Tribal Leaders Diabetes Committee

National Indian Health Board

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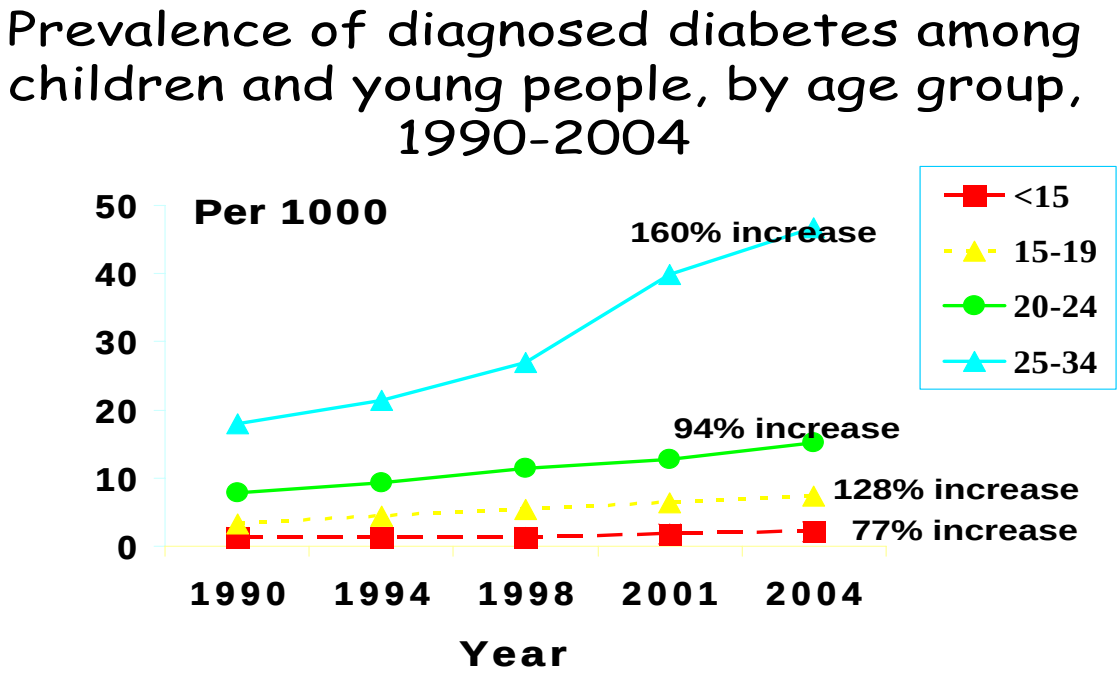
BEFORE THE SENATE COMMITTEE ON INDIAN AFFAIRS
OVERSIGHT HEARING ON DIABETES IN INDIAN COUNTRY
AND SPECIAL DIABETES PROGRAM FOR INDIANS

THURSDAY, FEBRUARY 8, 2007, 9:30 AM
SENATE RUSSELL BUILDING ROOM 485

Good Morning, Chairman Dorgan and Vice-Chairman Thomas, and members of the Indian Affairs Committee. I am Buford Rolin, Chairman of the Poarch Band of Creek Indians, Chairman of the Tribal Leaders Diabetes Committee (TLDC), and Vice-Chairman of the National Indian Health Board (NIHB). It is a pleasure to be here today to discuss with you the Special Diabetes Program for Indians (SDPI). This important program is making a critical difference in the prevention and treatment of diabetes and cardiovascular disease (CVD) for American Indians and Alaska Natives (AI/ANs).

As I am sure you are aware, the rates of diabetes for AI/ANs are the highest in the U.S., with rates of diagnosed diabetes in adults as high as 60% in some of our communities. Between 1997 and 2004, the prevalence of diabetes increased by 45% in all major regions (all ages) served by the Indian Health Service (IHS). The highest rate of increase has occurred among AI/AN young adults aged 25-34 years, with a 160% increase from 1990-2004. Alarmingly, type 2 diabetes rose 128% in AI/AN adolescents, 15-19 years old.



