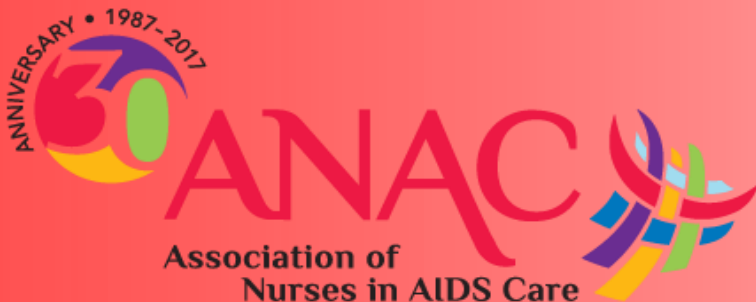




# *A 30-Year Journey Towards the Future*

Karen A. Daley, PhD, RN, FAAN

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## **Presentation Content:**

*A look at nurses' contributions over 3 decades of caring for PLWHA and to the future of HIV care and nursing*

- Interviews with 8 HIV nurse luminaries
- Phone interviews/conversations
- Personal reflections as a nurse leader in HIV/AIDS care

### **Two questions posed:**

- 1. Describe nursing's legacies in HIV/AIDS care over the past three decades.*
- 2. What do you believe will be the most important issues nurses will confront in the future as they provide care to PLWHA – and what are the implications for nursing research, practice and education?*

## Dr. Inge Corliss



**Inge B. Corless, PhD, RN, FNAP, FAAN**, is a Professor in the School of Nursing at the MGH Institute of Health Professions. At the MGH Institute Dr. Corless together with Dr. Patrice Nicholas developed the HIV/AIDS specialization. A member of the International HIV/AIDS Nursing Research Network, she is also a former President of the national Association of Nurses in AIDS Care, and currently is President of the Boston ANAC Chapter.

## Dr. Sheila Davis



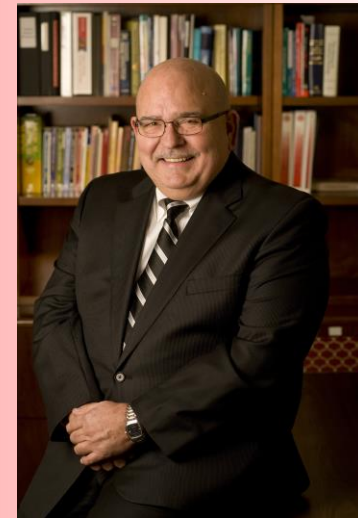
**Sheila Davis, DNP, ANP-BC, FAAN**, is currently the Chief of Clinical Operations and Chief Nursing Officer at Partners In Health a global health organization working in 10 countries. Sheila became involved in HIV care in the mid-1980s in nursing school and has worked in a number of settings domestically and globally in the HIV and infectious diseases fields as a nurse and nurse practitioner for thirty years. She worked as an Adult Nurse Practitioner at Massachusetts General Hospital for seventeen years in the infectious diseases outpatient unit and has been involved in a number of HIV community based organizations. Sheila has remained a strong advocate for people living with HIV globally.

## Dr. Donna Gallagher



**Donna Gallagher, PhD, M.S.N, ANP-BC, FAAN**, has been providing HIV care for PLWHA and education for health professionals domestically and internationally for over 35 years. She was the founder of Boston ANAC. In 1983, she developed the Harvard Health Plan AIDS Team, and in 1991 the Care Model for the Community Medical Alliance — the first Medicaid HIV HMO in the country. As PI of New England AIDS Education and Training Center for 29 years, Donna worked to ensure that providers understood high quality care. Her Global efforts have been in South Africa, Romania, Swaziland including HIV Health infrastructure building and Ebola relief efforts in Liberia.

## Dr. Bill Holzemer



**Dr. William L. Holzemer, PhD, RN, FAAN**, is recognized in the United States and internationally as an expert in academic nursing and HIV/AIDS care, serves as Dean and Distinguished Professor at the School of Nursing, Rutgers, The State University of New Jersey, and Professor Emeriti at UCSF. An NIH funded researcher, he recently completed a 4 year term on NINR's National Advisory Council. His national and international HIV work has focused upon symptom management, medication adherence, and stigma – with a goal of living well with HIV.

