

African Americans and Diabetes

Diabetes Mellitus is one of the most challenging health conditions facing 30 million African Americans. It is the 5th leading cause of death in African Americans between the ages of 45-64 and is the third leading cause of death in African American women of all ages in 1990. In 1993 1.3 million African Americans were known to have diabetes 3 times the number diagnosed in 1963.

STATISTICS (1993)

- for every white person who gets Diabetes 1.6 African Americans get Diabetes
- One in 4 black Women 55years and older has diabetes.
- 25% of blacks between 74-65 has diabetes.
- Afr. Amer. Are more likely to develop complications and disability from Diabetes.
- At age 45 or older the prevalence of Diabetes is 1.4 to 2.3 times as frequent as in whites.
- In the 65-74 age range 17.4 percent of black Americans had diagnosed diabetes compared to 9.5% of white Americans
- African American children have lower rates of Type 1
- African Americans 40 years of age and older have Type 2 or non-insulin-dependent Diabetes.

Diabetes and Pregnant African American Women

- Afri. Amer women have a 80percent higher gestational diabetes rate than white women
- These women are 2 times more likely to develop diabetes in future pregnancies and type 2 diabetes in 20 years.

Complications

- Afri. Amer develop a higher rate of blindness, kidney failure, and amputations from diabetes in comparison to white Americans

Kidney failure

- 2.5 -5.5 times more often than whites

Visual Impairment

- 40 percent higher in African Americans than whites

Amputations (1991 study)

- 19 percent higher than whites

CONCLUSION:

Approximately 1.3 million African Americans have been diagnosed with Diabetes in the United States. They are more likely to suffer from diabetic related kidney failure, visual impariment, and amputations than there white counterparts. Pregnant African American women have a 80% higher gestational diabetes rate than white women. For these reasons we must incease diabetes funding.

Diabetes in North American Indians and Alaska Natives

Dorothy Gohdes, MD

SUMMARY

The epidemic of non-insulin-dependent diabetes mellitus (NIDDM) in Native American communities has occurred primarily during the second half of this century. Although NIDDM has a genetic component, with rates highest in full-blooded Native Americans, the incidence and prevalence of the disease have increased dramatically as traditional lifestyles have been abandoned in favor of westernization, with accompanying increases in body weight and diminished physical activity. Anthropologic studies have shown that several tribes perceive diabetes as an assault from outside the community. Diabetes was once described as benign in American Indians; now, diabetes and its complications are major contributors to morbidity and mortality in all Native American populations, except the isolated Arctic groups whose lifestyles remain relatively unchanged. Insulin-dependent diabetes mellitus (IDDM) is rare in Native Americans and most cases of

IDDM are found in individuals with significant non-Native American ancestry.

Much of our understanding of the natural history of NIDDM in North American Indians is derived from the longitudinal epidemiologic studies of the Pima Indians in southern Arizona. The relationship of obesity to subsequent diabetes as described in studies of the Pimas is present in all Native American populations. Native American communities experience high rates of microvascular complications from diabetes, although the rates of cardiovascular disease differ from tribe to tribe. The differences may reflect genetically based variations in lipid metabolism or other coronary risk factors or, alternatively, differences in lifestyle. The extent of diabetes in Native American communities today demands public health programs that incorporate specific psychosocial and cultural adaptations for individual tribes.

INTRODUCTION

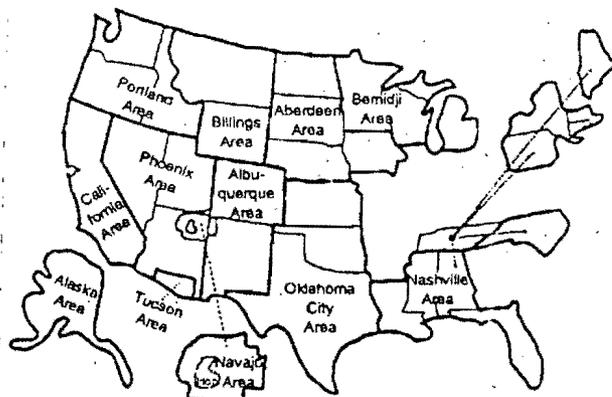
Native Americans are a diverse group of people whose ancestors lived in North America before the European settlement. In the United States alone, there are more than 500 tribal organizations. In addition to their tribal affiliations, Native Americans are often distinguished by language and/or cultural groups, some of which extend across both the United States and Canada. Contemporary Native American populations live in urban areas and on reservations or reserves in both countries. In the United States, 1.9 million individuals identified themselves in the 1990 Census as American Indian or Alaska Native, but only 1.2 million of these resided in the 33 reservation states served by the Indian Health Service (IHS), an agency of the U.S. Public Health Service.^{1,2} Few data exist on the health of urban Native Americans in either the United States or Canada. Overall, the Native American populations

of North America are young, with a median age in 1990 of 26 years, compared with 33 years for all races in the United States. In addition, Native Americans are disadvantaged both economically and educationally compared with the general U.S. population.

PREVALENCE

Because American Indians living on reservations are not included in U.S. national health surveys, data on the prevalence of diabetes in Native Americans residing in the United States are limited. Rates have been estimated from case registries maintained at health facilities, glucose testing at a community level, and surveys of self-reported diabetes. In the United States and Canada, prevalence estimates for diagnosed diabetes are available from health care facilities where care is provided at no charge to Native Americans. The IHS estimated the rates of diagnosed diabetes from

Figure 34.1
Indian Health Service Areas



Source: Indian Health Service

ambulatory care visits that covered 86% of the estimated 1 million American Indians served through the IHS in 1987³. Duplicate records were excluded by using unique patient identifiers. Rates were calculated for the regions shown in Figure 34.1. A similar estimate covering 76% of the Inuit and Canadian Natives living on reserves was also undertaken in 1987, using cases known to the Medical Services Branch of the Department of National Health and Welfare in Canada⁴. Crude and age-adjusted rates of diabetes from these two surveys are shown in Table 34.1^{3,4}. The rates decreased toward the north and west in Canada. Although a similar trend was not apparent in the United States, rates in the far northwest were relatively low in both countries. Rates of diabetes were higher in women than in men in all Canadian provinces, a trend also found for the United States in current diabetes estimates by the IHS. Women had higher rates of diabetes (13.2%) than men (11.0%) in a special medical expenditure survey of American Indians eligible for IHS services conducted in 1987⁵. In the survey, the age- and sex-adjusted diabetes rate in individuals age ≥ 19 years was 12.2%, compared with 5.2% in the general U.S. population. A summary of published studies⁶⁻²⁴ of diabetes prevalence in individual tribes in North America is presented in Table 34.2. These studies used criteria of the World Health Organization (WHO) and the U.S. National Diabetes Data Group (NDDG) for diagnosis of NIDDM^{25,26}.

Striking increases in the prevalence of diabetes in recent years have been described in Pima Indians and other tribes^{11,22,27-29}. Because the incidence of diabetes has also increased in Pimas, and presumably in other tribes, the increased prevalence in many tribes is prob-

Table 34.1
Diagnosed Diabetes in Native American Communities in the U.S. and Canada, All Ages, 1987

	Crude prevalence per 1,000	Age-adjusted prevalence per 1,000
United States		
Tucson	76	119
Aberdeen	60	105
Phoenix	65	104
Albuquerque	55	94
Bemidji	53	92
Nashville	63	87
Billings	50	86
Oklahoma	49	60
Navajo	32	56
Portland	29	49
Alaska	9	15
All IHS	45	69
Canada		
Atlantic	43	87
Quebec	29	48
Ontario	46	76
Manitoba	28	57
Saskatchewan	17	39
Alberta	22	51
Yukon	7	12
NW Terr. Indian	5	8
NW Terr. Inuit	3	4
British Columbia	9	16

U.S. rates are age-adjusted to the 1980 U.S. population; Canada's rates are age-adjusted to the 1985 Canadian population.

Source: References 3 and 4

ably due to an increased incidence and cannot be attributed solely to longer survival of diabetic individuals²⁷. Figure 34.2 shows the prevalence of diabetes in Pima Indians in each of three time periods since 1965²⁷. Appendix 34.1 compares prevalence of diabetes in Pima Indian men and women with prevalence of NIDDM in a sample of U.S. white men and women.

DETERMINANTS OF DIABETES

The longitudinal studies of diabetes conducted in Pima Indians since 1965 have provided extensive information about NIDDM and its natural history in American Indians. The form of diabetes that affects Pimas is characterized biochemically and immunologically as NIDDM, an observation that confirms the paucity of IDDM also noted in other tribes^{27,30}.

Table 34.2
Prevalence

Reservati

Southwest
Tohono

Gila Riv

New Me

Zuni, N

Jicarilla

Mescal

Navajo

Arizon

reserv

Navajo

Navajo

Navajo

Rocky M

Fort I

Nez P

Black

Crow

Fort

Fort

No

Wa

Ut

Nor

C

C

F

F

Table 34.2

Prevalence of Diabetes in North America Native Populations by Region

Reservation/Location	Tribe	Age	Date	Rate/1,000	Adjustment	Method	Reference
<i>Southwest</i>							
Tohono O'odham, AZ	Tohono O'odham	≥18	1985-86	183	None	Case registry w/record review	6
Gila River, AZ	Pima	30-64	1982-87	500	Age World pop.	Biennial community screening	7
New Mexico	Pueblo (Rio Grande)	≥35	1985	213	None	Case registry w/record review	8
Zuni, NM	Zuni	≥35	1985	282	None	Case registry w/record review	8
Jicarilla Apache, NM	Apache	≥35	1985	98	None	Case registry w/record review	8
Mescalero Apache, NM	Apache	≥35	1985	164	None	Case registry w/record review	8
Navajo, NM	Navajo	≥35	1985	165	None	Case registry w/record review	8
Arizona and New Mexico reservations	Apache	≥15	1987	101	Age U.S. 1980	Outpatient records not verified	9
Navajo, AZ and NM	Navajo	≥15	1987	72	Age U.S. 1980	Outpatient records not verified	9
Navajo, AZ	Navajo	20-74	1989	165	Age/sex U.S. 1980	Case registry community screening	10
Navajo, AZ	Navajo	≥20	1988	124	Age U.S. 1980	Community sample w/screening	11
<i>Rocky Mountain West</i>							
Fort Hall, ID	Shoshone/Bannock	All	1987	95	Age/sex U.S. 1980	Case registry w/chart review	12
Nez Perce, ID	Nez Perce	All	1987	105	Age/sex U.S. 1980	Case registry w/chart review	12
Blackfeet, MT	Blackfeet	≥15	1986	168	Age ≥15 U.S. 1980	Case registry w/chart review	13
Crow, MT	Crow	≥15	1986	85	Age ≥15 U.S. 1980	Case registry w/chart review	13
Fort Belknap, MT	Assiniboine/ Gros Ventre	≥15	1986	118	Age ≥15 U.S. 1980	Case registry w/chart review	13
Fort Peck, MT	Assiniboine/Sioux	≥15	1986	173	Age ≥15 U.S. 1980	Case registry w/chart review	13
Northern Cheyenne, MT	Northern Cheyenne	≥15	1986	59	Age ≥15 U.S. 1980	Case registry w/chart review	13
Wind River, WY	Shoshone/Arapaho	≥15	1986	125	Age ≥15 U.S. 1980	Case registry w/chart review	13
Utah and Colorado	Ute	≥15	1987	124	Age U.S. 1980	Outpatient records not verified	9
<i>Northern Plains</i>							
Cheyenne River, SD	Sioux	All	1987	106	Age U.S. 1980	Outpatient records not verified	14
Crow Creek, Lower Brule, SD	Sioux	All	1987	83	Age U.S. 1980	Outpatient records not verified	14
Devil's Lake, ND	Sioux	All	1987	111	Age U.S. 1980	Outpatient records not verified	14
Pine Ridge, SD	Sioux	All	1987	70	Age U.S. 1980	Outpatient records not verified	14
Rosebud, SD	Sioux	All	1987	82	Age U.S. 1980	Outpatient records not verified	14
Sisseton/Wahpeton, SD	Sioux	All	1987	64	Age U.S. 1980	Outpatient records not verified	14
Turtle Mountain, ND	Chippewa	All	1987	105	Age U.S. 1980	Outpatient records not verified	14
Standing Rock, ND/SD	Sioux	All	1987	125	Age U.S. 1980	Outpatient records not verified	14

