**Patrick Allen Roberts, (Hopi), Health Policy Fellow**
**National Native American AIDS Prevention Center and the Caring Ambassadors Program**

## I. INTRODUCTION

My name is Patrick Roberts, I am a Colorado constituent and a registered Tribal member of the Hopi Nation; my mother is member of the clay clan with the Hopi Tribe in a village 50 miles north of Winslow Arizona; the name of that village is Shongpovi. In addition, I am an LGBT (Two-Spirit) Native who has been living with HIV for thirty years.

I also represent two National public charities, The National Native American AIDS Prevention Center (NNAAPC), located in Denver Colorado, and the Caring Ambassadors Program, located in Oregon City, Oregon as a Health Policy Fellow.

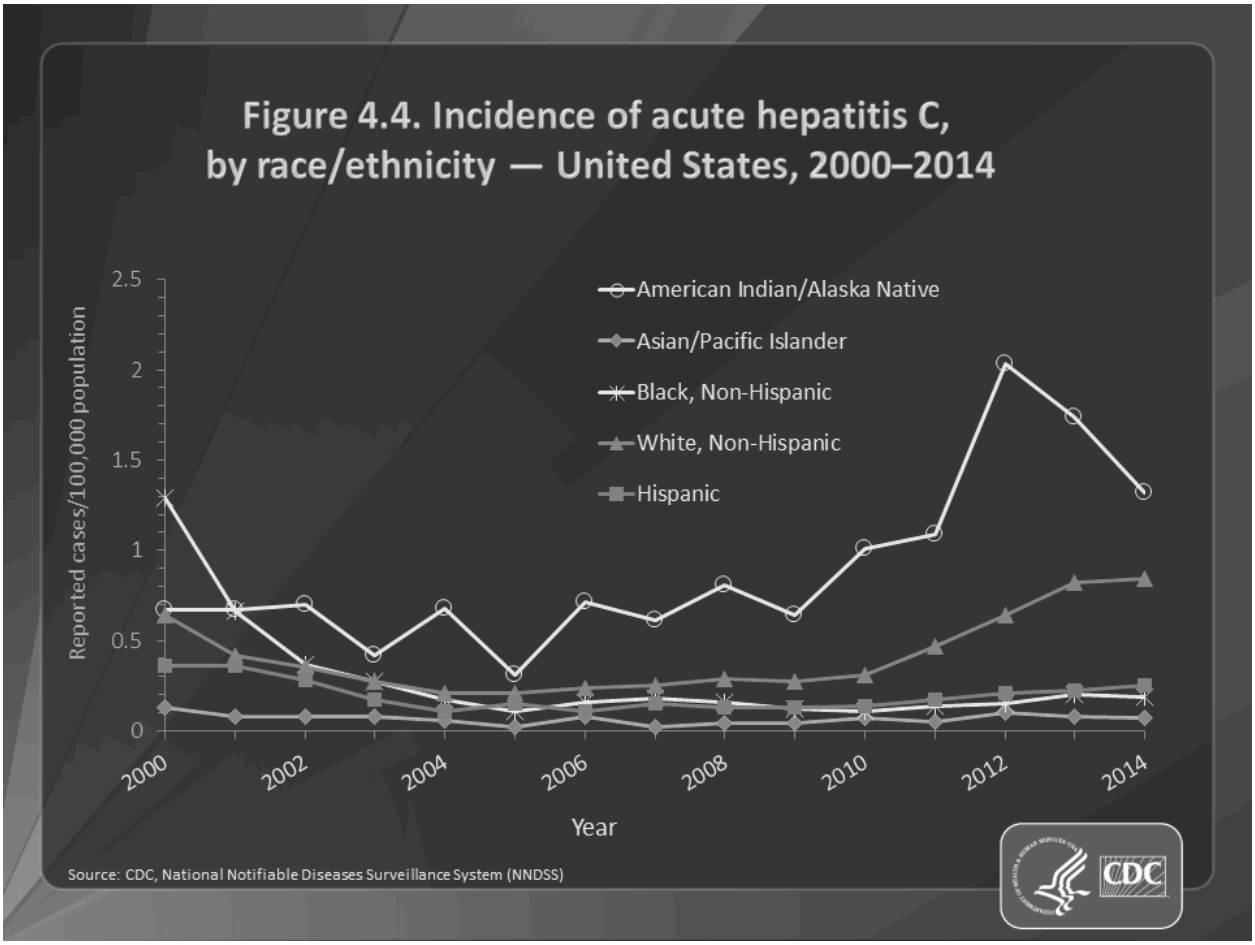
We respectfully submit our written comment on the disparities and lack of testing, treatment services related to hepatitis C within rural and urban tribal communities and recommended solutions to aid in the elimination goal for hepatitis C (HCV). We encourage Members of the U.S. House of Representatives Committee on Appropriations, Subcommittee on Interior, Environment, and Related Agencies to immediately investigate the opportunity to save money and eliminate the burden of hepatitis C by utilizing the creative financing recommendation contained in the recent report, "A National Strategy for the Elimination of Hepatitis B and C", by the National Academies of Sciences, Engineering, and Medicine. This report states clearly that the elimination of hepatitis B and C as a public health threat by the year 2030 is possible if Congress and the Administration provide strong leadership.

## II. THE STATE OF HEPATITIS C INFECTION IN INDIAN COUNTRY

Hepatitis C is the most common, chronic, blood-borne viral infection in the United States, yet it remains an unrecognized threat in the minds of many Americans. Hepatitis C is an insidious and often silent disease for many years. The early quiescent nature of chronic hepatitis C is one of the most fundamental reasons it poses such a perilous public health threat. Significant numbers of people currently infected with HCV are unaware of their infection and are likely to remain so for many years until the complications of chronic liver disease develop. Annually deaths due to hepatitis C have surpassed deaths due to HIV in the US.