Even though type 2 diabetes used to be rare in individuals under the age of 40, the prevalence of diabetes in AI/ANs under the age of 35 increased by 133% between 1990 and 2004. In 2003, of AI/ANs aged 35 years or older, nearly 70% had both diabetes and hypertension. The diabetes mortality rate is more than 3 times higher in the AI/AN population than in the general U.S. population (1999-2001). Complications of diabetes lead to much higher incidence rates of blindness, vascular insufficiency leading to amputation, and End Stage Renal Disease (ESRD) than in the general U.S. population. For instance, in 2000 in New Mexico, the age-adjusted lower-extremity amputation rate was 3.5 times higher for AI/ANs with diabetes than for non-Hispanic whites. In 2001, the age-adjusted ESRD incidence among American Indians in the Southwest was 2.4 times that of persons with diabetes in the U.S. In 2002, one in every four (24.8%) AI/AN elders over age 65 years had coronary heart disease.

The prevalence of diabetes varies among different tribes but is increasing in all IHS Areas. A recent analysis of the IHS system patient data for AI/ANs under age 35 years showed that the prevalence rate of diagnosed diabetes *doubled* in just 10 years—rising from 8.5 cases per 1,000 people in 1994 to 17.1 cases per 1,000 in 2004. These data are based on the 60% of AI/ANs who used the IHS system for health care services during the 10-year period. Therefore, the effective rate of the remaining 40% could show even higher rates.

In 1997, Congress authorized the initial SDPI in response to these alarming trends of disproportionately high rates of type 2 diabetes in AI/AN communities. The SDPI program emerged in the wake of increasing public concern about the human and economic costs of diabetes in the U.S. and its growing prevalence among the AI/AN population. Congress funded the program and directed the IHS to implement a grant process to distribute the funding of the

SDPI. The SDPI was implemented through consultation with tribal and urban health programs to develop the methodology and the process for distribution of the funds as grant awards.

In 2002, the Congress reauthorized the SDPI reauthorization for $150 million per year for FY 2004-2008. The IHS was directed to expand the program and implement a competitive grant program. The competitive grants were awarded to eligible entities for the implementation of specific interventions proven to prevent diabetes and reduce CVD risk, the most compelling complication of diabetes. Funds were also directed towards data improvement. In addition, distribution of funds to original SDPI grantees for the prevention and treatment of diabetes continued.

SDPI funds originally provided "seed money" to the 333 non-competitive grant programs to begin or enhance diabetes prevention programs in Indian communities as well as to address diabetes treatment. The result has been the creation of innovative, culturally appropriate strategies that address diabetes. The SDPI funds have significantly enhanced diabetes care and education in AI/AN communities, as well as built a desperately needed infrastructure for diabetes programs. The IHS has continued to develop and operate the original SDPI grant programs with 333 IHS, tribal and urban Indian grant programs in 35 states. In FY 2004, an additional 66 competitive grants (30 CVD risk reduction grants and 36 diabetes prevention grants) were added to the funding. Today, the IHS provides funding and support for diabetes prevention and treatment programs, services, and activities to 399 grant programs.

The SDPI funding is set to expire in October 2008. The American Diabetes Association (ADA), Juvenile Diabetes Research Foundation (JDRF) and the NIHB hosted a meeting June 13 – 14, 2006 to bring tribal leaders and key stakeholders together to discuss how to approach the reauthorization of SDPI funding during the 110th Congress. It was recommended by the diabetes associations and former congressional leader, Congressman George Nethercut, to seek reauthorization of the SDPI at an increase funding request of $200 million per year for five years.

