DEPARTMENT OF HEALTH AND HUMAN SERVICES

STATEMENT

OF

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BEFORE THE

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ON SPECIAL DIABETES PROGRAM FOR INDIANS

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STATEMENT OF THE INDIAN HEALTH SERVICE HEARING ON THE SPECIAL DIABETES PROGRAM FOR INDIANS

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Mr. Chairmen and Members of the Committee:

Good morning, I am Dr. Charles Grim, Director of the Indian Health Service (IHS). Today, I am accompanied by Dr. Kelly R. Moore, Clinical Consultant, National Diabetes Program, IHS. We are pleased to have this opportunity to testify on behalf of Secretary Leavitt on the Special Diabetes Program for Indians.

The IHS provides health services to an estimated 1.9 million Federally-recognized American Indians and Alaska Natives through a system of IHS, tribal, and urban (I/T/U) operated facilities and programs based on treaties, judicial determinations, and Acts of Congress. The mission of the agency is to raise the physical, mental, social, and spiritual health of American Indians and Alaska Natives the highest level, in partnership with the population we serve. The agency goal is to assure that comprehensive, culturally acceptable personal and public health services are available and accessible to the service population. Our mission is to promote healthy American Indian and Alaska Native people, communities, and cultures and to honor and protect the inherent sovereign rights of Tribes.

The Diabetes Epidemic

Diabetes has quickly emerged as one of the most serious and devastating health problems of our time. An estimated 20.8 million Americans have diabetes, representing 7.0% of the population. Only two-thirds of those affected have been diagnosed and are being actively treated. Although diabetes occurs in people of all ages and races, some groups have a higher risk than others for developing diabetes. Diabetes is more common in African Americans, Latinos, Asian Americans/Pacific Islanders than in non-Hispanic whites, and in elderly people than in people younger than the age of 65. However, American Indians and Alaska Natives bear the highest prevalence of diabetes in the U.S. population. Addressing this serious disease and its consequences for tribal communities is an important health priority for our nation.

In spite of our best efforts and successes so far in treating diabetes, the epidemic of diabetes continues to increase. Although diabetes is also increasing in the U.S. population as a whole, the increase in the Indian population is far more dramatic. While the prevalence of diabetes in the U.S. population almost doubled between 1980 and 2004, the prevalence of diabetes among American Indians and Alaska Natives was already higher in the early 1980's than in the U.S. population in 2004. Moreover, the

prevalence of diabetes among American Indians and Alaska Natives more than doubled during this time period. Indeed, American Indians and Alaska Natives have the highest age-adjusted rates of diabetes (16.3%) among all U.S. racial and ethnic groups. And, in some communities, the prevalence rate is as high as 60% among adults.

Rates of diabetes in American Indians and Alaska Natives vary across the country. The lowest rates are found among Alaska Natives with the highest rates found among the Nashville Area and Tucson Area tribes. Rates of increase in diabetes also vary across the country. While the Alaska Area has the lowest prevalence rate, data from IHS on the increase among adults from 1997 to 2002 show that Alaska has seen the greatest increase in this time period. Alarmingly, the disease increasingly affects American Indian and Alaska Native youth, threatening the health, well-being, and quality of life of future generations. IHS statistics show that in a 14-year period from 1990 to 2004, an increase of 128% was seen among 15–19 year-olds and a 77% increase was seen among American Indian and Alaska Native children and youth less than 15 years of age.

Special Diabetes Program for Indians

As part of the Balanced Budget Act of 1997, Congress established the Special Diabetes Program for Indians (SDPI) in recognition of the enormity of the diabetes epidemic among American Indians and Alaska Natives. Congress envisioned the Special Diabetes Program for Indians as a grant program that would provide funding for diabetes prevention and treatment services at IHS, tribal, and urban Indian health programs. Almost ten years since its inception, the Special Diabetes Program for Indians is now the most comprehensive, far-reaching diabetes program for American Indians and Alaska Natives, and serves as the foundation for diabetes prevention and treatment efforts for their communities across the U.S.

The Balanced Budget Act of 1997, provided \$30 million each year to the Indian Health Service over a five-year period (from FY 1998 to FY 2002) to establish grants for the "prevention and treatment" of diabetes in American Indian and Alaska Natives and stipulated a comprehensive evaluation of the program. Tribes and the IHS worked collaboratively to meet the legislative intent of the Special Diabetes Program for Indians through a process that included formal tribal consultation, developing funds distribution formulas, and establishing grant application and administrative procedures.