Table 34.2—Continued next page

Table 34.2—Continued

Reservation/Location	Tribe	Age	Date	Rate/1,000	Adjustment	Method	Reference
Yankton/Santee, SD	Sioux	All	1987	196	Age U.S. 1980	Outpatient records not verified	14
Winnebago/Omaha, NE	Winnebago/Omaha	All	1987	218	Age U.S. 1980	Outpatient records not verified	14
North and South Dakota reservations	Sioux	≥15	1987	117	Age U.S. 1980	Outpatient records not verified	9
Upper Midwest							
Red Lake, MN	Chippewa	All	1987	148	Age/sex U.S. 1980	Case registry verified/screening	15
MN and ND—Chippewa reservations combined	Chippewa	≥15	1987	144	Age U.S. 1980	Outpatient visits not verified	9
Ontario and Manitoba, Canada	Cree/Ojibwa	All	1983	28	None	Case registry w/chart review	16
SW Ontario, Canada	Oncida/Chippewa	≥5	1985	147	Age Canada 1985	Case registry w/chart review	17
Northeast							
St. Regis, NY	Mohawk	All	1989	49	Age U.S. 1980	Case registry w/chart review	18
River Desert/Lac Simon, Quebec, Canada	Algonquin	≥15	1989	150	None	Community survey	19
Nova Scotia, Canada	Micmac	All	1989	53	None	Case registry	20
South							
Choctaw, MS	Choctaw	All	1989	163	Age U.S. 1980	Case registry w/chart review	21
Cherokee, NC	Cherokee	All	1988	106	Age U.S. 1980	Case registry	22
Pacific Northwest							
Lummi, WA	Lummi	All	1987	40	Age/sex U.S. 1980	Case registry w/chart review	12
Tahola, WA	Quinalt	All	1987	50	Age/sex U.S. 1980	Case registry w/chart review	12
Makah, WA	Makah	All	1987	53	Age/sex U.S. 1980	Case registry w/chart review	12
Colville, WA	Colville	All	1987	52	Age/sex U.S. 1980	Case registry w/chart review	12
Spokane, WA	Spokane	All	1987	56	Age/sex U.S. 1980	Case registry w/chart review	12
Yakima, WA	Yakima	All	1987	75	Age/sex U.S. 1980	Case registry w/chart review	12
Umatilla, OR	Umatilla	All	1987	65	Age/sex U.S. 1980	Case registry w/chart review	12
Warm Springs, OR	Warm Springs	All	1987	75	Age/sex U.S. 1980	Case registry w/chart review	12
Far North							
Alaska	All native	All	1987	17	Age U.S. 1980	Case registry w/chart review	23
Alaska	Eskimo	All	1987	10	Age U.S. 1980	Registry verified w/chart audit	23
Alaska	Indian	All	1987	24	Age U.S. 1980	Case registry w/chart review	23
Alaska	Aleut	All	1987	29	Age U.S. 1980	Case registry w/chart review	23
Yukon Indian	Indian	All	1987	9	Age World pop.	Case registry not verified	24
NW Territories Indian	Indian	All	1987	7	Age World pop.	Case registry not verified	24
NW Territories Inuit	Inuit	All	1987	4	Age World pop.	Case registry not verified	24

Source: References are listed within the table

Fig
Pre

Prevalence (percent)

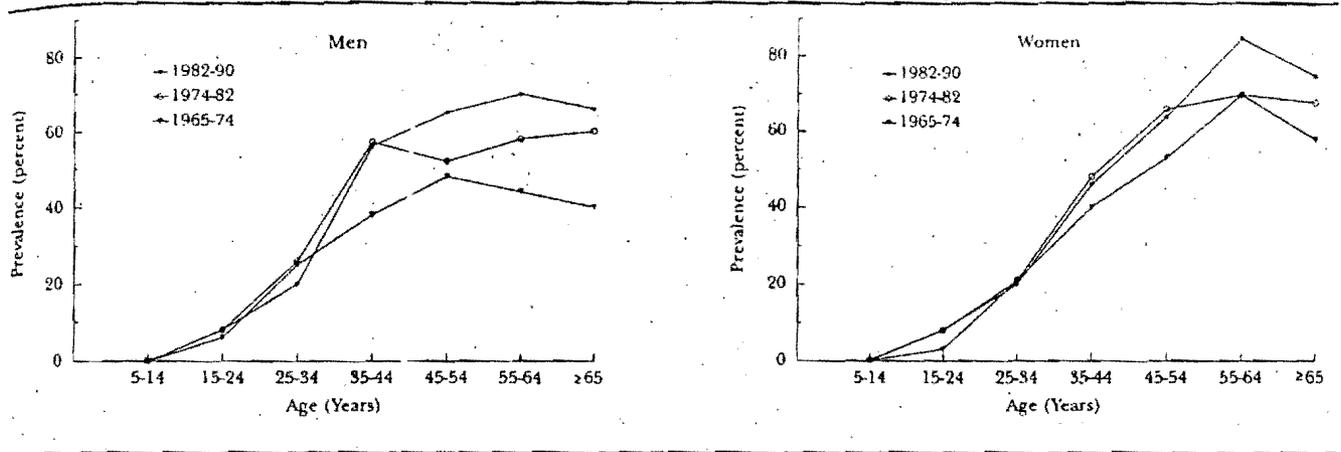
Sour

GE

Dia
Am
196
len
is h
tag
est
ope
is
sup
dis
ge
ple
maF
P
E

Figure 34.2

Prevalence of Diabetes in Pima Indians, by Age, Sex, and Time Period



Source: Reference 27

GENETICS

Diabetes rates are highest in full-blooded Native Americans, as first observed in Choctaw Indians in 1965 and subsequently in other tribes³¹⁻³³. The prevalence of diabetes in residents of the Pima community is highest in individuals of full Native American heritage (Figure 34.3)³³. In Pimas, diabetes rates are highest in the offspring of parents who themselves developed diabetes at a young age (Figure 34.4)³⁴. Diabetes is also familial in Oklahoma Indians, an observation suggesting that genetics and/or family lifestyles predispose individuals to NIDDM³⁵. Although the precise genetic components of NIDDM have not been completely described in American Indians, a genetic marker linked with insulin resistance, a major factor

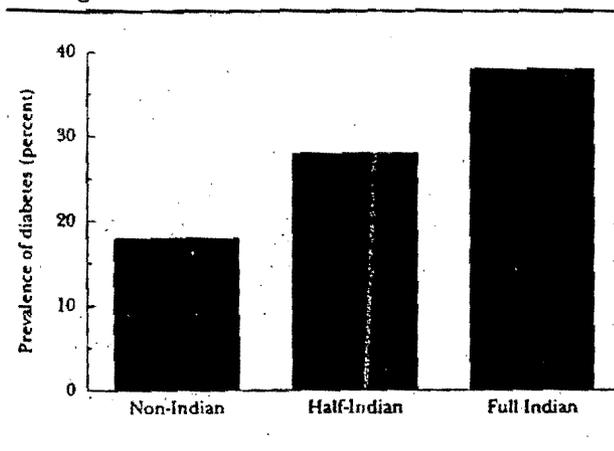
in the pathogenesis of NIDDM, has been described in Pimas³⁶.

OBESITY

Obesity is a major risk factor for diabetes in Pimas and is widespread in many tribes, with increasing rates of obesity measured in several communities in the United States and Canada^{11,37-41}. The interaction of obesity with genetic susceptibility to diabetes as measured by parental diabetes is shown in Figure 34.5 for Pimas⁴². A striking increase in obesity has occurred in Pimas in recent years (Figure 34.6)^{27,43}. In addition,

Figure 34.3

Prevalence of NIDDM in Pima Indians, by Indian Heritage

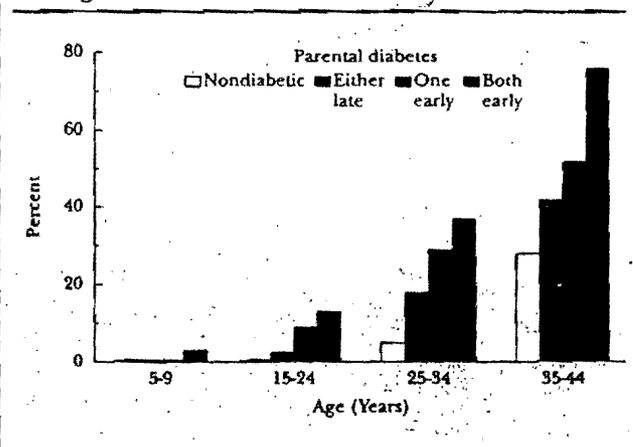


Data are age- and sex-adjusted.

Source: Reference 33

Figure 34.4

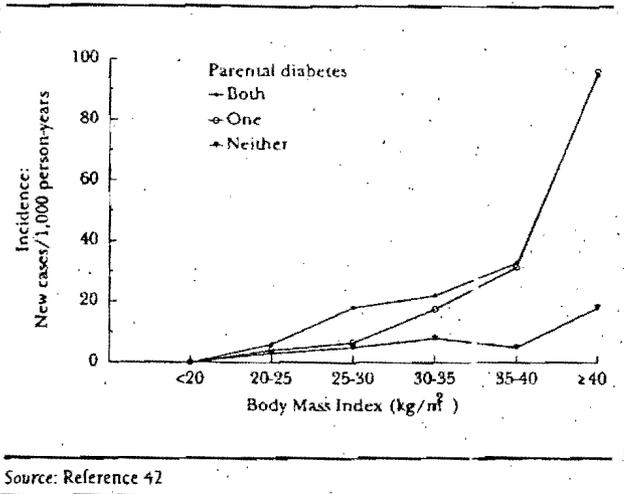
Prevalence of Diabetes in Pima Indians, by Presence and Age at Onset of Diabetes in the Parents



Persons for whom both parents had been examined were grouped into four groups according to parental diabetes: both early, one early, either late, or nondiabetic according to whether the parents had diabetes and whether the parental diabetes was diagnosed before or after age 45 years.

Source: Reference 34

Figure 34.5
Incidence of NIDDM in Offspring of Pima Indians
by Body Mass Index and Parental Diabetes



Source: Reference 42

longer duration of obesity has been shown to increase the risk of diabetes⁴⁴.