On October 6, 2006, the TLDC, with the assistance of the NIHB, mailed a letter to all tribal leaders seeking input as to the future of the SDPI. The letter specifically asked the tribal leaders whether they would support the amount of $200 million per year for five years as the amount of funding Indian Country should ask for from Congress. The tribes responded unanimously in support of reauthorization of the SDPI at an amount of $200 million per year for five years.

The ADA and JDRF have been great partners with the NIHB in efforts to secure appropriate funding for diabetes research and the SDPI. At the NIHB Annual Consumer Conference, the ADA and the NIHB participated in a workshop entitled "Advocacy for the Reauthorization of the SDPI: Awakening the Spirit and Working Together to extend the SDPI." The workshop presenters discussed advocacy efforts and the role Indian country could play in achieving reauthorization. The workshop attendees were asked to review "Awakening the Spirit" advocacy kits that will be distributed by the ADA and NIHB to Congressional offices.

The NIHB was recently informed that two young members of the Choctaw and Chickasaw Tribes will join 150 other children from across the U.S. to participate in the JDRF Children's

Congress, to be held June 17 -20th, in Washington, D.C. Delegates to the Children's Congress will converge on Capitol Hill to tell their stories and urge lawmakers to find a cure for type 1 diabetes. Desiree Cameron, of the Choctaw Nation, and Erica Rodebush, of the Choctaw and Chickasaw Nations, were selected from over 1,000 applicants. In a letter to members of Congress, Erica writes:

> *" I wish there were a cure for type 1 diabetes so I could live a more normal life like my friends and family. A cure would allow me to eat and drink without checking my blood sugars and counting carbs for insulin. Finding a cure would mean my parents wouldn't have to pay for my supplies that cost a lot. Me, my parents and brother would not have to worry about sleeping all night because my blood sugars wouldn't be low or go high and make me sick."*

As Chairman of my own tribe, the Poarch Band of Creek Indians, I wish that more Indian people could travel to Washington, D.C. to tell their stories as to how diabetes impacts their lives, the lives of their families and their communities. My mother had diabetes and I still remember to this day how she suffered from the illness.

Since its inception in 1997, the SDPI has become an essential and effective program to reduce the incidence of diabetes in AI/AN individuals and communities. In fact, it is proving to be both a successful effort and a good investment. A study published by the ADA in 2002 on the economic burden of diabetes in the U.S., estimated that it costs over $13,000 per year to care for one person with diabetes compared with $2,600 per year for persons without diabetes. Nearly 1/3 of every Medicare dollar is spent on people with diabetes. Individuals with diabetes have more than twice the prevalence of disability from amputation, loss of vision, and other seriously limiting medical conditions. People with diabetes are at greater risk for diabetes-related complications such as stroke, heart attack, blindness, kidney failure, limb amputation, nerve damage, severe dental disease, and complications of pregnancy.

The SDPI funding has enabled the IHS, tribal, and urban Indian programs to provide expanded prevention, screening and treatment diabetes services. Through an increase in prevention and screening activities, the economic costs of treating diabetes and diabetes-related complications in Indian communities should be lessened. But more importantly, the SDPI prevention and screening activities are intended to improve the lives of AI/ANs with diabetes and their families and communities by early detection and management.

The following is a sample of some of the prevention, screening, and treatment services provided by the IHS, tribal, and urban model diabetes programs:

- Clinical annual examinations of the eyes, teeth, and feet to prevent diabetes-related complications
- Newer and more effective medications and therapies, such as medications to lower blood glucose levels
- Laboratory tests to assess diabetes control and complications
- Screening of elders and children for risk factors associated with diabetes
- Nutrition education and counseling services by registered dieticians

- Culturally appropriate diabetes education and awareness activities
- Diabetes primary prevention programs for children and families
- Community-based healthy eating programs at area schools and nursing homes
- Community physical fitness activities

The SDPI has allowed many of the IHS, tribal and urban programs to provide preventive and other basic elements of diabetic care not that were not available to AI/ANs prior to the SDPI funding.