In the Consolidated Appropriations Act, 2001, Congress appropriated additional funding for the SDPI in addition to the initial \$30 million provided for the program. This appropriation included an additional \$70 million in FY 2001, \$70 million in FY 2002, and \$100 million in FY 2003, thereby extending the program and bringing the funding total to \$100 million each year for 2001-2003. Congress encouraged the IHS to implement a best practices approach, continue the ongoing diabetes prevention and treatment activities in tribal communities and to build upon partnerships with other organizations and lessons learned by the Indian special diabetes grant programs.

The SDPI reauthorization for \$150 million each year for FY 2004-2008, directed the IHS to expand the program and implement a competitive grant program for eligible entities for the implementation of specific interventions proven to prevent diabetes in people at risk for developing diabetes and reduce cardiovascular risk in people with diabetes, the most compelling complication of diabetes. Funds were also directed towards data improvement. In addition, distribution of funds to original SDPI grantees, now called the Community-Directed Diabetes Programs, for the prevention and treatment of diabetes continued.

IHS Diabetes Network

The IHS Division of Diabetes Treatment and Prevention (DDTP) provides leadership and programmatic administrative oversight to the SDPI grant program. The mission of DDTP is to develop, document, and sustain a public health effort to prevent and control diabetes in American Indians/Alaska Natives. This mission is accomplished by promoting collaborative strategies for the prevention of diabetes and its complications to over 1.9 million American Indians and Alaska Natives through an extensive American Indian and Alaska Native diabetes network. The network consists of a national program office; Area Diabetes Consultants in each of the 12 IHS Areas; 19 Model Diabetes programs in 23 different IHS and Tribal sites, and 333 non-competitive and 66 competitive local IHS, Tribal and Urban Indian SDPI grant programs. The 66 competitive SDPI grant programs, awarded in FY 2004, are comprised of 30 cardiovascular diseases (CVD) risk reduction demonstration projects and 36 diabetes prevention demonstration projects. This extensive diabetes network supports the SDPI grant programs by providing administrative support, training and technical assistance and the dissemination of the latest scientific findings and "best practices" to the programs. Now the most comprehensive rural system of care for diabetes in the U.S., the IHS combines both clinical and public health approaches to address the problem of diabetes and its complications.

Community-Directed Programs

Since 1998, the IHS has provided Special Diabetes Program for Indians funds to 333 IHS, tribal, and urban Indian health programs in 35 states to begin or enhance diabetes prevention and treatment programs. These grant programs make up the Community-Directed Diabetes Program. Each of the grant programs is unique in its diabetes prevention and treatment needs and local priorities. The Special Diabetes Program for Indians allows the grant programs to design and carry out interventions that will best address the problem of diabetes in their individual communities. The result has been the creation of programs that incorporate proven diabetes prevention and treatment strategies such as patient education, quality diabetes care services, and physical activity, nutrition, and weight loss activities in innovative, culturally appropriate diabetes program activities.

Targeted Demonstration Projects

In 2002, Congress extended the funding for the Special Diabetes Program for Indians through 2008 and added an additional \$50 million per year to the program (P.L.107-360) for its current total of \$150 million each year for 2004-2008.

The IHS set aside \$27.4 million of Special Diabetes Program for Indians funding per year from FY 2004 through FY 2008 for a new grant program, called the Special Diabetes Program for Indians "Demonstration Projects." Sixty-six selected grant programs were awarded grants for one of two programs within the Special Diabetes Program for Indians Demonstration Projects.

Diabetes Prevention Demonstration Project

The Diabetes Prevention Demonstration Project focuses on preventing diabetes in American Indians and Alaska Natives at risk for developing the disease. This project adapted, and is currently implementing, the curriculum from the National Institutes of Health (NIH) Diabetes Prevention Program (DPP). The results of this landmark clinical trial, published in 2002, demonstrated that individuals with pre-diabetes could prevent diabetes through lifestyle changes and, to a lesser extent, with a medication called metformin. The DPP included American Indians and thus the interventions were specifically tested on this population.

Many of the Special Diabetes Program for Indians grant programs were already working on diabetes prevention interventions prior to release of the NIH Diabetes Prevention Program study findings in 2002. The Special Diabetes Program for Indians Diabetes Prevention Demonstration Project funds provided the resources to build stronger diabetes prevention programs by translating the promising study findings through implementation of a common, structured diabetes prevention education program in 36 sites.

Healthy Heart Demonstration Project

The Healthy Heart Demonstration Project focuses on reducing the risk of cardiovascular disease in American Indians and Alaska Natives who already have diabetes. This program is currently implementing a clinical, team-based, case management approach to treat risk factors for cardiovascular disease. This approach is based on current models for chronic disease care and the latest cardiovascular disease prevention clinical guidelines.