Central obesity was characteristic of Canadian Indians studied in Manitoba and Ontario⁴⁰. In young Pimas, waist-to-hip ratio, a measure of central obesity, was more strongly associated with diabetes³⁸ than body mass index, a measure of overall obesity³⁸. In Navajo women, a small study found an increased waist-to-hip ratio associated with a statistically significant increased risk of diabetes, but a similar association was not significant in Navajo men⁴⁵. Appendix 34.2 shows data on obesity and other metabolic variables in Native American groups included in the Strong Heart Study.

LIFESTYLE

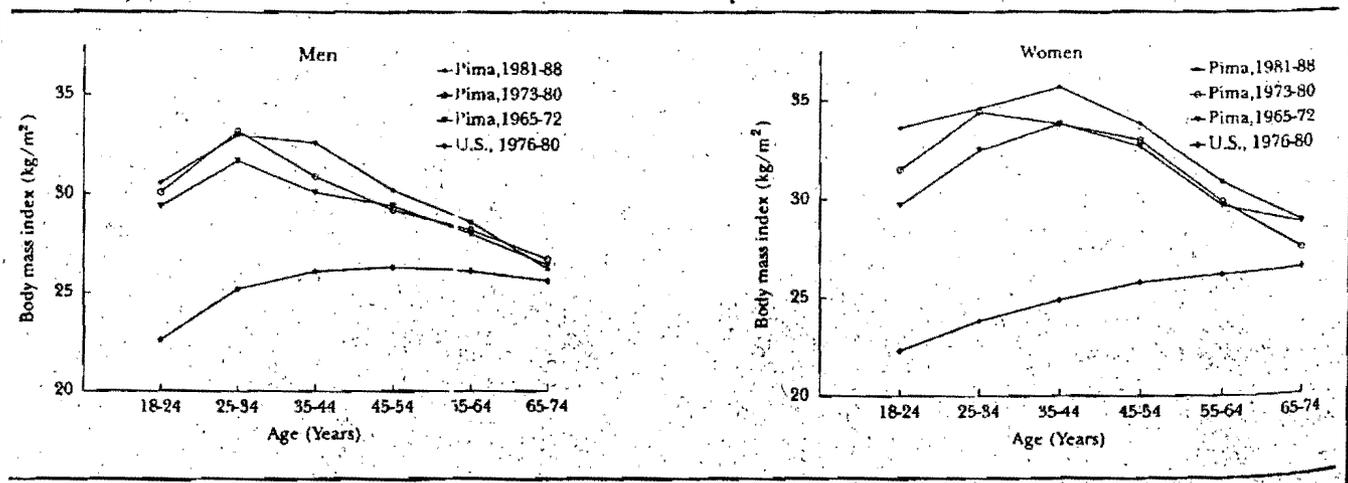
Both diet patterns and physical activity have changed markedly in Native American communities over recent decades. Although detailed longitudinal surveys are not available for most tribes, the disruption of traditional agriculture and hunting has resulted in increased consumption of fat—typical of the contemporary western diet. In Pimas, a high-calorie diet has been associated with the development of diabetes²⁷. Carbohydrate intake was the single strongest predictor of NIDDM but was closely related to total calorie and fat consumption.

Physical activity has decreased as individuals have acquired motorized transportation and sedentary occupations. Diabetic Pimas reported less lifetime and current physical activity than nondiabetic individuals⁴⁶. A recent case-control study in Zuni Indians showed the risk of presenting with diabetes decreased significantly with increasing physical activity, even after adjusting for obesity, suggesting that physical activity itself decreased the risk of NIDDM independently of body weight⁴⁷.

PATHOGENESIS

Studies of the pathogenesis of NIDDM in Pimas indicate that insulin resistance, as measured by nonoxidative glucose disposal, is an early metabolic defect⁴⁸. Longitudinal studies have found that insulin secretion and insulin resistance increase as individuals develop impaired glucose tolerance⁴⁹. Insulin levels then fall as frank NIDDM develops, often at a relatively young age^{50,51}.

Figure 34.6
Mean Body Mass Index in Pima Indians and the U.S. White Population



Data for U.S. whites are from the Second National Health and Nutrition Examination Survey.

Source: References 27 and 43

Energy
an at
the c
studi
famil
subs
have
sity
the c
to m
are a
labo
our
NID
Pim
chan
limit
india
tion

The
strial
stat
dea
Am
the
onl
of
cau
dea
she
1,2
a c
dia
the
Na
cer
tal
th
tir
At
de
M
cr
it
in
ti
ti
E
E

Energy metabolism and obesity have been studied in an attempt to characterize a "thrifty gene"⁵². Although the exact causes of obesity have not been explained, studies in Pimas have found energy expenditure to be familial and a low metabolic rate to be predictive of subsequent weight gain. Detailed metabolic studies have not been conducted in other tribes, but a propensity to obesity and NIDDM is widespread, as has been the change from traditional high-carbohydrate diets to modern high-fat diets. Contemporary high-fat diets are associated with deterioration of carbohydrate metabolism in both Pimas and Caucasians⁵³. Although our understanding of the current "epidemic" of NIDDM in Native Americans is based on studies of Pimas, the interaction between environmental changes and genetic susceptibility to NIDDM is not limited to Pimas but appears to be widespread in all indigenous North Americans, as well as other populations throughout the world.

MORTALITY

The mortality from diabetes in Native Americans is striking, yet it is seriously underestimated in U.S. vital statistics data. The figures published for diabetes death rates in 1986-88 showed the age-adjusted American Indian death rate was 2.7 times the rate for the general U.S. population². These figures reflect only cases in which diabetes was the underlying cause of death, not those in which it was a contributing cause or those in which diabetes was not listed on the death certificate. Mortality rates by IHS Area are shown in Table 34.3. During 1984-86, there were 1,252 Native American deaths with diabetes listed as a contributing cause of death and 708 deaths with diabetes listed as the underlying cause⁵⁴. In addition, the National Mortality Followback Study found that Native American heritage was underreported on death certificates by 65%⁵⁴. When the 1986-88 relative mortality rates are adjusted for underreporting of heritage, the diabetes mortality for Native Americans is 4.3 times the rate for whites. In a New Mexico study, American Indians experienced 3.6 times the diabetes death rates of whites⁵⁵. Over a 30-year period in New Mexico, diabetes death rates in American Indians increased 550% in women and 249% in men. A mortality study on Canadian Indian reserves in seven provinces found the risk of death from diabetes to be 2.2 times higher for native men and 4.1 times higher for native women than the rates for the Canadian population as a whole⁵⁶.

Detailed mortality studies in Pimas during 1975-84 found that the age- and sex-adjusted death rate from

Table 34.3
Age-Adjusted Mortality Rates for Deaths Due to Diabetes, American Indian and Alaska Native Population, 1984-89

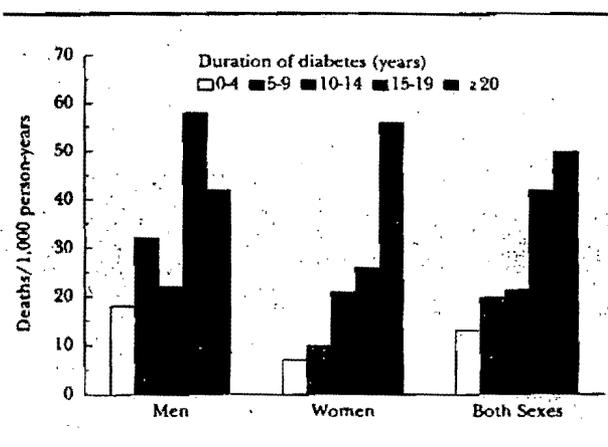
IHS Service Area	Rate per 100,000 population			
	1984-86	1985-87	1986-88	1987-89
Total	24.5	25.2	26.2	29.1
Aberdeen	44.7	41.3	35.6	50.1
Alaska	5.7	5.9	5.8	7.6
Albuquerque	25.0	32.4	33.1	32.8
Bemidji	32.9	29.4	28.6	39.0
Billings	24.8	27.8	23.6	40.1
California	10.4	15.2	15.5	15.3
Nashville	30.5	30.4	39.5	45.0
Navajo	21.2	23.8	23.6	27.4
Oklahoma	21.3	20.1	20.6	21.1
Phoenix	54.0	51.4	53.9	53.2
Portland	15.5	18.3	24.2	25.4
Tucson	52.9	59.0	69.6	68.1

Data are for populations residing in the IHS service areas and are age-adjusted to the 1940 U.S. Census; Alaska rates are based on <20 deaths.

Source: Indian Health Service Program statistics

diabetes was 11.9 times greater than the 1980 death rate for all races in the United States⁵⁷. Diabetic nephropathy was the leading cause of death in diabetic Pimas, followed by ischemic heart disease⁵⁸. Longer duration of diabetes (Figure 34.7)⁵⁸ and proteinuria⁵⁹ were both associated with increased mortality. A 10-year followup of a cohort of diabetic Oklahoma Indians also showed striking death rates: 5% annually for men and 4% for women, which were three and four times the rates expected for men and women in the general Oklahoma population⁶⁰. Circulatory disease

Figure 34.7
Age-Adjusted Mortality of Pima Indians by Duration of Diabetes



Data are for deaths due to natural causes in diabetic individuals age ≥35 years.

Source: Reference 58

causes of death in this cohort exceeded those attributed to diabetes as the underlying cause. Although the contributions of diabetic renal disease and atherosclerotic heart disease to overall diabetes-related mortality vary among tribes, both clearly contribute to the very significant mortality from diabetes in North American Indian communities.

COMPLICATIONS

DIABETIC NEPHROPATHY

End-stage renal disease (ESRD) registries in the United States and Canada have documented that Native American populations are at high risk for entering treatment for kidney failure. During 1981-86, ESRD rates in Canadian Natives were 2.5 to 4 times the national rates, depending on the assumptions used to determine the native population⁶¹. One-fourth of the ESRD cases were attributed to diabetes. In the United States, the age-adjusted ESRD incidence for Native Americans during 1983-86 was 2.8 times the rate for whites, with 55% of Native American cases attributed to diabetes⁶². In 1987-90, the diabetic ESRD incidence for Native Americans was six times higher than the white rate (Figure 34.8)⁶³. Reports from individual tribes confirm that high rates of diabetic renal failure occur in many tribes, including the Navajo, Cherokee, Alaska Native, Sioux, Pima, Zuni, Chippewa, and Oklahoma tribes^{14,15,23,64-68}. In Pimas, diabetic nephropathy surpassed ischemic heart disease as the leading cause of nontraumatic death during 1975-84⁵⁸.

The natural history of diabetic kidney disease in Pimas has been well defined⁶⁹. Both overt diabetic nephropathy and ESRD increase as the duration of diabetes increases⁷⁰. High blood pressure and hyperglycemia predict the development of overt nephropathy. Similarly, fasting blood glucose and hypertension were found to be significant risk factors for the development of renal failure in Oklahoma Indians⁶⁸. Diabetic offspring who have at least one parent with diabetes and proteinuria are at greater risk to develop nephropathy than diabetic offspring whose parents do not have proteinuria⁷¹. Studies of glomerular function in Pimas also showed that individuals with recent-onset NIDDM had higher glomerular filtration rates than nondiabetic Pimas⁷². Both clinical and epidemiologic studies have suggested that the natural history of diabetic nephropathy in Pimas is similar to diabetic nephropathy in individuals with IDDM (Figure 34.9)^{66,73}.

