USET
SOVEREIGNTY PROTECTION FUND

Nashville TN Office
711 Stewarts Ferry Pike, Ste. 100
Nashville TN 37214
P: (615) 872-7900
F: (615) 872-7417

Washington DC Office
400 North Capitol St., Ste. 585
Washington DC 20001
P: (202) 624-3550
F: (202) 393-5218

Transmitted via HepHIVStrategies@hhs.gov

March 11, 2019

Tammy R. Beckham, DVM, PhD
Director
Office of HIV/AIDS and Infectious Disease Policy
U.S. Department of Health and Human Services
Room L001
330 C Street SW
Washington, DC 20024

RE: Request for Information (RFI): Improving Efficiency, Effectiveness, Coordination, and Accountability of HIV and Viral Hepatitis Prevention, Care, and Treatment Programs

Dear Director Beckham,

On behalf of the United South and Eastern Tribes Sovereignty Protection Fund (USET SPF), we write to provide comment to the U.S. Department of Health and Human Services (HHS) regarding the agency's request for information on the National Viral Hepatitis Action Plan (NVHAP) which is set to expire in 2020. In order to help inform the next iteration of the NVHAP, the agency seeks input from stakeholders to improve "efficiency, effectiveness, coordination, and accountability" of viral hepatitis prevention, care, treatment, and cure policies, services, and programs within HHS. As the agency gathers input from various stakeholders on improving Hepatitis C (HCV) programs within HHS, the agency must strongly consider the significant and disproportionate effect that HCV has had within Tribal Nations. The NVHAP must fully reflect the unique HCV treatment circumstances of Tribal communities and include critical strategies on how the agency will ensure Tribal governments and citizens have access to quality health care.

USET SPF is a non-profit, inter-tribal organization representing 27 federally recognized Tribal Nations from Texas across to Florida and up to Maine[1]. Both individually, as well as collectively through USET SPF, our member Tribal Nations work to improve health care services for American Indians. Our member Tribal Nations operate in the Nashville Area of the Indian Health Service (IHS), which contains 36 IHS and Tribal health care facilities. Our citizens receive health care services both directly at IHS facilities, as well as in Tribally-operated facilities under contracts with IHS pursuant to the Indian Self-Determination and Education Assistance Act (ISDEAA), P.L. 93-638.

---

[1] USET SPF member Tribal Nations include: Alabama-Coushatta Tribe of Texas (TX), Aroostook Band of Micmac Indians (ME), Catawba Indian Nation (SC), Cayuga Nation (NY), Chitimacha Tribe of Louisiana (LA), Coushatta Tribe of Louisiana (LA), Eastern Band of Cherokee Indians (NC), Houlton Band of Maliseet Indians (ME), Jena Band of Choctaw Indians (LA), Mashantucket Pequot Indian Tribe (CT), Mashpee Wampanoag Tribe (MA), Miccosukee Tribe of Indians of Florida (FL), Mississippi Band of Choctaw Indians (MS), Mohegan Tribe of Indians of Connecticut (CT), Narragansett Indian Tribe (RI), Oneida Indian Nation (NY), Pamunkey Indian Tribe (VA), Passamaquoddy Tribe at Indian Township (ME), Passamaquoddy Tribe at Pleasant Point (ME), Penobscot Indian Nation (ME), Poarch Band of Creek Indians (AL), Saint Regis Mohawk Tribe (NY), Seminole Tribe of Florida (FL), Seneca Nation of Indians (NY), Shinnecock Indian Nation (NY), Tunica-Biloxi Tribe of Louisiana (LA), and the Wampanoag Tribe of Gay Head (Aquinnah) (MA).