## Dr. Ann Kurth



**Ann E. Kurth, PhD, CNM, MPH, FAAN**, is Dean, and Linda Koch Lorimer Professor of the Yale University School of Nursing. She is a member of the 2014-2018 US Preventive Services Task Force, vice chair of the Consortium of Universities for Global Health, and a Fellow of the American Academy of Nursing and of the New York Academy of Medicine. An epidemiologist and clinically-trained nurse-midwife, Dr. Kurth's research focuses on HIV/reproductive health and global health system strengthening. She established one of the first nurse-managed HIV clinics in the U.S. Midwest and her work has been funded by the National Institutes of Health, the Bill & Melinda Gates Foundation, UNAIDS, CDC, HRSA, and others. Dr. Kurth has received awards for her science and leadership including the Friends of the National Institute of Nursing Research Ada Sue Hinshaw Award and the International Nurse Researcher Hall of Fame award from Sigma Theta Tau International.

## Dr. Jeffrey J. Kwong



**Jeffrey Kwong, DNP, MPH, ANP-BC, FAANP**, is an Associate Professor of Nursing at Columbia University where he oversees the Adult-Gerontology Primary Care Nurse Practitioner Program and HIV specialty. Additionally he maintains a clinical practice at Gotham Medical Group in Manhattan and serves as an educational consultant for New York State's HIV Clinical Education Initiative and the Northeast/Caribbean AIDS Education Training Centers. He is certified by the HIV/AIDS Nurse Certification Board and the American Academy of HIV Medicine. Jeffrey is the President-Elect of the Association of Nurses in AIDS Care.

## Dr. F. Patrick Robinson



**F. Patrick Robinson, PhD, RN, ACRN, CNE, FAAN**, is Dean of the School of Nursing and Health Sciences at Capella University. A past ANAC president, he was awarded both the Frank Lamendola Memorial Award for exemplary leadership in HIV/AIDS care and the Life Time Achievement Award. HANCB also awarded him Certified Nurse of the Year. Indiana University School of Nursing named him a distinguished alumnus and honored him at its centennial anniversary as one of the top 100 Alumni Legacy Leaders. Dr. Robinson is a fellow of the American Academy of Nursing. He currently serves on the advisory council for the NLN Foundation for Nursing Education.

## Dr. David Vlahov



**David Vlahov PhD RN, FAAN** is Associate Dean for Research and Professor at the Yale School of Nursing. He led the ALIVE study involving the recruitment and semiannual follow-up of 3,000 persons who inject drugs to learn about HIV and hepatitis risk and progression. His work was instrumental in HIV prevention and treatment guidelines. He has published over 650 papers. NIH has recognized his work with a MERIT Award, Johns Hopkins University elected him to their Society of Scholars, and he is an elected member of the National Academy of Medicine and the American Academy of Nursing.

# Three decades of nursing legacies for PLWHA

## *Dominant Themes:*

- I. Shining a light on the essence and best of nursing
- II. Exhibiting courage in the face of fear and uncertainty
- III. Bearing witness to and experiencing profound loss, isolation, suffering, joy and love
- IV. Partnership and community as sources of knowledge, support and advocacy
- V. Reciprocal benefit for patients and caregivers
- VI. Stigmatization of PLWHA as well as caregivers
- VII. Constant need to adapt practice as knowledge and science advanced for PLWHA
- VIII. Global influence on care of PLWHA

# I: Shining a light on the essence/best of nursing

In the early years of the epidemic, nurses filled the vacuum with humanity, compassion and skill where no biomedical treatment or cure existed:

- *“Nursing’s legacy centered around the heart of what nurses do – we provide unconditional comfort, guidance, advocacy, and education.... looking beyond the labels that were put upon people and recognizing that underneath everything was a person who needed to be cared for....”*
- *“It unearthed our social justice roots....”*
- *“...It was precisely our distinctive philosophies, attributes, and ways of being as nurses that had the greatest impact. Biomedicine was of no use, rather our approach to holism, palliation and support were what made a difference. ...It was exquisite nursing.”*

## II. Exhibiting courage in the face of fear/uncertainty

Nurses ventured into frightening and potentially hazardous territory in response to overwhelming human need and suffering:

- *“Many of us jumped into communities that we were not familiar with... “we jumped into the world of advocacy, stigma and the underserved.”*
- *“We did it without plans or map, half blind, scared and wounded....”*
- *“I saw my first patient with HIV in 1983; we really didn’t have a name and he wound up in my practice because it was assumed to be cancer. Soon after his death, the buzz about HIV began, not good information, a lot of fear. This was a difficult time but soon nurses rose from the fear and even when it was not clear how transmission took place – or how transmittable it was – nurses stepped forward. Not all nurses....”*

## II. Exhibiting courage in the face of fear/uncertainty (cont.)

- *“In the beginning of the epidemic, nurses were the ones to provide comfort to those individuals who were severely debilitated or dying from opportunistic infections. It was the nurse who may have been the only person who would bathe, or feed, or touch someone with advanced HIV – ensuring that those who were so frail or debilitated would be comforted or cared for with dignity.”*

### **III. Bearing witness to and experiencing profound loss, isolation, suffering, joy and love**

We were they – sharing and guiding the journey for so many and enduring endless loss and death without losing hope:

- *“...we were friends, family and lovers – there were no options but to respond.” “[we cared] with a resolve that can only be borne out of rage and grief...”*
- *“I lost so many people I cared for and loved as I accompanied them on their journey at least part of the way – it was an honor to do so....”*
- *“The initial group like myself decided that the patients affected needed end of life care and support. That is what we did.”*
- *[thirty years ago] “...the staff nurses had told me there was an HIV+ patient on the floor. I stood at the door and introduced myself and asked if I could come in and speak with him....he mentioned that I was the first person to come into his room.... As a nurse and human being I will always be glad I took the time to sit*

### III. Bearing witness to and experiencing profound loss, isolation, suffering, joy and love (cont.)

- *“I encountered my first AIDS patient in 1986.... He was young – maybe a year or two older than me.... I saw myself, my friends, and our possible future in him; a common experience for many of us.... This personal as professional and indeed political.... it generated a type of nursing practice that is hard to describe in words: a true paradox of joy/sorrow, fear/hope, needing to be there while needing to escape....”*

## IV. Partnership and community as sources of knowledge, support and advocacy

Nurse caregivers had confidence in their ability to ‘figure it out’ in partnership with patients and with support from one another:

- *“...[the affected communities enhanced] our clinical abilities as we had to figure it out while we were doing it as there was no guidebook or textbooks on how to provide nursing care in this complex disease.”*
- *“We found each other, taught each other and supported each other through so much loss. We partnered with our patients who often knew more than us about this disease and treatment and help[ed] advocate for a new paradigm of care partnership.”*
- *“...nurses led the way out of the fear and began providing fair and compassionate care. We had very little support and clung to each other for information from Boston to San Francisco. Most of our*

## IV. Partnership and community (cont.)

- *“Nurses provided creative support for diseases that were not often seen. Many of the early ANAC members wrote the book on care for HIV patients. We partnered with patients and providers from all other professions to try to create as much knowledge and quality care for patients.”*
- *“I think overall a true legacy of HIV nurses is the fact that many nurses have stuck with the patients and their colleagues throughout the good and bad times. They have been true advocates and care partners. In many ways, the partnerships between HIV nurses and patients has impacted healthcare across the board.”*
- *“In this description lies our greatest legacy as HIV nurses – the creation of a community of caregivers....”*

## **V. Reciprocal benefit for patients and caregivers**

As is so often the case for caregivers, nurses described the profound impact of the patient experience on their own lives:

- *“...[we] were welcomed and embraced and we learned and grew – and that made our worlds so much richer and our lives changed forever....”*
- *“Stumbling into the HIV epidemic in the 1980’s changed the course of my life and put me on a path that is still evolving.”*
- *“Every single person made an impact on my life and made me who I am today.”*
- *“As I reflect back, I don’t regret the decision to step up in those early days. I am a better nurse and person because of it.”*
- *“What these efforts [related to policy and disease prevention] have in common is the insistence on destigmatizing and creating equitable care for all.”*

## VI. Stigmatization of PLWHA as well as caregivers

Not everyone supported nurses who provided care as some found themselves villified and stigmatized due to overwhelming fear:

- *Some disappointments included being stigmatized by our own colleagues. ...a dramatic fall from from being ‘the angel cancer nurse’ to the ‘despised HIV nurse’ often yelled at and accused of bringing HIV into the hospitals and clinics and putting them at risk.”*
- *“...the past three decades of nursing in AIDs care can be summed up in the progressive destigmatization of the disease and the people with the infection to be able to have persons with HIV live their lives with confidence and dignity.”*
- Stigma as a continuing phenomenon in HIV care. Advocacy component of care will be ongoing and necessary as long as there are new generations of populations, policymakers and nurses; importance of making sure next generation of nurses stay as well-informed as early nurse pioneers in HIV care.