Cardiovascular disease is the leading complication of diabetes, and the number one killer of American Indian and Alaska Native adults. The Strong Heart Study, an ongoing study of cardiovascular disease in 13 American Indian and Alaska Native communities, has demonstrated that diabetes is a major risk factor and accounts for the majority of risk for cardiovascular disease events in American Indians and Alaska Natives. The

incidence of cardiovascular disease in American Indians and Alaska Natives now exceeds rates in the general U.S. population. The funds for the Special Diabetes Program for Indians Healthy Heart Demonstration Project offer hope that American Indian and Alaska Native communities can reverse these troubling trends by implementing a more intensive, structured case management approach to addressing cardiovascular disease risk in American Indians and Alaska Natives with diabetes.

Evaluation

Pursuant to Public Law 105–33 as amended by P.L.107-260, the IHS conducted a comprehensive evaluation of the SDPI Community-Directed Diabetes Programs. These data have been presented in two interim reports to Congress. In 2000, the IHS submitted the first report, which included descriptions of the Community-Directed Diabetes Programs and their activities to date. The IHS presented a more extensive evaluation of the Community-Directed Diabetes Programs in the second report, which was published in 2004. The IHS used well-established public health evaluation methods to document the accomplishments of the Community-Directed Diabetes Programs.

During the first few years of the Special Diabetes Program for Indians, short-term outcomes included accomplishments related to developing the infrastructure needed to start and enhance diabetes prevention and treatment activities. For example, the Special Diabetes Program for Indians grant programs needed to hire staff, develop their programs, and offer diabetes prevention and treatment services such as foot care, physical activity, and diabetes education services.

As the grant programs gained expertise in diabetes care, the IHS Division of Diabetes obtained information on intermediate outcomes. Intermediate outcomes can be measured to determine if the grant programs' activities and services resulted in measurable changes such as increasing awareness of diabetes and reducing risk factors for diabetes and its complications.

Long-term outcomes, including whether the Special Diabetes Program for Indians results in reduced complications and death from diabetes, eventually, can be measured; however, the current trends in diabetes-related complications and deaths may take years to reverse given the magnitude of the diabetes epidemic in American Indian and Alaska Native communities. Therefore, planning for initial long-term outcome measurements has focused on ensuring that data systems are in place to measure trends over time.

Short-term Outcomes

Compared to their level of services prior to the funding (before 1998), the programs funded under the Special Diabetes Program for Indians achieved numerous improvements (short-term outcomes) in diabetes prevention and treatment services as

of FY 2002 and FY 2005 through increases in the following services:

- Availability of basic clinical exams, newer medications and therapies for diabetes treatment, laboratory tests to assess diabetes control and complications, screening for diabetes and pre-diabetes in a variety of locations, including screening for adults and elders and children and youth
- Use of key elements of quality diabetes care, Multidisciplinary diabetes team staffing, Availability of nutrition education services by Registered Dietitians and Public Health Nutritionists, Conduct of community diabetes needs assessments
- Partnerships between tribal leaders and tribal members on diabetes-related issues, Local community partnerships, Partnerships with outside organizations, Policies addressing diabetes prevention and care
- Availability of organized diabetes education programs and support services, Availability of culturally appropriate diabetes education materials and education approaches, A variety of diabetes education methods, Availability of continuing education opportunities for health care providers
- A variety of traditional approaches
- Funding of primary prevention activities, Diabetes awareness activities, Availability of physical fitness activities, Availability of community nutrition services, Collaborations with the U.S. Department of Agriculture to improve nutrition in communities, Diabetes primary prevention programs for children and youth, Screening and management of overweight and obesity among children and youth, Nutrition education programs for children and youth, Communitybased healthy eating programs for children, youth, and families, Physical activity programs for children and youth, Availability of breastfeeding promotion programs.

Intermediate and Long-term Outcomes

A variety of intermediate and long-term outcomes have also been achieved since implementation of the Special Diabetes Program for Indians, including improvements in the following:

- Control of blood glucose, blood pressure, total cholesterol, LDL cholesterol, and triglycerides
- Treatment of risk factors for cardiovascular disease, to prevent and delay the progression of diabetic kidney disease and to detect and treat diabetic eye disease
- Baseline Measures The IHS improved the accuracy of baseline long-term outcomes measures (prevalence and mortality) so that the ultimate successes and outcomes of the Special Diabetes Program for Indians can be measured accurately. The IHS established a Diabetes Data Warehouse using RPMS

(Resource and Patient Management System) data to measure accurately the long-term complications of diabetes.

