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Ryan White Part C

Statement of

Donna E. Sweet, MD, MACP, AAHIVS

Professor,
University of Kansas School of Medicine,
Department of Internal Medicine
KU IM Midtown Clinic
Wichita, KS

Board Chair,
American Academy of HIV Medicine
Washington, DC

Chairman Pallone, Ranking Member Deal, and distinguished Members of the Committee. I am honored to be here today to discuss the reauthorization and extension of the Ryan White Program. Today I will focus on Part C of the Ryan White Program.

I am a Professor of Internal Medicine at the University of Kansas School of Medicine-Wichita. I received my medical degree from the University of Kansas School of Medicine in 1979, and completed my residency in internal medicine in 1982. I joined KUSM-W's Department of Internal Medicine as an instructor, and became professor in 1993.

In addition to my duties with the school and clinic, I have previously served as President of the Advisory Board for the Sedgwick County Board of Health and as Chair for the Board of Regents of the American College of Physicians (ACP), the nation's largest medical specialty society. In 1995 I was one of 130 researchers and clinicians invited to take part in the first White House Conference on HIV and AIDS. I serve as director and principal investigator for the medical school's Ryan White III Comprehensive AIDS Resources program, the only such program in Kansas. I was one of the founders and am now Principal Investigator of the Kansas AIDS Education Training Center.

I am also a credentialed Specialist in HIV/AIDS, and the current Board Chair of the American Academy of HIV Medicine, headquartered here in Washington DC. The Academy is a professional organization of HIV medical providers, offering its members education and credentialing in HIV specialty care.

The mission of the HIV Program at KU Internal Medicine Midtown is to provide care and early intervention services to all HIV-positive individuals in the state of Kansas, regardless of ability to pay. The HIV Program seeks to provide quality community-based medical care, education and research throughout Wichita, as well as the rest of the state. The KU Internal Medicine Midtown facility is located in Wichita, KS. In addition, care is provided in outreach clinics in Garden City, Salina and Pittsburg every

six to eight weeks. Our program is “considered the gold standard for HIV care in the state” according to the Primary Care Assessment Tool (2000) administered by the Health Resources and Services Administration (HRSA).

You all are quite familiar with the need for the Ryan White Program. Part C funds nearly 400 community health centers and clinics that provide comprehensive HIV and medical care throughout the U.S. The program targets the most vulnerable communities: people of color, women, and the poor. Part C clinics provide care to approximately 250,000 people living with HIV/AIDS, and are on the front lines of offering HIV-related counseling and testing. Many have mixed sources of funding, including Parts A, B, C and D of the Ryan White Program. Part C clinic also serve as medical homes, providing the whole range of medical services to keep patients healthy.

Today, I would like to take you inside Part C of the Ryan White program – to the front lines of medicine fighting for the lives of people living with HIV/AIDS.

The HIV Program KU Internal Medicine Midtown provides care and treatment to 1246 patients as of today. Of these, 40% would have no coverage if it were not for the Ryan White Care Act. We provide ongoing, comprehensive care to an ever-increasing number of patients, regardless of their ability to pay. My clinic has an average annual increase of over 100 new patients a year (in Kansas- not New York or California). However, we are still working off the same number of Ryan White dollars we have received since 1999. To broadly paint the picture: In the last 10 years my clinic’s patient load has doubled, and my funding has remained the same.

Because of a decade of level funding – or in spite of it – the clinic runs with the utmost administrative efficiency. It’s worth noting that labs are one of our most significant costs. My Chairman at the school likes to remind me that I can, in a sense, “give away” my time as I see fit, but that the lab bills come to his desk. As part of standard monitoring for every HIV patient in my clinic, every three months we run CD4 and viral load counts,

as well as routine diagnostic blood work, altogether costing $160 every three months per patient. If any of those results indicate salient problems, a genotype lab is run, costing $350 (which, incidentally, Medicaid only reimburses for $250).

To supplement our insufficient federal dollars, we will often do things like annual bake sales and picnics to help raise money for the clinic and its patients. Even though we are committed to do things like this to keep the clinic afloat, it is hard to believe that we have to resort to girl-scout-styled fundraising to care for the sick in a country like ours.

There seems to be a commonly held belief that program cuts will only affect administrative functioning and that medical services for the sick will somehow always be available (through Ryan White, or Medicaid, or some other program); this is a false assumption. For this reason, the class of Core Medical Services must continue to be prioritized in the Act. There are many things I would like to provide to my patients, like travel vouchers and food assistance, but not at the expense of their medical care. For every patient I take on, without additional funding to the program, I have to work to find ways to provide even the most essential components of medical care.