Diabetic retinopathy has been reported in many tribes^{13,15,22,74-76}. Detailed studies of the incidence and risk factors for retinopathy have been reported for the Pima and several tribes of Oklahoma Indians⁷⁷⁻⁸³. Rates of retinopathy and risk factors are summarized in Table 34.4. An association of insulin therapy with diabetic retinopathy similar to that found in U.S. studies has also been found in Native Americans in Canada⁸⁴.

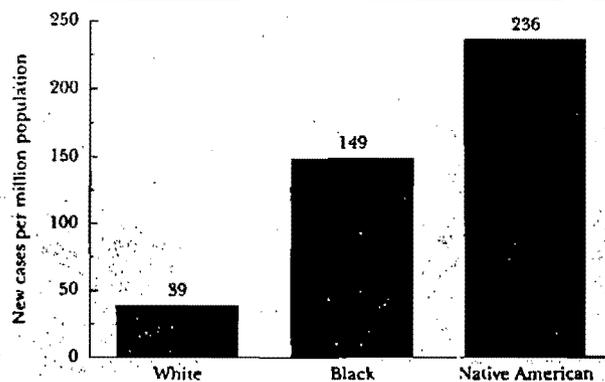
DIABETIC RETINOPATHY

Diabetic retinopathy has been reported in many tribes^{13,15,22,74-76}. Detailed studies of the incidence and risk factors for retinopathy have been reported for the Pima and several tribes of Oklahoma Indians⁷⁷⁻⁸³. Rates of retinopathy and risk factors are summarized in Table 34.4. An association of insulin therapy with diabetic retinopathy similar to that found in U.S. studies has also been found in Native Americans in Canada⁸⁴.

LOWER EXTREMITY AMPUTATION

Lower extremity amputation (LEA) rates are unfortunately high in many tribes, although the rates in small

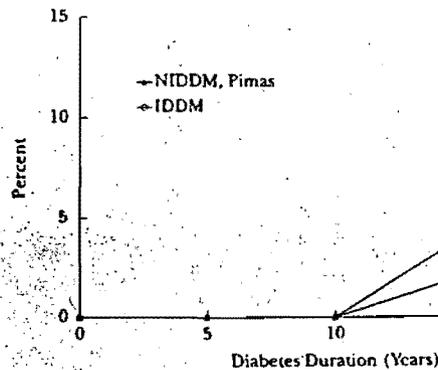
Figure 34.8
U.S. Incidence of Diabetic ESRD, 1987-90



ESRD, end-stage renal disease.

Source: Reference 63

Figure 34.9
Cumulative Incidence of Diabetic ESRD in Pima Indians with NIDDM and in Individuals with IDDM



ESRD, end-stage renal disease.

Source: References 66 and 73

Table 34.4

Diabetic Retinopathy in American Indians

Ref.	Group	Retinopathy (%)	Risk factors
<i>Retinopathy Prevalence</i>			
79	Oklahoma	24.4	Hyperglycemia
75	Oklahoma	49.3	Hypertension
80,82	Pima	18	Duration of diabetes Insulin therapy
<i>Retinopathy Incidence</i>			
81	Oklahoma	72.3	
<i>Proliferative Retinopathy Incidence</i>			
83	Oklahoma (mean 12.7 years followup)	18.5	Hyperglycemia Duration of diabetes Cholesterol Systolic blood pressure Insulin therapy
82	Pima (after 20 years followup)	14	Young age at diagnosis Duration of diabetes Background retinopathy Hypertension Proteinuria Renal insufficiency Neuropathy Cholesterol Insulin therapy

Source: References are listed within the table

studies vary among reservations^{13-15,22,23}. During 1982-87, Navajos experienced hospital discharge rates of 74 per 10,000 for LEA, compared with 240 per 10,000 for the Indians of southern Arizona⁸⁵. Ten percent of identified diabetic patients in southern Arizona had a recorded history of LEA on their medical records in 1985-86⁶. Several studies have reported higher LEA rates in males than in females^{6,76,85-87}. Duration of diabetes has been reported as a significant risk factor for LEA in several tribes^{86,87}. Prospective data on risk of foot ulceration and LEA in Chippewa Indians showed 9.9 times higher foot ulceration rates and 17 times higher amputation rates in diabetic patients without protective sensation, compared with patients who retained the ability to perceive the 5.07 Semmes-Weinstein monofilament⁸⁸. Of 358 diabetic individuals, 7.7% had severe peripheral neuropathy as evidenced by lack of sensitivity to the 5.07 monofilament.

Rates of first LEA in retrospective studies were 13.7 per 1,000 diabetic person-years in Pima Indians (1972-84) and 18 per 1,000 in Oklahoma Indians (1972-80)^{86,87}. Hyperglycemia, retinopathy, nephropathy, and signs of neuropathy including medial artery calcification were predictive risk factors for LEA in Pimas⁸⁶. Although amputation rates in Pimas increased with age, the effect of age was not significant after controlling for duration of diabetes. Similar

risk factors were reported for first LEA in Oklahoma Indians, although no indicators of neuropathy were reported⁸⁷. Five-year survival after amputation was 40% in Oklahoma Indians and 61% in Pimas^{86,87}. Hypertension was a significant risk factor in the Oklahoma tribes but not in the Pima. These variations suggest that peripheral vascular disease and neuropathy may differ significantly among tribes in their contribution to LEA.

PERIODONTAL DISEASE

Periodontal disease rates in Pima Indians were 2.6 times higher in diabetic patients than in nondiabetic individuals⁸⁹. Destructive periodontal disease was also more severe in diabetic individuals⁹⁰. The frequency of edentulousness increased markedly with diabetes duration⁹¹. At 20 years duration, 75% of diabetic Pimas were edentulous. The presence of retinopathy and poor glycemic control were associated with an increased risk of periodontal disease.

INFECTIONS

Although the pathogenesis of infections as complications of diabetes is not simple, it is clear that infections are of particular importance in Native Americans. Tuberculosis mortality in American Indians in 1987 was 5.8 times higher than the rate for all races in the United States². A case-control study in Sioux Indians showed that diabetic individuals were 4.4 times more likely to develop tuberculosis than nondiabetic individuals⁹². Mortality from infectious diseases in Pimas is significant⁵⁷. Although overall infectious disease mortality rates did not differ between diabetic and nondiabetic Pimas during 1975-84, the number of deaths studied was small⁵⁸. Five of the six deaths from coccidioidomycosis, a disease endemic in the Southwest, occurred in diabetic patients. Similarly, 81% of the 26 cases of necrotizing fasciitis, a rare but severe soft-tissue infection, reported from the Phoenix Indian Medical Center during a 9-year period occurred in diabetic patients⁹³. Thus, infections associated with diabetes in Native Americans are of particular concern. Unfortunately, detailed epidemiologic data on the particular associations are lacking for most tribes.

GALLBLADDER DISEASE

Gallbladder disease and diabetes have been linked together in Native Americans as part of a "New World syndrome" with both a genetic and evolutionary basis⁹⁴. In an analysis of gallbladder disease in Pimas

during a 20-year period, no excess risk of death was found in diabetic individuals with gallstones compared with individuals with normal glucose tolerance and gallstones⁹⁵. However, Pimas with gallstones experienced both increased mortality from gallbladder cancer and total mortality from other causes. Overall cancer mortality, however, was not significantly different between diabetic and nondiabetic Pimas⁵⁸.

CATARACTS

The incidence of visually disabling cataracts as estimated by first cataract surgery was higher in Pimas, compared with the U.S. population as a whole⁹⁶. After controlling for age and sex, diabetic individuals experienced more than twice the rate of cataract extraction than nondiabetic individuals. Cataract surgery rates increased with longer duration of diabetes and in those treated with insulin.

CARDIOVASCULAR DISEASE

Although our understanding of the epidemiology of cardiovascular disease is incomplete, studies of specific tribes clearly suggest that diabetes is a major risk factor for cardiovascular disease in all Native American populations.

ISCHEMIC HEART DISEASE

Our understanding of cardiovascular disease in Native Americans and its relationship to diabetes and other risk factors is evolving. Rates of ischemic heart disease have changed markedly in recent years, and both the rates and the relative contribution of known risk factors appear to vary among tribes⁹⁷. Ischemic heart disease and stroke rates in Canadian Indians have equaled or exceeded Canadian national rates in recent years, sparing only the more isolated and less acculturated communities⁹⁸. In Pima Indians, a tribe with low coronary heart disease rates, diabetes is a major risk factor for coronary artery disease⁹⁹. All fatal coronary events in Pimas during 1975-84 occurred in diabetic individuals. Reports from many tribes describe myocardial infarction or ischemic heart disease in association with diabetes^{13,15,23,100-103}. The Strong Heart Study of diabetic and nondiabetic American Indians age 45-74 years in Arizona, Oklahoma, and North and South Dakota was designed to quantify cardiovascular morbidity and mortality and to compare risk factors among tribes¹⁰⁴. Major electrocardiogram (ECG) abnormalities were significantly higher

in diabetic individuals in all tribes, with the association greatest in Arizona, where cardiovascular disease rates were lowest¹⁰⁵.

The interactions among diabetes and its risk factors and cardiovascular disease are complex and have been studied in detail only in Pimas, where the influence of hyperinsulinemia, insulin therapy, insulin resistance, and hypertension have been examined¹⁰⁶. In this tribe, neither endogenous hyperinsulinemia nor exogenous insulin therapy was prospectively associated with ECG abnormalities. In addition, mean blood pressure was not correlated with insulin resistance¹⁰⁷. Diabetes and insulin resistance, however, were associated with increased levels of very low-density lipoproteins and decreased high-density lipoproteins¹⁰⁸. In a preliminary report from the Strong Heart Study, rates of hypercholesterolemia varied among different tribes¹⁰⁴. The WHO study of vascular disease in diabetes also found higher mean cholesterol values in Oklahoma Indians than in Pimas¹⁰³. The relative influences of diabetes and insulin resistance on cardiovascular disease remain unknown.

HYPERTENSION

From the limited data available, hypertension in Native Americans in the United States appears to be less prevalent than in the general U.S. population^{105,109}. In Canada, however, a sample of Canadian Indians had higher diastolic blood pressures than the overall Canadian population⁹⁹. Diabetes and hypertension coexist at varying rates in the United States¹⁰⁹. The relative risk of diagnosed hypertension in diabetic patients compared with nondiabetic individuals ranges from 4.7 to 7.7 in different IHS regions; overall, 37% of ambulatory diabetic patients had diagnosed hypertension. Hypertension in diabetic individuals has been reported in 46.5% of Navajos, 53% of Cherokees, and 48.6% of Canadian Cree and Ojibwa tribes^{22,110,111}.

STROKE

There is a paucity of published data on stroke rates in diabetic Indians. In Pima Indians, stroke-related mortality did not differ between diabetic individuals and those with normal glucose tolerance; however, the number of stroke events was small⁵⁸. In diabetic Alaska Natives, rates of stroke were similar to rates found in a white diabetic population²³.

