatric practitioners, social workers, researchers, community service agencies and advocates as well as nursing home, assisted living and home care providers.

The Marian S. Ware Alzheimer
Program Kickoff and Brainstorming
Retreat on Alzheimer's Care exceeded
all expectations. The presentations
described above brought attention to the
synergy between all of the current work
in AD and resulted in an energy and
enthusiasm that was present throughout
the day. Most exciting was the potential
for new collaborations, conversations
were lively and continued as the audience left the building.

By mid-day, Dr. Trojanowski and Secretary Eisenhower had already discussed in detail several plans for next year's event, with the hope, of course, that the need for such retreats will ultimately be eliminated. As Wendy Campbell, President of the Alzheimer's Association Delaware Valley Chapter, explained "Our goal is to put ourselves out of business."

You may view all of the presentations from the Marian S. Ware Alzheimer Program Kickoff and Brainstorming Retreat on Alzheimer's Care at the University of Pennsylvania Institute on Aging website: http://www.uphs.upenn.edu/aging/ware.shtml

FELLOWS IN THE SPOTLIGHT

The IOA Fellows Program brings together researchers, clinicians, and educators with varied interests and remarkable achievements in the field of aging. There are two levels of fellowship: IOA Fellows are University of Pennsylvania standing faculty representing the 12 schools within the University; Associate Fellows represent PENN staff, adjunct or clinical associate faculty as well as colleagues from other US institutions who have demonstrated a keen interest in aging-related research, education or services.

The Institute on Aging is honored to include among the Fellows Program nationally-recognized members of the University of Pennsylvania faculty such as Allan I. Pack, M.B., Ch.B., Ph.D and Neville E Strumpf, PhD, RN, C, FAAN.

Allan I. Pack, M.B., Ch.B., Ph.D.

Chief, Division of Sleep Medicine Director, Center for Sleep and Respiratory Neurobiology Professor of Medicine, Neurology, and Psychiatry

Dr. Allan Pack is a Professor of Medicine, Chief of the Division of Sleep Medicine in the Department of Medicine

and Director of the Center for Sleep and Respiratory Neurobiology (CSRN) at the University of Pennsylvania. The CSRN is a Medical School-based, multi-departmental, multi-school collaboration of investigators interested in sleep, sleep disorders, circadian rhythm and chronobiology. The Center helps to foster interactions among the more than 20 faculty at the University with a primary interest in this area. He is also the program director of a Specialized Center of Research (SCOR) in Neurobiology of Sleep and Sleep Apnea. This is an outgrowth of a previous SCOR in Neurobiology of Sleep and Sleep Apnea that Dr. Pack directed for 10 years.

Dr. Pack has ties to the Institute on Aging that go back to the inception of the Center for Aging in 1979. He is currently the holder of numerous grants to study sleep disorders in the elderly and molecular mechanisms of sleepiness. He has also developed a research group studying the molecular mechanisms of sleepiness and insomnia in old age, the most profound consequence of sleep apnea. He and his colleagues are investigating a number of different potential molecular mechanisms and are conducting studies on rodents (rats/mice) as well as in model systems, in particular the fruit fly Drosophila.

Dr. Pack's major area of research is in obstructive sleep apnea. He played a major role in developing the field of neural mechanisms of apnea, demonstrating with his colleagues landmark observations that led to new attempts to develop a pharmacotherapy for this common disorder.

Dr. Pack has also developed a large program of patient-oriented research. He directs a Clinical Research Center for Sleep and there are active projects investigating the following: genetic basis for sleep apnea; screening for sleep apnea in high risk populations, in particular, commercial vehicle drivers; outcomes of therapy for the disorder; and determinants of compliance to therapy.



This patient-oriented research activity is supported by the multi-disciplinary Penn Center for Sleep Disorders, which Dr. Pack directs. This accredited sleep center provides a full range of clinical services and has faculty from the Departments of Medicine, Neurology, Pediatrics, Otorhinolaryngology and Head and Neck Surgery, Psychiatry, and Oral and Maxillofacial Surgery involved in its activities.

