

## OUR FEATURED COMMUNITY ADVISORY BOARD MEMBER MICHAEL MAGINN, ILLINOIS

■ After receiving an HIV diagnosis in 1984, Michael Maginn started becoming more involved in the HIV/AIDS community by volunteering at various community-based organizations. His professional career, however, still remained in the hospitality industry. That began to shift though, as he felt the need to become more involved and to give back to the HIV/AIDS community. In 2004, when the Central Illinois FRIENDS of People with AIDS, a community-based organization in Peoria, Illinois, was looking for an Executive Director (ED), he jumped at the opportunity. As the ED, he focused on providing Ryan White Part B supportive services, emergency housing, and financial assistance, as well as furniture and appliance donation deliveries.

At the time, FRIENDS was funded to provide annual 3-day retreats for the HIV community with attendees participating from all areas of the state. These retreats provided individuals the chance to be in a safe and open environment, while attending educational and therapeutic workshops to help with their disclosure issues, medication adherence, and overall health and wellbeing. It was there that Michael realized that people were not being heard regarding their barriers to care and their satisfaction or dissatisfaction with the quality of their own healthcare. In essence, their opinions were not being valued and they needed more representation.

It was around this time in 2011 that Michael was approached to see if he would be interested in representing Illinois as the national member for the Medical Monitoring Project (MMP) Community Advisory Board (CAB). He gladly joined, both because he felt that this would be a great opportunity for his own personal growth, but more importantly, he could help recruit persons, so that their voices could be heard and used to generate change in the services and healthcare offered to persons living with HIV, particularly those in rural areas.

It was throughout these years with MMP that helped him realize that the issues, barriers, and challenges reported by most MMP participants were similar in scope. He now believes that by working together, we can help address and erase some of these issues, including some of the barriers, stigma, and health disparities. It was with this mindset that he began participating in the MMP Journal Club, which last year, brought attention to the internalized stigma surrounding HIV through several infographics and fact sheets. Michael's feedback also helped spur the CDC to develop Spanish versions of those same infographics to reach a critical audience.

Although Michael is the only representative of his local MMP CAB, he has also continued to use his networks to help publicize other MMP findings at various health conferences, meetings, and health fairs and to various audiences, including providers and people living with HIV. And his network is considerable. Ten years after he began working at FRIENDS, he transitioned to a position with the Illinois Public Health Association (IPHA), the oldest and largest public health association in the state, as their HIV Program Manager, Coordinator of the Illinois HIV Care Connect initiative, and Illinois Prevention Lead Agent for Regions 1, 3, and 5. His work with IPHA brings him into contact with quite a few of the 98 organizations affiliated with IPHA, which includes local health departments, colleges and universities, and various public health organizations. His role as Prevention Lead Agent also brings him into contact with multiple public health programs that he oversees, including 1) HIV targeted testing, 2) CDC behavioral interventions, 3) targeted gonorrhea, chlamydia, syphilis, and hepatitis C testing, 4) hepatitis A and B vaccinations, 5) surveillance based services, and 6) routine testing data collection.

At the same time, he has also worn different hats in the HIV/AIDS community. He has been a Client Representative for the Ryan White Part B consortium. He is also a current member of the Illinois ADAP Medical Issues Advisory Board, Getting to Zero Campaign, Illinois PrEP Working Group, and the Illinois HIV Integrated Planning Council, where he is the co-chair of the Epidemiology and Needs Assessment Committee.

Michael's focus has always been to give back to his community and to give those in the community a voice and representation on a national level. In all of those regards, it is safe to say that he has succeeded.



## OUR FEATURED PROVIDER ADVISORY BOARD MEMBER CAROLE TRESTON, RN, MPH, ACRN, FAAN - ANAC



■ Carole Treston had just graduated from nursing school in the mid-1980s when she began working as a pediatric (“peds”) ICU nurse in North Phila – a community hard hit by poverty, drugs, and social and economic inequalities. It was there that she ended up on the front lines of the HIV/AIDS epidemic.

As she recalls, “There were kids admitted to the ICU and dying from this new diagnosis in peds called ‘AIDS’ and for each sick kid, there was also a very sick or dead mother. Often, it was the grandmothers who were the ones holding the family together.” This was before AZT was approved in kids – the only treatment was IVIG (intravenous immune globulin) – and on top of that, the poverty, drug addiction, poor housing, fear, and stigma added to the immense stress of having very sick children with no treatments.

Service delivery clearly needed to change to better meet the needs of these young patients and their families. As such, the AIDS service was created. The

service was a five-person team that included a nurse (Carole), social worker, administrative assistant (who became absolutely critical to their team), and two physicians. The team quickly expanded care not only to the children, but to their parents with AIDS. The clinic became one of the first in the country to have a patient-centered comprehensive family HIV/AIDS program and to include NIH-sponsored clinical trials.

It was here – amid the climate of fear and misinformation that surrounded HIV/AIDS that Carole became a strong proponent of evidence-based approaches to treating HIV and delivering healthcare with both compassion and empathy. She also became a strong advocate for implementing structural changes that are essential to public health and wellness, as well as human rights. To her, HIV/AIDS represents a prime example of the intersection between healthcare and social justice based in human rights.

Carole continued to provide HIV clinical care for another 16 years and since 2000, has worked as a healthcare administrator. She is currently the Executive Director (ED) for the Association of Nurses in AIDS Care (ANAC). In her current role, she has continued advocating for evidence-based approaches to care, including updated treatment approaches and utilizing self-management and shared decision making. In that respect, she would like to see more focus placed on provider-based analyses, learning more about persons not virally suppressed and their barriers, as well as the impact of immigration crackdowns on HIV care within immigrant communities.

As the ED for ANAC, she has also been focused on shining a light on the critical and unique roles of nurses and nurse practitioners (NPs) in healthcare. She notes that while nurses are the largest percentage of the health care workforce, the contribution of nurses to successful health care outcomes and individual patient experiences is sorely underreported and acknowledged. She is often reminded of the time when she was a patient and had to trust an unnamed registered nurse to get her through a very difficult night post-emergency surgery. For many hours, the nurse was both a comfort and caretaker, expertly tending to a plethora of equipment, while monitoring changes in Carole’s condition. This same situation happens thousands of times a day in various settings across the globe. The challenge for Carole is how to measure the impact of this on patient recovery and well-being at an individual and community level and then translate it to policy, investments, and social capital that recognize the important and varied contributions of nurses to individual and population level healthcare and outcomes.

This is one aspect of the Medical Monitoring Project (MMP) that she appreciates, as MMP has continually sought the input of nurses and recognizes the critical roles that nurses play in the design and implementation of HIV prevention and treatment programs. She has even invited MMP researchers to present at a plenary at ANAC’s annual conference in November 2018 on evidence-based approaches to HIV and viral hepatitis care. A “Best of Conference” webinar series will also be made available to nurses beginning in late 2018 to early 2019.

Thirty years later, there are still challenges in patient care that need to be addressed. She has observed a fall-off in interest HIV/AIDS among new clinicians, whether they are NPs, infectious disease doctors, or primary care providers, as well as a shortage of highly qualified and easily accessible health providers. However, she is also inspired by the incredible resilience of those living with HIV despite the many barriers that they have faced and credits their advocacy work and leadership in how far we have come in the 35-year battle.