DIABETES AND PREGNANCY

DIABETES ANTEDATING PREGNANCY

The short- and long-term interactions of diabetes and pregnancy are of major concern for both mother and offspring in Indian communities. Although IDDM is rare in North American Indians, young Pima women with NIDDM antedating pregnancy experienced the same pattern of congenital abnormalities described in pregnancies complicated by IDDM¹¹². Diabetes antedated pregnancy in 7 (1%) of 591 Zuni Indian women during 1989-90, and in 38 (2%) of 1,854 Tohono O'odham women during 1984-88^{113,114}. In the latter group, gestational diabetes was diagnosed before the 20th week of pregnancy in 25 (42%) of 59 of the gestational diabetic pregnancies, suggesting that diabetes may also have antedated pregnancy in these cases. Preexisting diabetes occurred in 13 (0.3%) of 4,094 Navajo women who delivered during 1983-87 in IHS facilities on the Navajo Reservation¹¹⁵. For Pima women, a diagnosis of diabetes antedating pregnancy was associated with increased rates of perinatal mortality, large-for-gestational-age births, toxemia, and Caesarian section, compared with women with normal glucose tolerance¹¹⁶.

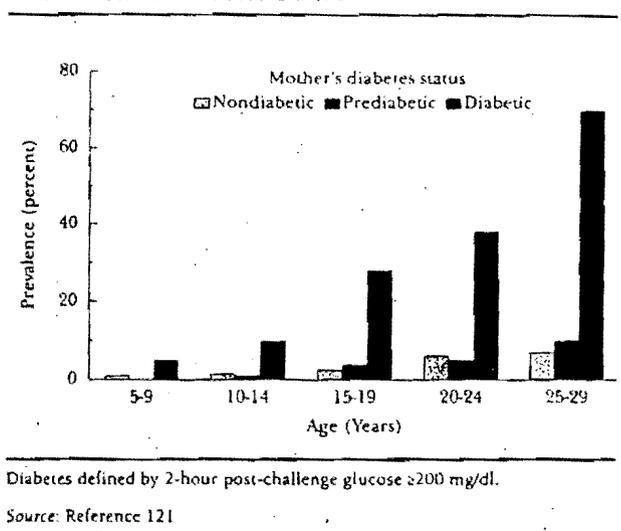
GESTATIONAL DIABETES

Gestational diabetes mellitus (GDM) diagnosed according to O'Sullivan and Mahan criteria has been reported in many tribes with varying rates. For example, 14.5% of pregnancies in Zuni, 3.4% of deliveries in Navajo, and 5.8% of deliveries in Yupik Eskimo women were in women with GDM^{113,115,117,118}. Impaired glucose tolerance during pregnancy diagnosed in Pima Indians by WHO criteria was associated with rates of fetal and maternal complications that were intermediate between the rates experienced by normal and overtly diabetic women^{25,113,119}. Follow-up studies of American Indian women with a history of abnormal glucose tolerance during pregnancy found high risks of developing subsequent overt diabetes: 27.5% of Pima women developed diabetes within 4-8 years and 30% of Zuni women with GDM developed diabetes within 0.5-9 years^{113,119}.

The longitudinal studies of diabetes in the Pima community have revealed striking associations of diabetic pregnancy with obesity and diabetes in the offspring¹²⁰⁻¹²³. By age 20-24 years, offspring of a diabetic pregnancy had a higher rate of diabetes (45%) than offspring of prediabetic women (8.6%) or nondiabetic women (1.4%) (Figure 34.10)¹²¹. Fasting hyperin-

Figure 34.10

Prevalence of Diabetes in Pima Offspring by Age and Maternal Diabetes Status



sulinemia, obesity, and abnormal glucose tolerance occurred at an earlier age in offspring of women with abnormal glucose tolerance, compared with offspring exposed to normal glucose levels *in utero*^{121,122}.

Because of the longitudinal nature of the Pima studies, these data are unique. However, the widespread emergence of NIDDM in Native American children has been noted in both the United States and Canada, suggesting that the interactions of diabetes and pregnancy, which are well described in Pima Indians, are probably not limited to one tribe but pose major public health challenges in many North American indigenous communities^{124,125}.

HEALTH CARE DELIVERY AND PREVENTION

PREVENTIVE HEALTH SERVICES

The magnitude and scope of health problems related to diabetes in American Indian communities have evoked changes in the health care systems that were originally designed primarily to prevent symptomatic infectious disease and to promote maternal and child health¹²⁶. Efforts to organize consistent preventive health services for diabetic patients and to evaluate patient outcomes in the primary health care setting have used public health techniques such as surveillance and registries^{88,127-133}. Programs of high-quality diabetes care have been organized in rural, isolated Native American communities^{127,128,133}. These programs incorporate unique features, with each program

designed specifically to promote the involvement of the community it serves. The importance of Native American community involvement in the implementation of practice guidelines was specifically noted by the Expert Committee of the Canadian Diabetes Advisory Board¹³⁴. Today, preventive health care programs in Native American communities combine the strategies successfully used in the past for infectious diseases with the newer diabetes care guidelines. In some cases these preventive strategies overlap. Because of the high risk of the reactivation of tuberculosis in diabetic individuals, the IHS has recommended systematic tuberculosis prophylaxis for diabetic American Indian patients⁹². Effective intervention strategies continue to be studied in the United States and Canada.

EDUCATION

Just as diabetes clinical guidelines have been adapted for the needs of Native American Indians with diabetes, educational programs and materials have also been developed and evaluated systematically to target these cultures¹³⁵⁻¹³⁷. Nutrition education has emphasized single-concept messages rather than conventional dietary exchange systems¹³⁷. Diabetes education programs that involve the community have evolved by using a stepwise approach to implementing national diabetes education standards¹³⁸. Native American interpreters trained in diabetes terminology have become crucial to the success of diabetes education in cross-cultural settings¹³⁹. Diabetes training for community health representatives and Alaska village health aides has been organized to promote effective preventive care and education from within the community by mobilizing community health workers.

PRIMARY PREVENTION

Both the historical experience of Native American communities and the growing understanding of the pathophysiologic interactions between genetics and lifestyle suggest that NIDDM can be prevented in Native Americans. In response to the growing burden of diabetes, communities have organized health promotion efforts to increase fitness and decrease obesity¹⁴⁰. For example, the Pueblo of Zuni has maintained a community-based prevention program for more than 10 years^{141,142}. Metabolic control improved in the program's diabetic patients who exercised, compared with patients who did not¹⁴³. A recent retrospective study in Zuni found that even after adjusting for obesity, the odds of presenting with diabetes decreased with increasing exercise frequency in this high-risk community⁴⁷. Diabetes prevention efforts

have spread to many Native American communities. These efforts include the revival of traditional physical activities and native foods to promote a healthy lifestyle¹⁴⁰. Formal clinical trials to test the feasibility of preventing NIDDM will be of major significance to these communities.

PSYCHOSOCIAL AND CULTURAL STUDIES

The growing burden of diabetes in Native Americans has stimulated communities and investigators to ex-

Table 34.5
Psychosocial and Cultural Studies of Diabetes in Native Americans

Books

Diabetes and Native Americans: The impact of lifestyle and cultural changes on the health of indigenous peoples. Joe J. Young R, eds. Moulton Press, Berlin, 1994

Monographs

Diabetes in Canadian native population: Biocultural perspectives. Young TK, ed. Canadian Diabetes Association, 1987

Pine CJ: *Diabetes and behavior: American Indian issues.* American Indian and Alaska Native Mental Health Research. Monograph 1:94-115, 1988

Rokala DA, Bruce SG, Meiklejohn C: *Diabetes mellitus in native populations of North America: An annotated bibliography.* Monograph, Series No. 4. Northern Health Research Unit, Department of Community Health Services. University of Manitoba, Winnipeg, 1991

Articles

Camazine SM: Traditional and western health care among the Zuni Indians of New Mexico. *Soc Sci Med* 14B:73-80, 1980

Hagey R: The phenomenon, the explanations and the responses: Metaphors surrounding diabetes in urban Canadian Indians. *Soc Sci Med* 18:265-72, 1984

Hüttlinger K, Krefing L, Drevdahl D, Tree P, Baca E, Benally A: "Doing battle": A metaphorical analysis of diabetes mellitus among Navajo people. *Am J Occup Ther* 46:706-812, 1992

Jackson MY, Broussard BA: Cultural challenges in nutrition education among American Indians. *Diabetes Educator* 13:47-50, 1987

Lang GC: Diabetics and health care in a Sioux community. *Human Organization* 44:251-60, 1985

Lang GC: "Making sense" about diabetes: Dakota narratives of illness. *Medical Anthropology* 11:305-27, 1989

Miller P, Wikoff R, Keen O, Norton J: Health beliefs and regimen adherence of the American Indian diabetic. *American Indian and Alaska Native Mental Health Research* 1:24-36, 1987

Tom-Orme L: Chronic disease and the social matrix: A Native American intervention. *Recent Advances in Nursing* 22:89-109, 1988

Womack RB: Measuring the attitudes and beliefs of American Indian patients with diabetes. *Diabetes Educator* 19:205-09, 1993

amine traditional and modern perspectives on diabetes. Several anthropologic studies have documented the interpretations of Native Americans affected by diabetes regarding the etiology of the disease, the experience of illness, and the efficacy of treatment. Native American communities perceive diabetes as a new disease that has come from the outside. If approaches to diabetes in both individuals and communities are to be effective, these efforts require appropriate cultural adaption to local health beliefs. Selected references from the growing number of studies

are presented in Table 34.5. These studies are the foundation for the important cultural understandings that must develop along with the scientific framework to enable Native Americans to control the diabetes epidemic.

Dr. Dorothy Gohdes is Director, Indian Health Service Diabetes Program, Albuquerque, NM.

Diabetes in North American Indians and Alaska Natives

Diabetes in the Native American population has limited data because only those served by the Indian Health Service (IHS), an agency of the U.S. Health Service, were surveyed. Indians living on reservations are not included in US national survey's. However, in the United States, 1.9 million individuals identified themselves in the 1990 Census as American Indian or Alaska Native, but only 1.2 million of these resided in the 33 reservation states served by the IHS. The following data is based on the 1.2 million in the 33 reservation states.

The 1987 survey by IHS showed that 12.2% of Indian children (19 years of age and younger) are diabetic compared to 5.2% in the general population.

MORTALITY RATE

In 1989, Type 2 (Adult) diabetic mortality rates in the American Indian and Alaska Native population is 2.7 times the rate of the US general population. From 1984-86 1,252 Native American deaths were diabetic related, 708 deaths listed diabetes as the underlying cause. Allowing for the under reported death certificates of Indians in northern America by 65% the National American Feedback study found that the diabetic mortality rate of Native American is 4.3 times the rates of whites. In New Mexico the rate is 3.6 times that of whites. On Canadian Indian Reservations the mortality rate is 2.2 times higher than in Canadian men and 4.1 times higher than in Canadian women. Studies done in Pima Indians from 1975-84 found that their mortality rate is 11.9 times greater than the 1980 death rate for all races in the United States.

- Longer duration of Diabetes and Proteinuria were both associated with increased mortality

Medical Expenditure Survey of American Indians (IHS)

- Indian Women w/Diabetes 13.2%
- Indian Men w/Diabetes 11.0%

Genetics

- A genetic marker linked with insulin resistance, has been described in Pimas.
- Diabetes is higher in Full-blooded Native Americans.
- In Pimas, Diabetes I higher in the offspring of parents who developed Diabetes at a young age.
- The Pima tribe of Arizona has the highest rate of diabetes in the world. Approximately 50% of Pimas between the ages of 30-64 have diabetes.