Indian Country has been disproportionately impacted by HCV. According to the Centers for Disease Control and Prevention (CDC), AI/ANs are experiencing devastating effects of HCV infections, including:

- the highest mortality rate at 10.8 deaths per 100,000 population compared to a national average of 4.5 deaths per 100,000 in 2016;
- 2.3 times higher (age-adjusted) rates of chronic liver disease and cirrhosis deaths compared to Whites in 2016;
- a 9% increase in mortality rates from 2010 to 2016; and
- 2.9 times higher HCV incidence (number new of cases) rates compared to Whites in 2016.

In the USET SPF region, there are approximately 1,000 known HCV cases, with over 100 new cases every year since 2014. The most common mode of transmission for new diagnoses is sharing needles within the USET SPF region, as in other areas in Indian Country.

Among USET SPF member Tribal citizens, the two age groupings with the greatest rates of HCV are those aged 25–34 and 53–73. Those born after 1965 are at the greatest risk with 72% of those affected. Nationwide, HCV prevalence rates are 1.6% of the population while in the IHS Nashville region the prevalence rate is 2.3%. Between 2013 and 2017, the incidence of HCV have increased from 87 cases to 139 cases.

Data shows that the most common route of transmission of HCV cases, 60%, is attributed to injection drug use. With AI/ANs experiencing the second highest overdose fatality rate nationwide at 13.9 deaths per 100,000[2], it is consistent that HCV has been closely attributed to the national opioid overdose epidemic and increased injection drug use. Despite the disproportionate impact the increase in HCV infection has had within Tribal communities, USET SPF is concerned that Tribal Nations have habitually been left out of national efforts to address this disease, as well as efforts to address the opioid epidemic, which has significantly contributed to the increase of HCV in Indian Country. Though USET SPF is glad to see the federal government, including Congress, take steps to address the unique treatment needs of Indian Country by providing opioid addiction treatment funding streams within legislation, much greater resources are required to fully address the HCV and the opioid crisis within Indian Country through all federal agencies. USET SPF reminds HHS of the unique federal trust responsibility to Tribal Nations and urges the agency to use its authority to ensure Tribal Nations are fully included in any conversations seeking to address HCV. Below, we provide comments to HHS on how the agency can work to fulfill the federal trust obligation to ensure Tribal Nations have access to comprehensive HCV treatment and preventative health care as well as reflect this obligation within the NVHAP.

Inclusion of Federal Trust Responsibility in NVHAP

USET SPF is disappointed in the lack of language within the current NVHAP referencing the federal trust responsibility to Tribal Nations to provide comprehensive health care, despite the document being authored by a federal agency. The federal trust obligation was established through the Constitution, and has been upheld and honored by numerous treaties, laws, Supreme Court decisions, as well as Executive Orders as a result of millions of acres of land and resources ceded to the U.S. by Tribal Nations. With growing rates of HCV within Indian Country, it is essential that HHS acknowledge the federal trust responsibility within the NVHAP. Any plan guiding the work of HHS, including the NVHAP, must reflect the commitment by the agency to uphold the federal trust obligation that Tribal Nations have access to quality and culturally competent healthcare both in the language used and the goals articulated.

[2] Seth P, Scholl L, Rudd RA, Bacon S. Overdose Deaths Involving Opioids, Cocaine, and Psychostimulants — United States, 2015–2016. MMWR Morb Mortal Wkly Rep 2018;67:349–358. DOI: http://dx.doi.org/10.15585/mmwr.mm6712a

Direct Funding for HCV Treatment and Prevention

The federal government has a trust responsibility to ensure Tribal Nations have access to resources, financial and otherwise, to address HCV in our communities. Among the vital resources needed to combat HCV in Tribal communities is access to direct federal funding for treatment and prevention programs, however, no direct funding stream currently exists.

Funding for Tribal Epidemiology Centers

Because Tribal Nations are often located in remote rural areas, recruiting and retaining physicians, especially specialty physicians such as hepatologists and gastroenterologists, is difficult. For this reason, direct funding to Tribal Nations and Tribal Epidemiology centers (TEC's) to administer HCV treatment is required. Though telehealth is a potentially effective method for providing treatment, there are currently only small pilot projects in some areas for telehealth programs in Indian Country for HCV treatment.