Data from the IHS Diabetes Care and Outcomes Audit provide evidence of the Special Diabetes Program for Indians grant programs' success in implementing cost-effective and cost-saving screening and treatment activities for diabetes complications. Since the Special Diabetes Program for Indians began in 1998, the grant programs' activities have contributed to:

- Increasing the number of people with diabetes screened for kidney disease.
- Increasing the number of people with diabetes who are screened for diabetes eye and foot disease.
- Improving blood sugar control with population mean A1C levels decreasing from 8.9% to 7.9%.
- Decreasing population mean diastolic blood pressure by 2 mmHg from 78 to 76 mm Hg.
- Decreasing population mean cholesterol from 206 mg/dl to 192 mg/dl.
- Decreasing population mean triglyceride levels from 260 mg/dl to 230 mg/dl.

The Special Diabetes Program for Indians Demonstration Projects grant programs successfully began implementation of the rigorous Demonstration Project activities in FY 2006. The IHS is conducting a comprehensive evaluation of the program to answer questions on program effectiveness and outcomes based on solid, statistically accurate, and timely data. The final year of this five-year project will be dedicated to disseminating the project results and lessons learned throughout the Indian health system.

Costs of Diabetes

Diabetes costs the United States \$132 billion in 2002 in both direct and indirect costs. Yet numerous analyses have demonstrated the cost-effectiveness of delaying or preventing diabetes and its complications. The highest costs associated with diabetes are related to treating and managing its complications such as eye disease, foot disease, and kidney disease. Programs that effectively reduce and manage diabetes complications do, in fact, reduce costs associated with diabetes complications.

In the Diabetes Prevention Program, both the lifestyle intervention and medication intervention that resulted in preventing or delaying diabetes for at least three years were cost effective. Improving delivery of the intervention through a group setting at similar levels of effectiveness would further improve cost effectiveness. When applied to young people at risk (age 25 to 45 years), the intervention is actually cost saving.

The Centers for Disease Control and Prevention (CDC) Diabetes Cost-Effectiveness Study Group found that screening and early treatment of diabetes reduces the lifetime occurrence of kidney failure by 25%, blindness by 35%, and lower-extremity amputation by 22%. On average, diabetes is diagnosed 5.5 years earlier with screening programs that screen people for diabetes on routine medical care visits. Such screening programs have a greater benefit and are more cost-effective for younger people and minority populations than for the general population.

Many of the activities of the SDPI Community Directed Programs relate to diabetes prevention, early detection of diabetes and its complications as well as improved delivery of care, not only improve quality of life, but also represent an effective utilization of health care system resources. And, in many instances may likely result in cost savings. The new SDPI Demonstration Projects hold great promise to offer similar economically favorable outcomes. A defined economic analysis team is investigating the direct costs of the Demonstration Project interventions in American Indian and Alaska Native communities and this effort will contribute further to our knowledge of how investments in quality diabetes prevention and treatment affect economic costs associated with diabetes.

Summary

The Special Diabetes Program for Indians has brought Tribes together over these past 9 years, working toward a common purpose and sharing information and lessons learned along the way. The IHS has shown through its public health evaluation activities that these programs have been very successful in improving diabetes care and outcomes, as well as in launching primary prevention efforts, on reservations and in urban clinics. Our evaluation of the Special Diabetes Program for Indians and diabetes clinical measures suggests that population-level diabetes-related health is better among our American Indian/Alaska Native patients since the implementation of SDPI. The greatest benefit for American Indians and Alaska Natives with diabetes has likely been in the reduction in microvascular complications-eye, kidney and nerve diseases-due to improvement in long-term high blood sugar levels. Further reducing microvascular and macrovascular complications-atherosclerosis, coronary heart disease, stroke, and peripheral vascular disease-will require continued efforts to improve glucose, blood pressure and cholesterol values. However, the greatest long-term benefit will most likely be from the diabetes primary prevention activities now becoming commonplace in American Indian and Alaska Native communities. In its nine years, the Special Diabetes Program for Indians has demonstrated the positive public health impact that is possible when tribal and Congressional initiatives are focused on a common outcome.

The IHS has demonstrated, through the SDPI, its ability to design, manage, and measure a complex, long-term project to address a chronic disease in partnership with Tribes and other Indian organizations as well as collaborative involvement of other federal agencies and private organizations in a successful manner. What's more, IHS has shown that it can successfully work with tribal partners to help them progress from whatever their starting position—be it a fully functioning clinical diabetes program, a rudimentary community program, or no program at all—along a continuum of diabetes excellence so that all improve in some way. Significant infrastructure has been established where there was none. Basic programs have become centers of

excellence. Innovation has become commonplace in these programs, and the sense of "tribal ownership" is now entrenched. And positive signs such as a decrease in incidence of diabetes-related End Stage Renal Disease among American Indians in the Southwest are starting to be seen.

Mr. Chairman, that concludes my prepared remarks and I would be pleased to answer any questions you or other members of the Committee may have.