Complications

- Kidney Failure-** Native Americans are 2.5 - 4 times at greater risk to enter kidney failure treatment
- One-fourth of all End-Stage Renal-Disease cases were contributed to Diabetes
 - 1983-86 ESRD incidence for Native Amer. was 2.8 times the rate of whites with 55% contributed to Diabetes

US Incidence of Diabetic ESRD

- Out of 1 million new cases between 1987-90
- 39 is white
- 149 is black
- 236 is Native American

Native Americans have a six times higher rate of developing ESRD (kidney failure) than the general population

Cataracts

Cataract surgery is higher in Pimas compared to the general population

Amputation

-Leg amputations are had by people w/ diabetes 15 to 40 times more often than people without diabetes. Each year 54,000 people lose their foot or leg to Diabetes.

Native Americans are 3 to 4 times greater to have an amputation than the general population.

CONCLUSION

Diabetes in the Native American population is growing at alarming rates. Statistics have shown that the Native American has a higher incidence of ESRD and Mortality rate than the general population. Furthermore, IHS officials claim that the diabetes program was funded at only 75% of need. These facts are enough to support the President's recommendation to increase IHS diabetes funding to \$2.5 million.

what are the IHS numbers for diabetes since 1993 → 1999? what are the IHS #'s in general?

1993 - 1997

National Center, 1660 Duke Street, Alexandria, VA 22314
(703) 549-1500 Telex: 901132

FACSIMILE TRANSMISSION
FACSIMILE TELEPHONE NUMBER: (703) 836-7439

SCIENTIFIC AND MEDICAL DIVISION

TO: Sarah Bianchi	FROM: Richard Kahn, PhD
FAX NO: 202-456-5557	EXT: 2065
OFFICE NO:	DATE: 8/4/97

Please call if you have any trouble receiving transmission or did not receive the number of pages shown below:

Total of 7 page(s), including this cover

**MESSAGE FOLLOWS: Sarah, call me this afternoon to let me know the next step.
Thanks. Richard.**

The mission of the American Diabetes Association is to prevent and cure diabetes and to improve the lives of all people affected by diabetes.

August 4, 1997

The Diabetes Quality Improvement Project

Background

Diabetes is a serious disease that affects over 16 million Americans, and over 150,000 people die each year because of it. It strikes individuals of all ages and socioeconomic groups, and individuals of African, Asian, and American Indian descent are particularly vulnerable. The annual cost of diabetes has been reported to be nearly 100 billion dollars and thus it ranks as one of the deadliest and most costly diseases known to mankind.

Most of the morbidity and mortality of diabetes is due to the complications associated with the disease: blindness, kidney failure, nerve damage, and cardiovascular disease.

Diabetic retinopathy is the leading cause of new blindness in people under 65; diabetic nephropathy is the leading cause of end stage renal disease (kidney failure) in the United States; neuropathy results in the second leading cause of lower extremity amputation with over 50,000 Americans annually losing a limb because of diabetes; diabetic macrovascular disease leads to accelerated coronary heart disease and peripheral vascular disease, both of which result in premature death.

Studies show that many, if not all, of the complications of diabetes can be slowed or even prevented by better management on the part of the health care team and the patient. Improved blood glucose control, and regular eye and foot examinations are but three of the practices that have been unequivocally shown to reduce complications and thereby diminish the heavy personal and financial toll attributed to diabetes.

August 4, 1997

Fueling the heavy burden of diabetes is the fact that diabetes care in America is suboptimal. Numerous studies and reports have documented that physicians are not delivering the care known to be beneficial. For example, the rate of an annual eye exam in managed care plans averages less than 40%. People with diabetes deserve better.

The inability of consumers and health care purchasers to determine if medical care is appropriate and necessary has given rise to the concept that the health care system should be held accountable for what is done, and the outcomes achieved. This principle of accountability has resulted in the development of so called "performance and outcome measures," administered through "report card" systems. Except for HCFA's requirement for managed care plans to submit limited performance measurement data, all such systems in effect today are voluntary, and all are administered by non-profit organizations dedicated to improving the health care provided to Americans.

The multiplicity of report card systems, each with their own measures, has created unnecessary work and confusion. A consolidation of measure sets would be greatly appreciated, and would be a powerful tool to improve care and allow comparison of care across all delivery systems (e.g., managed care vs. fee-for-service).

The Diabetes Quality Improvement Project is a coalition of public and private entities whose aim is to develop a set of diabetes-specific performance and outcome measures to

August 4, 1997

be adopted nationwide by consumers, purchasers of health care, and health care professionals.

Structure and Scope of Work

The coalition is comprised of four "organizations:" the American Diabetes Association (ADA), the Foundation for Accountability (FACCT), the Health Care Financing Administration (HCFA), and the National Committee for Quality Assurance (NCQA). The ADA is the nation's largest and leading voluntary health agency dedicated to improving the lives of people with diabetes. The FACCT is dedicated to ensuring that consumers and purchasers of health care have the necessary information to make health care decisions; its Board of Trustees includes large consumer groups and purchasers, who collectively represent over 80 million Americans. The HCFA is the largest purchaser of health care in America. Through its Medicare and Medicaid programs purchases health care for about one-fourth of all people with diabetes (the largest single purchaser of care for the diabetic population). Since the cost of diabetes has been shown to be as much as three to four times greater than the cost of care for similar, but unaffected, persons, HCFA has considerable interest in reducing the burden of diabetes, not only to reduce the cost of care but also to improve quality of care, enhance outcomes of care, and receive value for the money spent. NCQA is dedicated to assessing and reporting on the quality of care delivered by managed care plans. Its primary mission is to make true competition, based on the

August 4, 1997

value of care and not simply the price, possible in the market for health care services.

NCQA develops and maintains a set of standardized performance measures used by more than 90% of health plans. More than three-quarters HMO enrollees are in a plan that has been reviewed by NCQA.

The coalition has agreed to work through a committee of leading experts in the field of diabetes care and performance measurement. The project will be funded largely by HCFA. Although each of the coalition entities has, in some form or fashion, independently developed and promulgated diabetes measures, most are very incomplete. It is thought that a common set of comprehensive measures, supported by ADA, FACCT, NCQA, and HCFA, will have a tremendous impact on health care delivery, and the ability of patients to seek out and receive the most effective and appropriate care.

The work of the coalition is expected to be completed by the end of 1998, at which time a comprehensive diabetes measurement set will be released. Shortly thereafter, consumers and others will be able to make important decisions about diabetes care, at the individual provider and health plan levels, based on objective quality information.

August 4, 1997

Summary and Significance

The concept of accountability for performance has recently emerged as a major force to guide and influence health care delivery. Consumers and purchasers of health care want value and benefit, and are asking for the development of systems whereby the critical information to make necessary decisions is readily available and widely understood.

Diabetes is costly and very serious and, most notably, relatively few people with diabetes get the care they need to avoid the medical problems directly associated with the disease. High quality care for people with diabetes has been shown to make a difference and thus, health care providers and health care organizations should be held accountable for what is done, and what is achieved.

The ADA, FACCT, and NCQA currently have leading roles in promoting and assuring high quality health care. Each organization has carved out a unique role in the health care system. For the first time, they are combining their experience and expertise and using it to improve diabetes care. In addition, they are joined by the HCFA, a powerful force in health care, and one that often sets the tone and direction for the entire health care system, not just the delivery of care for older Americans. Never before has such a coalition from the public and private sectors been assembled to make such a concerted effort to directly affect the health care given to so many Americans.

August 4, 1997

Acting together, this coalition has the opportunity and ability to improve the lives of people with diabetes more than any other single activity or action in this decade. Given the countless failed attempts to assure the delivery of high quality diabetes care, even though a wide variety of drugs and medical supplies and equipment are available that have great utility, the nationwide implementation of one set of diabetes-specific performance and outcome measures could likely rank among the most significant advances in diabetes care in this century. In addition, the work of this unique coalition, and its application to one of our nation's leading chronic diseases, will serve as an important model for how care given for other chronic diseases can be improved.

File Diabetes

**Remarks for Mrs. Mary Delaney
Presidential Announcement on Diabetes Investment
August 8, 1997**

Thank you. Mr. President I am honored to be here today to celebrate this announcement and to tell you and others here with us what an important difference the new diabetes investment you signed into law this week will make in my life and in the lives of the 16 million Americans who suffer from diabetes.

I was diagnosed with diabetes 11 years ago. I am not the first in my family to get this disease. Before me, my father had diabetes. This disease affects too many of our families. Nearly half of all people with diabetes are older Americans. It is also all too common among African-Americans who suffer from this disease at nearly double the rate.

Managing this disease has not been easy for me or my family. It has also been a difficult financial burden on my family. Neither Medicare nor my supplemental insurance covers my blood glucose monitor, which can cost \$60 or more. It also does not cover the box of strips that I need to monitor my blood sugar which costs as much as \$50 each month.

In addition, there are other things such as needles and rubbing alcohol and a host of other costs associated with my diabetes care that my family must pay for. These costs may not seem significant but combined with our family's other health care costs, it has been at times too much to manage.

In fact, there have been many times when I have tested my blood sugar less frequently than recommended by my doctor because I simply cannot afford to buy more testing strips. And just last week, my monitor stopped working. I will not be able to test my

blood sugar until I get the resources to have it fixed.

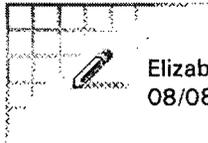
I know that I am luckier than many diabetes patients, however. My supplemental insurance did pay for a class that taught me how to use the monitor and how to manage my own diabetes. But many of my friends and millions of other Americans have not been so fortunate. They do not have health coverage which pays to teach them how to care for themselves at home to help them avoid some of the horrible complications that can come with this disease.

Mr. President, the new Medicare benefit that you signed into law this week will help millions of older Americans like myself get the health care they need to manage this disease. For me, it will ensure that I can always afford the strips and monitors that I need to test my blood sugar and manage my illness. It will mean that I never have to compromise my diabetes care. For millions of others, it will mean that they learn the tools to manage their diabetes and live longer.

By increasing the number of Americans who can treat their diabetes at home, we will reduce the number of Americans who suffer from the difficult and costly complications, such as kidney disease or blindness. This will not only reduce the financial burdens for many, but it will also help save the Medicare program money as fewer beneficiaries will need more extensive, costlier care.

Mr. President, diabetes affects too many vulnerable Americans. Your leadership will improve the lives of so many of them. Thank you.

And now I am pleased to introduce Chief Joyce Dugan, the Chief of the Eastern Band of Cherokee Indians.



Elizabeth R. Newman
08/08/97 01:18:04 PM

Record Type: Record

To: Sarah A. Bianchi/OMB/EOP

cc:

Subject: 1997-8-8 remarks on diabetes

----- Forwarded by Elizabeth R. Newman/WHO/EOP on 08/08/97 01:17 PM -----



SUNTUM M @ A1
08/08/97 11:49:00 AM

Record Type: Record

To: See the distribution list at the bottom of this message

cc:

Subject: 1997-8-8 remarks on diabetes

THE WHITE HOUSE

Office of the Press Secretary

For Immediate Release

August 8, 1997

REMARKS BY THE PRESIDENT
IN ANNOUNCEMENT ON DIABETES INITIATIVES

Georgetown University Hospital
Washington, D.C.

11:27 A.M. EDT

THE PRESIDENT: Thank you very much. I would like to thank Dr. Wiesel and all the people here at the Georgetown Medical Center for hosting us. I want to thank Mary Delaney and Chief Joyce Dugan and Sandra Puczynski for their speeches and for their example.