While an estimated 1 million Americans have been infected with the human immunodeficiency virus (HIV), at least 2.7 to 3.9 million Americans are chronically infected with the hepatitis C virus. American Indian /Alaskan Natives (AI/AN) people have both the highest rate of acute hepatitis C (HCV) infection and the highest HCV-related mortality rate of any U.S. racial/ethnic group; **in 2014, the rate of acute hepatitis C in AI/AN was 1.32 cases per 100,000. From 2002 - 2012, new hepatitis C infections increased by 82.6% amongst AI/AN. From 2002 - 2013, the incidence rate of acute hepatitis C remained higher for AI/AN relative to other racial/ethnic groups.**

Funding for data collection and inclusion of AI/AN in all data sets for a more accurate reporting is needed to eliminate the virus. Data sets should be streamlined with tribes, state and national registries and electronic data collection should be funded in tribal clinics and agencies.




In 2014, rates of acute hepatitis C among AI/ANs; are the highest compared to any other ethnic minority group.

**III. THE LACK OF HEPATITIS C TREATMENT ACCESS**

We encourage you to review the IHS budget and develop a program similar to what was done within the Department of Veterans Affairs to test and treat all AI/ANs living with HCV regardless of stage of liver disease. Under the current Affordable Care Act, access to hepatitis C medications is limited. And now hepatitis B and C are excluded (as a pre-existing condition) from the proposed American Health Care Act. Hepatitis C is preventable and treatable, yet early treatment is not covered. NNAAPC, through its testing efforts, has identified AI/ANs who are hepatitis C positive and are unable to access lifesaving treatment. Further, American Indians, Alaska Natives, and Native Hawaiians, that rely on IHS Purchased/Referred Care Funds for services, or Medicaid, are not able to access the expensive hepatitis C treatments. The Cherokee Nation's Hepatitis C Elimination Program is a model that can be used within all Native communities. The cost of end-stage liver disease caused by cirrhosis from hepatitis C infection or liver transplants can be avoided through early screening and treatment, ultimately lowering the cost to patients, providers, and Medicaid programs.

**IV. HEPATITIS C ELIMINATION IS POSSIBLE**

In October 2015, Dr. Jorge Mera, Director of Infectious Disease with the Cherokee Nation developed a hepatitis C elimination program; partnering with the University of New Mexico's Project ECHO Program which incorporated multiple providers to screen, treat and cure AI/ANs at risk or who are hepatitis C positive. At the start of the elimination project an estimated 5,000 members of the Cherokee Nation were infected with hepatitis C. Over a period of three years; the goal of the project was to screen 85% of the targeted population who are over the age of 20 years, to treat 85% of those who are positive with hepatitis C, and to cure 85% of those treated. The project was expanded to screen ages to 20 years and older, incorporated rapid testing to all outlying clinics, incorporated dental screening to the targeted age group, and implemented an electronic medical record (EMR) lab "trigger" system reminding medical staff to conduct the HCV rapid screening test.

Within the first 60 days of (the) project implementation the Cherokee Nation's Project, **(8) eight pregnant Cherokee women were identified as hepatitis C positive**. Increased screening resulted in the identification of ***(1) one new hepatitis C positive case per day***.

To date, nearly 300 patients have been treated for hepatitis C. ***Based on 12-weeks of treatment 96% sustained a positive cure rate***. Most importantly, the intention to treat (cure rate) reached 86%, which is 1% over the initial goal to treat HCV. Three very important outcomes stand out:

- Increase screening for hepatitis C results in more accurate prevalence rates
- Early intervention to screen, identify and that hepatitis C infection works in Native communities.
- The actual HCV rate for the Cherokee Nation is 5.8% as compared to the CDC's estimate of 2.8%.

**V. FUNDING HEPATITIS C ELIMINATION**

Hepatitis C treatment is cost effective but due to the high rate of infection it puts a strain on Medicaid, the IHS budget, and tribal health. We encourage committee members to adopt the committee recommendation 6.1 in A National Strategy for the Elimination of Hepatitis B and C;

> *6-1: The federal government, on behalf of the Department of Health and Human Services, should purchase the rights to a direct-acting antiviral for use in neglected market segments, such as Medicaid, the Indian Health Service, and prisons. This could be done through the licensing or assigning of a patent in a voluntary transaction with an innovator pharmaceutical company."*

**VI. CONCLUSIONS**

***(1)*** We respectfully ask for increased funding to IHS to participate in the World Health Organization elimination goal by 2030. ***(2)*** We respectfully request the committee to investigate the benefit of purchasing the rights to a direct acting antiviral to aid in the elimination of hepatitis C by 2030. ***(3)*** The Cherokee Nation Project highlighted the need for better data with the actual rate of 5.8% compared to CDC's estimate of 2.8%. We respectfully request increased funding for data collection and inclusion of AI/AN in all data sets for a more accurate reporting. Data sets should be streamlined with tribes, state and national registries and electronic data collection should be funded in tribal clinics and agencies. ***(4)*** We respectfully ask this committee to request that the Senate on Indian Affairs Committee, conduct an expert hearing to address the state of viral hepatitis in populations served by the Indian Health Service and American Indian community-based organizations that serve our Native people. We ask that community stakeholders be invited to speak at the hearing so they may address firsthand experience related to hepatitis C infection in their community.

We have an opportunity that rarely exists in medicine (cure), we need your political will to ensure a cure for all. Delaying treatment will result in tens of thousands of unnecessary deaths and billions in wasted health care costs. Curing people puts them back to work, increases productivity, increases the quality of life, and reduces transmission to others. We look forward to working with you to make hepatitis history. Thank you for your time and consideration.

Sincerely,

Patrick Roberts