As Chairman of the TLDC, I have had the unique opportunity to work closely with Dr. Charles Grim, Director of IHS, and with Dr. Kelly Acton, Director, IHS Division of Diabetes Treatment and Prevention Program, to oversee the development of many of the culturally sensitive and appropriate diabetes programs throughout Indian Country. In 1998, the IHS formally established the TLDC to provide advice and input on diabetes-related issues and its complications for AI/ANs. The TLDC's collaborative effort with the IHS has been an important outcome of the SDPI. The IHS recognized from the start of this program that it would have to make careful choices about where to invest these funds and knew these choices would best be made with input from tribal leaders. The TLDC provides that knowledge.

The IHS, tribal, and urban model diabetes programs have developed and implemented a variety of community and education programs that reflect the specific needs of their local communities. While I cannot begin to describe all of the model diabetes programs, I would like to highlight a few:

- The Fort Berthold Model Diabetes program located in New Town, North Dakota, has created community activities such as cooking classes and menu planning for local area schools. The program created educational activities such as a "Diabetes Bingo" game to help educate community members on prevention and treatment of diabetes. While this model diabetes program has developed community and education opportunities for their members, the program faces challenges such as lack of space for an exercise room or to conduct group activities. Funding has been a problem to meet staffing and traveling needs. Excessive travel costs are due to the long distances between communities. Because of limited funding, trips to outlying communities have been reduced. If it were not for the SDPI funding, the program would not have been able to establish a self glucose monitoring program or a diabetic optometry or foot clinic.

- The Fort Totten Model Diabetes Program, located in Fort Totten, North Dakota, organizes several community activities such as a Diabetes Walk/Run, a Diabetes Alert Day, a community blood screening and health fair, and other community awareness events in partnership with the local Headstart program, tribal law enforcement, Elderly meals, Four Winds School, tribal WIC program, and the Expanded Food & Nutrition Education program.

- The Whirling Thunder Wellness Program, operated by the Winnebago Tribe of Nebraska, is a multidisciplinary program with 76 years of cumulative diabetes experience and

includes a physician assistant, two R.N.s, a fitness director, dietician, prevention specialist, two fitness specialists, and an eye care manager. The program has established community activities such as a Healthy Choice Pow Wow Food Stand, a "Bison in Nutrition" intervention, and a Kidz Café offering healthy menus and nutrition education.

- The IHS Zuni Service Unit Diabetes Program, in Zuni, New Mexico, has identified 25% of those ages 29 and older and 50% of those ages 49 and older as having diabetes. A Zuni Wellness Center has been established for individuals at risk of diabetes to exercise and participate in health promotion activities. The Center has earned the reputation for quality advances in fitness and health promotion and cites "community empowerment" as necessary to its success.

While these are just some of the examples of the model diabetes programs located throughout Indian Country, all of the programs continue to face many challenges. There is a lack of staff and staff turnover, lack of data/case management systems, and lack of adequate facility space to provide basic services and to hold community, educational, and fitness activities.

An overall concern of these programs is that the number of known AI/ANs with diabetes has increased due to more accurate data reporting, but the staffing and budget needs have not kept pace. For example, the Blackfeet Diabetes Program identified 331 people with diabetes in 1988, and in 2000, identified over 1,000 people with diabetes; yet the number of staff has been reduced from six to four.

The vision of the TLDC is to empower AI/AN people to live free of diabetes through healthy lifestyles while preserving cultural traditions and values through tribal leadership, direction, communication, and education. The SDPI is a vital program needed to fulfill the mission of the TLDC. The SDPI needs to be reauthorized with an increase in funding. If the program is not reauthorized, all of the work and accomplishments of the last ten years will be lost, and many AI/AN lives and communities as well.

I appreciate the Committee on Indian Affairs scheduling this oversight hearing on diabetes in Indian country, and especially, the Special Diabetes Program for Indians. Thank you for inviting me to testify and I am happy to answer any questions you may have.