Dr. Pack is committed to the training of new investigators. He directs two training grants - one for postdoctoral fellows in sleep and circadian rhythm and an MD/PhD program with a particular focus in this area. He has trained a number of investigators in the United States who are active in the area of sleep apnea. Trainees also come to his lab from other countries and he has trained investigators from Canada, the United Kingdom, and Japan.

Dr. Pack has been active in the American Thoracic Society. He was the founding Chairperson of the Respiratory Neurobiology and Sleep Assembly. He served on its Long-Range Planning Committee. He is currently a member of the Planning Committee of the American Thoracic Society. Dr. Pack also served as the Medical Director of the National Sleep Foundation in Washington, DC from 1994 to 1996. He is currently a member of the Board of Directors of the American Lung Association of Southeastern Pennsylvania. Dr. Pack has served on the Respiratory and Applied Physiology Study Section at the National Institutes of Health and currently serves as an ad hoc reviewer for the NIH. He also served on the Advisory Board of the recently created National Center for Sleep Disorders Research at the National Institutes of Health from 1994 to 1997.

Dr. Pack earned his medical degree (MB, ChB) from the University of Glasgow. He also did his residency and fellowship in pulmonary diseases at this institution. He received a Ph.D. in mathematical modeling from the University of Glasgow in 1976. He joined the faculty at the University of Pennsylvania that same year. Dr. Pack has published over 150 articles and chapters, has co-edited two books, and has edited a text entitled Sleep Apnea: Pathogenesis, Diagnosis and Treatment.

Neville E Strumpf, PhD, RN, C, FAAN



Edith Clemmer Steinbright Professor in Gerontology, and Director of the Center for Gerontologic Nursing Science

Dr. Strumpf is a widely acclaimed researcher, best known for work with her colleague, Lois Evans, D.N.Sc., R.N., Viola MacInnes/Independence Professor in Nursing. Their breakthrough research led to a reduction in the use of

restraints for frail older people in hospitals and nursing homes throughout the nation. Drs. Strumpf and Evans conducted the only clinical trial funded by the National Institute on Aging aimed at reducing physical restraints used in nursing homes.

IOA TO CO-HOST

a Multi-Disciplinary Anti-Aging Meeting with the Center for Human Appearance in Spring 2005

The Institute on Aging and the Center for Human Appearance are partnering to host an exciting and unique two day event at the University of Pennsylvania on March 18 and 19, 2005 – The Art & Science of Anti-Aging Therapies: Convergence of Theory and Practice.

The two-day meeting agenda combines surgical, medical and non-pharmacological approaches to the healthy aging of the body and mind. Physicians, other health providers and the public will find information about recent research, diagnostics, treatment protocols, nutritional interventions and biomedical breakthroughs for preventing and ameliorating diseases of aging. In addition, surgical and non-surgical techniques for appearance related aging issues will be presented.

The meeting is free of charge and Continuing Education credits are available.

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She received (with Dr. Evans and Doris Schwartz) the Maes-MacInnes Award (1992) for a contribution of singular impact on the nursing profession; was selected (with Dr. Evans) as the Sigma Theta Tau International Honor Society in Nursing's Cameo Researcher (1994); and received (with Dr. Evans) the Sigma Theta Tau International Baxter Foundation Episteme Award (1995), nursing's most prestigious research recognition.

Most recently Drs. Strumpf and Evans received the Doris Schwartz Gerontological Nursing Research Award from the Gerontological Society of America (2001). Dr. Strumpf completed a three-year project funded by the Robert Wood Johnson Foundation to examine the implementation of a model of palliative care in nursing homes, as well as a National Institute of Aging-funded study of falls prevention among inner city elderly.

Currently, Dr. Strumpf is Director of the Center for Gerontologic Nursing Science and the Hartford Center of Geriatric Nursing Excellence, where she continues to develop new models of care that enhance the quality of life for frail elders. Dr. Strumpf implemented a much-emulated approach to integrating gerontology into the undergraduate nursing curriculum in the 1980's.