There has been some discussion over recent years of the concept of the patient-centered "medical homes." That is what my Ryan White Part C clinic is, and has been since 1994. Medical homes take a patient-centered, team approach to providing ongoing, comprehensive, and well-coordinated care. Medical homes develop programs that treat the whole patient by utilizing a multi-disciplinary team to provide the range of services that patients need to stay healthy. In my clinic, case management, psychological counseling, dental care, pharmacy management, adherence counseling, and - when needed - palliative care, are all brought together under one roof. This approach has been central to our ability to retain patients after an initial diagnosis with HIV. Also, Part C is the model for quality implementation. Quality assurance activities are a mandatory part of Ryan White Part C, and as such, help us to continually improve early interventions.

The real effect of the Ryan White Program, if it were allowed to lapse for even of a short amount of time, would be seen on the front lines of the disease, in clinics like mine, who are Ryan White grantees.

HRSA HIV/AIDS Bureau (HAB) has made a determination that it cannot continue to run the Ryan White program after September 30th unless Congress "repeals the repealer" language in the statute and extends the program. Currently funded grantees could continue to utilize the Ryan White Funds that have already been obligated to them, but would face immediate and dire consequence shortly after those funds were no longer available.

For my clinic, that would mean losing access to: Part C money that pays for treatment of 40% of my patients and the bulk of my staff; part B money that funds my case managers; and ADAP money that provides drugs for my patients who can't afford them, 80% of my patients.

On January 1st, I would no longer be able to pay my staff, and they would have to be let go. I have not had any staff turnover in 5 years. These people are well-trained in caring for my HIV patients, and keep my office running. They are well-qualified, and would no doubt find other employment quickly. However, the loss to my clinic would be irreversible. If the Ryan White program were to face a gap in service of even a couple of months, years of investment in staff and infrastructure would be lost.

Without Part C, my patients would have no other place to go for life saving services and treatment. There is absolutely no place in the state where they could find similar treatment. There is a Federally qualified health center (FQHC) in Wichita that receives federal funding to treat the uninsured, but they have no specialty in HIV care. Without Part B of Ryan White, my patients would not be able to access the HIV drugs made available to patients through the ADAP program. If the Ryan White Program is not

reauthorized in a timely manner, the same things would happen in hundreds of communities and Part C clinics across the country.

Without care, patients' lives would be lost. Over the past 20 years, HIV has become a highly manageable disease with proper care and treatment. In the mid 1990s, mortality rates plummeted as new medications and treatments allowed better ways of fighting the virus. Nationwide, the trend is the same – improved medical care has led to decreased mortality. Patients are living longer, which brings about a new set of medical challenges. Treating HIV is enormously complex, but it becomes even more so when you add the medical needs of an elderly patient. Fortunately, in my clinic, I now see only 15 to 20 deaths a year. But, that number will increase dramatically if the population loses access to the care they need. The Ryan White Program is invaluable to the patients and providers that it funds. Congress must not delay in reauthorizing it.

Over the past year, numerous HIV/AIDS organizations have come together through the Federal AIDS Policy Partnership (FAPP), to form a consensus on reauthorizing the program. I have participated in those discussions. I urge the committee to consider the recommendations of the Community Consensus document, which you have received.

Among those recommendations, I would like to highlight a few that are important to me as a provider:

- 3 Year Reauthorization - The recommendation for the program to be reauthorized for at least 3 years is important for grantees like me. We need to have assurance of a stable and continuous funding stream in order to conduct our business and plan for the future of our practice and our patients.

- Authorization Levels – Included in legislation that was under discussion this year was a 3.7 percent increase for the majority of the Parts. This is significantly less than the annual increase for Community Health Centers. As someone running a

clinic that has to do its own fundraising, I would appreciate consideration of language authorizing “such sums as necessary” in the program.

- Core Medical Services - Grant carve-outs for ancillary services may leave doctors unable to run labs for patients, or provide needed drugs after they arrive at the clinic. When funding for these services is carved out of the Part of the program intended to directly provide for medical care, it undermines life-line medical services for patients. The provision of Core Medical Services must be protected.

Additional recommendations are listed in the community consensus document, and I would urge the committee to thoughtfully consider them.

In closing, I would like to leave the committee with a few thoughts: Without the Ryan White Program, my clinic would never have been created. Without a timely reauthorization of Ryan White, it may cease to exist. Without my clinic, my patients will not receive the care they need to manage their disease. And without that care, the disease they live with every day may unnecessarily and prematurely claim their lives. The Ryan White program works; it is critical to the care and treatment of those affected by this nation’s largest epidemic. I urge the committee to reauthorize the program with all due haste.

Thank you for the opportunity to testify today about Ryan White Part C, and my experience as an HIV Specialist. This concludes my testimony. I will be happy to answer any questions.