* [As you might imagine, over the course of my tenure I have had occasion to come to quite a number of ceremonies like this. I don't believe I have ever heard three people back to back speak so powerfully, so clearly, so eloquently about a matter of great national concern. And I think we should give them all another hand. (Applause.)

I'd like to thank all of the people who are here today, diabetes patients, families, activists and advocates. Especially, I'd like to acknowledge the people on the platform -- Stephen Satalino, the Chair of the American Diabetes Association. Joan Beaubaire, the former head of the Juvenile Diabetes Foundation, is also here. Her son works for me at the White House, so I get a little extra prodding on this from time to time. (Laughter.)

I'd like to say a special word of thanks to Mary Tyler Moore, who has awakened the conscience of our nation and indeed the entire world about this issue, for her long and tireless and selfless efforts. Thank you, Mary. (Applause.)

I want to thank Dr. Philip Gordon, the head of diabetes research at NIH. He's here with us today. And the NIH will play a major role in the work that we are discussing here.

None of us could write the history of the century that is about to end without a big chapter on the miracles modern medicine and science have wrought in our lives. Polio, mumps, diphtheria -- the diseases that robbed so many families of beloved infants and toddlers for centuries have been virtually eradicated. Premature babies who just a decade ago would not have had a chance at life beyond the intensive care unit are growing into happy and healthy children. Powerful treatments are prolonging the lives and improving the quality of lives of people with HIV and AIDS all across our country, raising new hopes for people living with the disease.

But there are still frontiers to conquer and still too many among us whose lives and futures are dimmed by disease and illness, as we have heard so powerfully today. Diabetes is the seventh leading cause of death in our country, and perhaps equally profoundly affects the lives of millions and millions of people who have it every day.

The historic balanced budget legislation I signed on Tuesday is about more than balancing the books; it also honors our values, increases our chances of keeping the American Dream alive in the 21st century and improves the lives of every American. There are some little-known but very important provisions in this new balanced

budget that will take us a tremendous step forward in our fight against diabetes. These investments total more than \$2 billion over the next five years. They will strengthen our efforts to find a

cure, to help our most vulnerable citizens better manage the disease, to prevent some of its most traumatic, costly and life-threatening complications.

These investments represented the committed efforts of many members of Congress and our administration. But I must recognize, especially two: first, Congressman Elizabeth Furse, whose daughter is here and who has diabetes, led the Bipartisan Congressional Diabetes Caucus in an absolutely tireless fight to include the Medicare investments that are in this bill. And I thank her. She has done magnificently. Thank you. (Applause.)

And I must tell you, I wish very much that the Speaker of the House, Newt Gingrich, could be with us today. When we have a disagreement, it is normally well-publicized. (Laughter.) And widely understood. (Laughter.) But I wish the American people could see the numerous private conversations that we have had together in quiet rooms about diabetes.

He watched his mother-in-law live with diabetes and became a great champion for people struggling with it, a tireless advocate for greater investments and research, prevention and care, and one of the very first people who ever spoke to me not only about the human dimensions of the disease, but the enormous percentage of our public funds in Medicare and, to a lesser extent, in Medicaid, that could be devoted to other purposes were it not for the crushing burden of diabetes-related problems directly resultant from our failure to invest as we begin to invest today. I know we play a leading role in making these new initiatives a part of the budget, and I appreciate both what he and Elizabeth and others have done.

Now, this new legislation will do three things. It expands Medicare benefits for the more than 3 million senior citizens diagnosed with diabetes. Mary talked about that. We all know that early investments in prevention can save us millions in expensive treatments down the line. If left untreated, diabetes can lead to devastating complications such as blindness, amputations and kidney disease. This new benefit will make testing strips and other methods of monitoring blood glucose levels, as well as instructions on how best to manage the complicated disease, available to all Medicare beneficiaries with diabetes.

It will empower Medicare patients to take better care of themselves at home and to avoid complications that can lead to costly hospital stays and destroy health.

Second, the new legislation will enable Health and Human Services Secretary, Donna Shalala, to boost funding for Type I or juvenile diabetes research by \$150 million over the next five years. Nearly one million Americans have Type I diabetes, and as many as half of them are children. Even when the disease is managed carefully, the patients almost always experience further complications. That's why we cannot rest until we find a cure that will free our children from this disease. And this unprecedented

grant will help us to do that.

Third, we will provide a five-year, \$150-million grant to the Indian Health Service for diabetes prevention, research and treatment in our Native American communities. And I want to say a special word of thanks to Senator Domenici of New Mexico for his special efforts on this project.

As Chief Dugan has made it clear, Native Americans are three times as likely as white Americans to have this disease; far less likely to find adequate treatment for it. Too many Native Americans are suffering from the grimmest complications of diabetes. This grant will bring public health services, schools and nutrition

programs together to reach children and families living on reservations, and to provide them with the information and tools to prevent and manage diabetes.

And I might say, I told Chief Dugan before I came up here that my grandmother's grandmother was a Cherokee who would be very proud that there is a woman chief who is doing such a magnificent job. (Applause.) Thank you.

Next month, our scientists at NIH will be hosting a workshop to bring researchers from all across the country to share ideas and discuss the most promising avenues of diabetes research. And we will establish a new and unprecedented public-private partnership to bring our nation's leading health care providers, purchasers, and consumers together to develop uniform guidelines for diabetes care. Through the guidelines, we can ensure that all doctors provide their patients with thorough and vigilant care, such as regular eye and foot exams, to stay as healthy as possible.

Taken together, these initiatives can make life-changing differences for millions of Americans. I was very heartened to hear the American Diabetes Association say that these new investments in diabetes are as important for people with diabetes as the discovery of insulin in 1921. Let us pray that it will be so.

Let me finally say that discussing this in rather clinical terms cannot possibly convey the human impact that Sandra did in talking about her child. On the way over here today, I was remembering that 23 years ago plus now, when I began my career in political life, the first chairman of my campaign was only a year older than me and was already a bank president at the age of 28 or 29, but he died a few years ago from complications from diabetes. When I lived in Arkansas, I used to sing in a church choir with a man who had to quit singing because of complications from diabetes, and I have these vivid memories every Sunday of standing there looking at him sitting in the church with the pain on his face of not being able to do it anymore.

This morning I got a note from a friend of mine I'd like

to read to you. "For the last 17 years my son has gone to sleep scared, scared that his blood sugar would drop and his body would be ripped apart with a diabetic seizure. Every day for the last 17 years, my son and his family have worried about the opposite effects of having his blood sugar remain at too high a level and thereby causing the early onset of blindness, heart failure and loss of limb. Until today, there simply wasn't enough money available for scientific research to have a real hope to find a cure. Now there is."

It is easy to say that in the last 50 years we experienced in science the age of physics, the age of space travel and the beginning of genetic research; but that in the next 50 years, the 21st century in science will be an age of biology. The important thing is that for people and their families with diabetes, it can be an age of longer, happier, richer lives.

Thank you very much. (Applause.)

END

11:39 A.M. EDT

Message Sent To:

NEW DIABETES INVESTMENTS TO IMPROVE TREATMENT, PREVENTION, AND RESEARCH FOR AMERICANS WITH DIABETES

Today President Clinton highlighted a set of four initiatives that will improve the lives of the at least 8 million Americans who have been diagnosed with diabetes. Three of these initiatives were included in the balanced budget the President signed into law on Tuesday. The President also emphasized that this new investments emerged as a result of a strong bipartisan partnership with Speaker Gingrich. The American Diabetes Association (ADA) stated that "taken together, these new investments in diabetes, announced by President Clinton today, are as important for people with diabetes as the discovery of insulin in 1921." The President announced:

- (1) **An important new Medicare benefit** which will help pay for the critically necessary supplies and self-management instruction which will help the 3.2 million older Americans who suffer from diabetes better manage their treatment.
- (2) **A new \$150 million investment in diabetes research to prevent and cure Type I (often known as juvenile) diabetes**, to be allocated by Health and Human Services Secretary Donna Shalala.
- (3) **A new \$150 million investment for prevention and treatment of diabetes among Native Americans**, who are almost three times as likely to suffer from the disease as others in the U.S. population;
- (4) **A new public/private effort to assure and improve high quality care for Americans with diabetes**. This effort will review current treatments for diabetes to determine the degree to which they are effective, to recommend alternative approaches that ensure high quality care, and to develop more consistent quality measures for diabetes patients, health plans, and health providers across America.

A New Medicare Benefit to Help People With Diabetes Better Manage Their Care.

The balanced budget expands Medicare's coverage of benefits for people with diabetes by \$2.1 billion over five years. In so doing, it expands the number of people able to take advantage of self-management tools will increase the number of Americans who properly manage their diabetes, thereby helping to prevent the debilitating and costly complications too often associated with the disease. Under the new balanced budget, Medicare will cover self-management training offered by physicians and other certified providers rather than only in hospital-based programs as it traditionally has. This will help ensure that more beneficiaries with diabetes can access the necessary education to manage this disease. In addition, Medicare will make blood glucose monitors (including testing strips) available to all beneficiaries with diabetes, whereas Medicare currently covers only insulin-dependent patients. Ensuring Medicare beneficiaries have access to these supplies will help improve their treatment and has great potential to reduce costs. This new legislation was introduced and strongly advocated by Rep. Furse, Rep. Nethercut, and Senator Breaux.

A New \$150 Million Investment to Help Research a Cure for Type I (Juvenile) Diabetes.

The HHS Secretary is allocated \$30 million annually for five years for research to help find the cure for diabetes. Americans with Type I diabetes with this disease often suffer severe consequences, even when they receive the best treatment and care. The HHS Secretary will have discretion to target the new funds to the best scientific opportunities. This represents the largest single new investment in Type I diabetes.

\$150 Million Investment to Help Prevent and Treat Diabetes Among Native Americans. The HHS Secretary is allocated \$30 million annually for five years to be used to provide services for diabetes prevention and treatment for Native Americans. The death rate from diabetes is almost three times higher in the Native American population than in the U.S. population as a whole. This new funding will go to help improve prevention efforts (such as improved diet, exercise and other factors that reduce the likelihood of diabetes) and help identify the disease as early as possible. It will also help more Native Americans with diabetes get the necessary information about managing diabetes, for example, by improving linkages between families, public health services, schools, and nutrition programs. Moreover, it will expand access to affordable treatment so that more Native Americans get the care they need to help reduce costly and extensive complications. IHS will work in partnership with Tribes, Urban Indian Health Centers Facilities, and other agencies within HHS, such as the CDC.

A New Diabetes Quality Improvement Project.

Numerous studies by organizations such as the ADA and National Committee on Quality Assurance (NCQA) have shown that many patients are not receiving the medical care known to reduce diabetes complications such as blindness and amputation. In fact, an NCQA study shows that the rate of an annual eye exam in managed care plans averages less than 40 percent. The multiplicity of report cards, each with their own measures, has created confusion and made it difficult to compare and improve care across all delivery systems.

The President announced a major year-long collaborative effort to review current treatments for diabetes to determine the degree to which they are effective, to recommend alternative approaches that ensure high quality care, and to develop more consistent quality measures for diabetes patients, health plans, and health providers across America. Such measures will monitor whether proper care was delivered (for example, an annual eye exam) or health outcomes were achieved (such as appropriate blood glucose levels).