## VII. Constant need to adapt practice as knowledge and science advanced for PLWHA

Beginning with 'the decade of hope' described as an avalanche of scientific advancement, relentless vigilance is needed to keep up:

- *"...New medications, creative care models, longer life span for patients (though still only a few years), strategies to deal with side effects, increased understanding of transmission, prevention, the success of the 076 [AZT] trial showing prevention of transmission from mother to child. The science and the research was overwhelming. It was a fulltime job just keeping up with the avalanche of information."*
- *"1996 brought a roller coaster of hope with the success of the protease inhibitor presented as 'the cure' only to be later in the year noted to be a way to slow the disease but was not a cure...."*
- *"We became experts in symptom management, adherence and complex antiretroviral regimens, all the while making sure the patient and family in front of us remained at the center of our*

## VII. Constant need to adapt practice.... (cont.)

- *“...We had to become experts in lipodystrophy, wasting, peripheral neuropathy and fight for better drugs with short and long-term side effects. ...abruptly and joyously change from treating a deadly virus to a chronic illness for most of our patients, and help them and their families through the amazing but complex reorientation, while also focusing on those left behind.”*
- *“The disease is now considered more of a chronic illness.... and are now learning along with providers how to grow old with HIV.”*
- *“People pushing policy [and practice]...not waiting for science”*

## VIII. Global influence on care of PLWHA

Transformation of population health requires global engagement:

- *“Nurses have played a critical role not only on the domestic level, but also internationally. Nurses are the primary clinicians that have provided care and antiretroviral treatment to entire communities in countries most heavily impacted by HIV.”*
- Nursing’s legacies in HIV care have been transformational relative to patient-centric practice and in its influence globally as nurses continue to work to scale out innovative, culturally-sensitive and community-based models of care (ex. population-based Chronic Care Model).
- Importance of Ryan White Act as largest US HIV-specific discretionary grant program and third largest source of federal funding in US. PEPFAR built extensively on the experience of the Ryan White Act.
- ANAC nurses seeding global health nurse leadership

# **Important issues nurses will confront in the future as they provide care to PLWHA**

1. Integration of HIV nursing knowledge, including behavioral, psychosocial & SDH considerations into general nursing practice – APRN as specialty HIV practice
2. Education of all nurses key – knowledge sharing and advocacy
3. Ongoing outreach to and advocacy for at-risk populations
4. Need for more nursing research intentionality for developing and evaluating models for chronic disease & care of aging populations with HIV
5. Continuing focus and research on expanding prevention science & modalities (e.g. PReP, PEP) – particularly for at-risk populations
6. Ability to integrate technology into practice to advance care and prevention

## Important issues nurses will confront (cont.)

7. Need for continued engagement in advocacy for evidence-based public policy. *Silence still equals death...* in this and other health arenas.
8. Continuing focus on funding and resource needs for at-risk populations in US and globally.
9. Broadening our view of how to strengthen the PH system & promote the shift towards disease prevention. The next decade will not just be about infectious diseases, but about population displacements, environmental issues & access to basic resources.

# **A vision for a preferred future for nursing**

- Patient-centered care
- Interdisciplinary, team-based, nurse-led care
- Evidence-based care – not based in arbitrary or tradition-based care delivery models
- Coordination/continuity/accountability across the care continuum
- Enhanced translation of evidence and new knowledge into practice – making greater use of technology
- Move beyond tasks in professional nursing – optimize patient outcomes utilizing unique competencies of nurses
- Positive work environments
- Investment of resources in prevention, not simply illness care – and the integral role nurses can and should play

*“Few will have the greatness to bend history itself, but each of us can work to change a small portion of events. It is from numberless diverse acts of courage and belief that human history is shaped. Each time a person stands up for an ideal, or acts to improve the lot of others, or strikes out against injustice, he sends forth a tiny ripple of hope, and crossing each other from a million centers of energy and daring those ripples build a current which can sweep down the mightiest walls of oppression and resistance.”*

Robert F. Kennedy

# Thank-you!



# ANAC

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