In addition to treating HCV in Indian Country, funding for prevention activities through TEC's is critical. In 2010, the Indian Health Care Improvement Act was reauthorized and included a provision designating TEC's as public health authorities under the Health Insurance Portability and Accountability Act. As such, TEC's must receive direct funding to provide technical support and implement HCV prevention and education programs for Tribal Nations.

Pharmaceutical HCV Treatment Costs

Newer treatments for HCV pharmaceutical interventions continue to evolve, having lower side effects and higher cure rates. However, these pharmaceutical treatments are often very costly and place a great financial burden on Tribal governments and Tribal treatment programs. One of the more common HCV treatments costs $1,125 per pill, $94,500 for a 12-week course of treatment. IHS, the primary funder of AI/AN health care is continuously and significantly underfunded at approximately 50% level of need. As a result, the costs of providing these life-saving medications often falls on Tribal governments, who are often struggling to provide their communities with basic services. The financial burden of providing life-saving HCV treatment to Tribal citizens should not fall on Tribal governments, as this is in violation of the federal trust obligation. Therefore, it is essential Tribal Nations have access to direct funding for HCV pharmaceutical treatment and prevention costs.

When it comes to existing funding streams for these critical services, Tribal governments and Tribal treatment and prevention programs currently have difficulty accessing federal funds for HCV programs as these funds are only available under competitive grant-based funding. Competitive grants are not reflective of the federal trust responsibility to provide healthcare to Tribal Nations, and results in few resources delivered to Tribal citizens. Similarly, Tribal Nations are forced to compete with states and other entities for limited dollars. Tribal Nations should not have to compete to provide their citizens with the HCV treatment they critically need, as this is a violation of the federal trust responsibility to ensure AI/ANs have access to comprehensive health care. USET SPF has consistently advocated for funding to Tribal Nations to be distributed via contracts and compacts under ISDEAA in recognition of the sovereign status of Tribal Nations, rather than attempting to deliver critical health care funding resources through grants. Through the NVHAP, HHS must acknowledge the gap in resources available to Tribal Nations due to the lack of direct funding, and work to include direct funding for Tribal Nations as part of the national strategy to address HCV within Indian Country.

Culturally Competent Treatment

The incorporation of traditional healing practices and a holistic approach to health care are fundamental within Indian Country and have become central to many Tribal treatment programs as Tribal communities have unique treatment needs with a strong link to historical trauma. Culturally appropriate care has had a

positive, measurable success within Tribal communities, particularly within certain USET SPF member Tribal Nations. Despite the successful outcomes when it comes to the treatment of HCV and opioid addiction, these treatment programs often lack adequate funding resources, therefore, treatment options that incorporate cultural healing aspects are oftentimes not available within or near Tribal communities. USET SPF underscores the importance of these critical treatment programs within Indian Country that are cognizant of historical trauma, respectful of community factors, and utilize traditional health care practices. We encourage HHS to reflect the importance of Tribally culturally competent treatment within the NVHAP, as well as the importance of access to adequate funding resources for continued and expanded access to these important treatment programs.

Conclusion

It is essential that the NVHAP fully reflect the unique HCV treatment circumstances of Indian Country. Further, the NVHAP, as well as all plans guiding the work of HHS, must reflect the commitment by the agency to uphold federal trust obligation that Tribal Nations have access to quality and culturally competent healthcare. Indian Country has been disproportionately impacted by HCV, therefore it is critical now, more than ever, that HHS address the disparities Tribal Nations face in access to critical funding resources when seeking to treat HCV infection within our communities. Should you have any questions or require further information, please contact Mr. Kitcki Carroll, USET SPF Executive Director, at kcarroll@usetinc.org or 615-495-2814.

Sincerely,

Kirk Francis
President

Kitcki A. Carroll
Executive Director