As an acknowledged leader of longstanding within Penn's School of Nursing, Dr. Strumpf is also known for her teaching and curriculum development expertise at all levels of education --undergraduate, masters and doctoral — "I have enjoyed a wide range of teaching experiences ranging from Freshmen Seminars on 'Images of Aging in Literature' to directing several post-doctoral fellowship programs in the School of Nursing." Currently her focus has been to mentor pre- and postdoctoral students with research focused in aging, senior and independent studies in aging, and the recent design and implementation of nursing's newest interdisciplinary graduate level curriculum offering the Palliative Care minor.

Dr. Strumpf is also one of the founders of the Penn Nursing Network's oldest practices, Gerontologic Nursing Consultation Service (GNCS). She continues to provide consultations for clinicians, consumers and academic institutions. Penn Nursing faculty founded the GNCS in the late 1980s in response to the growing number of requests for consultations from hospitals and health systems, nursing homes, area agencies on aging, law firms, as well as family caregivers.

Dr. Strumpf has received numerous honors for her contributions to the field of gerontology, including the American Nurses Association Gerontological Nurse of the Year (1994), the Pennsylvania Nurses' Association Nursing Education Award (1987) and the Distinguished Alumna Award (1996) from New York University. She is the author or co-author of more than 100 articles, book chapters and books. Dr. Strumpf received a bachelor's degree in nursing from the State University of New York at Pittsburgh in 1969 and a master's degree in nursing from Russell Sage College in 1973. She received a Ph.D., in nursing from New York University in 1982.

With all that she has accomplished on behalf of the aging population, Dr. Strumpf remains focused on the road ahead: The frail elderly population continues to grow in the U.S. and worldwide. My work, beginning with efforts to achieve restraint-free care, has evolved into studies about older cancer patients, exercise protocols to prevent falls, and development of a model of palliative care in nursing homes. With persistent and dedicated scholarship undergirding education and clinical practice, we can make a difference in elders' lives, including some day our very own.



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Casarett believes that the six-month eligibility criterion should be relaxed significantly or abolished altogether. He also believes that the choice between life-sustaining treatment and hospice is irrational and leads to unnecessary suffering. For instance, he believes the anti-retroviral treatment for HIV patients should be covered in the hospice benefit, as well as chemotherapy that offers low toxicity, home infusion therapy, and other treatments that prolong life and improve quality of life. Casarett notes that hospice patients' access to even purely palliative therapies can be limited by cost. "Palliative radiation is a good example," explains Casarett. "A patient with cancer could have shortness of breath because a tumor is occluding her airway. Radiation therapy might shrink the tumor and allow her to breath much more easily. This treatment is clearly palliative, but it's really expensive. Although I think hospice providers would want to offer that treatment to their patients, very few hospices can afford to."

Although Casarett urges a fundamental overhaul of the hospice benefit to increase access, he is not optimistic that this will happen anytime soon. In the mean time, he advocates for patient access to "bridge" or "pre-hospice" programs. Palliative care, Casarett says, can begin months or years before death. One of Casarett's previous studies found that many patients who are "upstream" of the mandatory six-month prognosis have as many or more needs than those who qualify according to the Medicare benefit.

Casarett is realistic, though, in his expectations for change; he notes that meaningful change will require public pressure and vocal activism. That activism, he says, has been slow in building momentum. "Becoming an effective advocate for hospice means acknowledging that you're going to die." Looking beyond patients and families for support, "disease-based organizations," Casarett feels, "would need to take a big leap to put lobbying efforts into learning how to die well; they want a cure."

According to Casarett, currently most of these organizations are focused on their own priorities, such as protecting NIH funding for research. He points to past examples of dramatic changes in the nation's health care system, the most notable of which was the explosion of activism for HIV research and care in the 1980s. "Explosion isn't too strong a word," says Casarett. "There was a critical mass of people who were angered and scared by the inertia with which the medical establishment was responding to the AIDS epidemic. They wanted something done, and done soon. They were able to effect change because they were angry and wouldn't take "no" for an answer," Casarett says.

He points out, though, that the same level of anger and frustration doesn't exist about end-of-life care and hospice. "People's expectations are simply too low," he says ruefully. "We think it's normal to die alone and in pain; that's the status quo." We have more than enough data to show us what the problems are and how we can improve end of life care," says Casarett, "but we need to foster public engagement, and the outrage that will turn those data into policy and, ultimately, a health care system that will take care of us at the end of our lives."