The performance and outcome measures are being developed by a coalition of four organizations: HCFA, the largest purchaser of health care for the diabetic population; the ADA, the largest voluntary health agency dedicated to improving the lives of people with diabetes; NCQA, which develops and maintains a set of standardized performance measures used by more than 90 percent of health plans; and the Foundation for Accountability (FACCT), an organization dedicated to ensuring that consumers have adequate information to make health care decisions. Together, these organizations will work to ensure that millions of consumers, purchasers, and health care providers utilize this new information to improve care.

FACTS ON DIABETES

There are 8 million Americans diagnosed with diabetes. Another 8 million are believed to have, but have not been diagnosed, with this disease. Over 3 million Americans diagnosed with diabetes are adults age 65 and over. Approximately half of all diabetes cases occur in people older than 55 years of age. African-Americans have diabetes at nearly double the rate of other Americans.

Diabetes is the seventh leading cause of death. Middle-aged Americans with diabetes have death rates twice as high as other Americans. The death rate from diabetes is nearly 3 times higher in the Native American population than in the U.S. population.

People with diabetes are more likely to suffer from heart disease, high blood pressure, and strokes. People with diabetes are 2 to 4 times more likely to suffer from cardiovascular disease, and 2 to 4 times more at risk for a stroke. High blood pressure affects nearly two-thirds of people with diabetes.

Diabetes is the leading cause of end-stage renal disease (ERSD), non-traumatic amputations, and blindness. Diabetes accounts for 36 percent of new ERSD cases (kidney disease) -- about 20,000 cases each year. In addition, 54,000 amputations are performed on diabetics each year, and up to 24,000 adults are blinded each year from diabetes.

The American Diabetes Association estimates that we spend \$92 billion per year on diabetes care. Of the total, costs directly attributable to diabetes total \$45 billion, while indirect medical costs, such as work loss, disability, and premature death total \$47 billion.

DIABETES AND MEDICARE

Medicare pays for ERSD for the non-elderly population as well. About 20,000 Americans develop this disease through diabetes each year, and Medicare expenditures on kidney dialysis for each of these people averages nearly \$40,000 annually.

TYPE I DIABETES

Between 700,000 and 1 million Americans have Type I diabetes and as many as half of these are children. Each year about 30,000 Americans are diagnosed with Type I diabetes.

Almost all Americans with Type I diabetes will likely suffer from at least one of the many complications arising from diabetes, including serious eye disease (e.g. blindness), amputation, heart disease, or kidney disease.

NATIVE AMERICANS AND DIABETES

Diabetes occurs at rates dramatically higher among Native Americans than in the general U.S. population. One third to one half of adults in certain tribal groups have diabetes.

Native Americans develop Type II diabetes at a younger age -- as young as age eight -- and suffer higher rates of complications including blindness, amputation, and kidney disease.

ELIZABETH FURSE
1ST DISTRICT, OREGON

COMMITTEE:
COMMERCE

SUBCOMMITTEE ON
ENERGY AND POWER

SUBCOMMITTEE ON
HEALTH AND ENVIRONMENT

SUBCOMMITTEE ON
FINANCE AND HAZARDOUS MATERIALS

Congress of the United States
House of Representatives
Washington, DC 20515-3701

OREGON OFFICE:
MONTGOMERY PARK
2701 NW VAUGHN, #660
PORTLAND, OR 97210-5331
(503) 326-2301
TOLL FREE (800) 422-4003
FAX (503) 326-5066

WASHINGTON OFFICE:
316 CANNON BUILDING
WASHINGTON, DC 20515
(202) 225-0855
FAX (202) 225-9497
e-mail: Rep.Elizabeth.Furse@mail.house.gov
www.house.gov/furse/

FAX TRANSMITTAL FORM
FAX NUMBER: (202) 225-9497
PHONE NUMBER: (202) 225-0855

Date: 10/27

To: Sarah Bianchi

Chris Tenning's Office

From: Chris Porter

Number of pages, including cover pages: 4

IF YOU DID NOT RECEIVE THIS TRANSMISSION IN ITS ENTIRETY OR IF YOU HAVE RECEIVED THIS TRANSMISSION IN ERROR, PLEASE CALL US IMMEDIATELY AT (202) 225-0855. THIS TRANSMISSION MAY INCLUDE CONFIDENTIAL INFORMATION AND IS INTENDED ONLY FOR THE INDIVIDUAL OR ENTITY NAMED ABOVE. ANY OTHER PERSON THAN THE INTENDED RECIPIENT (OR OTHERS AUTHORIZED BY THE INTENDED RECIPIENTS) IS PROHIBITED FROM READING, COPYING, OR DISTRIBUTING THIS TRANSMISSION.

COMMENTS:

Sarah - This is more than Chris needs,
but the agenda is on the 1st page + the
possible new issues are listed in order of
likelihood to be discussed.

[Signature]

603-526-7208

Swan B

Paul Branch

ELIZABETH FURSE
1ST DISTRICT, OREGON

COMMITTEE:
COMMERCE

SUBCOMMITTEE ON
ENERGY AND POWER

SUBCOMMITTEE ON
HEALTH AND ENVIRONMENT

SUBCOMMITTEE ON
FINANCE AND HAZARDOUS MATERIALS

Congress of the United States
House of Representatives
Washington, DC 20515-3701

OREGON OFFICE:
MONTGOMERY PARK
2701 NW VAUGHN, #660
PORTLAND, OR 97210-5391
(503) 325-2501
TOLL FREE (800) 422-4003
FAX (503) 326-5068

WASHINGTON OFFICE:
316 CANNON BUILDING
WASHINGTON, DC 20515
(202) 225-0855
FAX (202) 225-9497
e-mail: Rep.Elizabeth.Furse@mail.house.gov
www.house.gov/furse/

FAX TRANSMITTAL FORM
FAX NUMBER: (202) 225-9497
PHONE NUMBER: (202) 225-0855

Date: 10/27

To: Sarah Bianci

Chris Tenning's Office

From: Chris Porter

Number of pages, including cover pages: 4

IF YOU DID NOT RECEIVE THIS TRANSMISSION IN ITS ENTIRETY OR IF YOU HAVE RECEIVED THIS TRANSMISSION IN ERROR, PLEASE CALL US IMMEDIATELY AT (202) 225-0855. THIS TRANSMISSION MAY INCLUDE CONFIDENTIAL INFORMATION AND IS INTENDED ONLY FOR THE INDIVIDUAL OR ENTITY NAMED ABOVE. ANY OTHER PERSON THAN THE INTENDED RECIPIENT (OR OTHERS AUTHORIZED BY THE INTENDED RECIPIENTS) IS PROHIBITED FROM READING, COPYING, OR DISTRIBUTING THIS TRANSMISSION.

COMMENTS:

Sarah - This is more than Chris needs,
but the agenda is on the 1st page + the
possible new issues are listed in order of
likelihood to be discussed.



File
Diabetes
Caucus

To: Interested Parties
Fr: Christopher Porter
Legislative Director, Rep. Furse
Re: October 29th Meeting of Congressional Diabetes Caucus
Da: 10/28/97

The Congressional Diabetes Caucus will meet at 2PM on Wednesday, October 29th, at 2PM in 2359 Rayburn HOB. The Congressional Diabetes Caucus is has 101 bipartisan members, and is chaired by Rep. Elizabeth Furse (D-OR) and Rep. George Nethercutt (R-WA).

The meeting will be members-only, is scheduled to last approximately 30 minutes, and is designed to be a discussion on how to publicize the Administration's "Commitment to Fight Diabetes" (particularly the Medicare, research, and telemedicine initiatives), as well as determine an agenda for the Diabetes Caucus for the duration of the 105th Congress.

I. Proposed Agenda for Diabetes Caucus Meeting:

1. Introduction by Reps. Furse and Nethercutt (>5 mins)
Outline of achievements in diabetes:
--Medicare coverage of self-management training/strips
--Research funding for Type 1
--Research funding for Native Americans
--Diabetes Telemedicine Project
--NIH Diabetes Research Working Group
2. Remarks by Erskine Bowles, Chief of Staff to the President and former JDF President (5 mins.)
3. Remarks by Chris Jennings, Deputy Assistant to the President for Health Policy (5 mins.)
--Update on Medicare benefits implementation by HCFA before 7/1/98;
4. Discussion of publicizing recent achievements (5 mins.)
5. Discussion of future diabetes agenda (10 mins.)
--Opportunity for Caucus members to discuss concerns

II. Possible New Issues for the Caucus:

Medicare Coverage of Insulin Pump

Currently, HCFA does not cover insulin pump therapy. The insulin pump is a computerized device that regulates blood sugar levels, in lieu of traditional multiple daily injections. The pump is very effective for certain types of people with diabetes, and HCFA coverage of the insulin pump is supported by ADA, JDF, AACE, AADE, and manufacturers.

Medicare Coverage of Pancreas Transplantation

For selective populations of people with diabetes, pancreas transplantation is the only known "cure" for diabetes. Successful pancreas transplantation patients have a 77% chance of achieving insulin independence within one year. HCFA does not cover pancreas transplantation, and has insisted on studies to prove "quality of life" improvements despite the fact that such an improvement is self-evident.

Noninvasive Blood Glucose Meter/Technology Issues

There are a number of companies across the country pursuing the development of a noninvasive blood glucose meter. There is concern among some manufacturers that the FDA does not adequately understand diabetes. (Congresswoman Furse and Mr. Barton recently inserted language in the FDA reform bill alerting the agency to the importance of a noninvasive blood glucose meter.)

Quality of Care Issues (Managed Care and/or Medicaid)

As Congress turns to examine managed care, it's important that the unique health needs of people with diabetes don't get left out of the discussion. In addition, it has come to our attention that services for people with diabetes is extremely inconsistent across different managed care plans and each needs to be fully evaluated. A corollary to this issue is the increasing role of managed care in the Medicaid program, and its impact on care for people with diabetes.

Oversight of National Diabetes Education Project

The National Diabetes Education Project is a joint venture between the NIDDK and the CDC to educate the public about the serious health issues of diabetes. To date, the NDEP has held meetings and discussions without any input from the Caucus. It appears that the NDEP and the Caucus have very similar goals, and the potential for collaboration should be examined.

Promoting Diabetes Research at NASA

Currently, NASA is engaged in diabetes research in protein crystal growth, culture of human islet cells, and fiber optic probe technology for diabetic retinopathy. There are a number of companies pursuing this research and the Caucus may be interested in strengthening political support for these efforts.

Islet Cell Transfer: Macroencapsulation, Microencapsulation, and Xenotransplantation

Islet cell transfer is one of the most promising areas of diabetes research, but remains subject to political attacks. Scientists across the country are examining different facets of islet cell research, including macroencapsulation, microencapsulation, and xenotransplantation involving pigs.

Improving Physician Knowledge of Diabetes Care Issues

The GAO report issued earlier this year on quality of care for Medicare beneficiaries with diabetes. The GAO report clearly demonstrated that physicians often lack the necessary education and expertise to adequately treat people with diabetes. Improving patient care by working with providers is one of the top priorities of the Diabetes Quality Improvement Project, and the Caucus could oversee their work.

Recruitment of NIH Diabetes Researchers

The recent NIH conference on diabetes confirmed that there is a shortage of quality scientists going into diabetes research. While attracting quality research is partially a function of the funding levels, it is also clear that the diabetes research community is somewhat static. The Caucus might want to explore ways (perhaps with scientific organizations) to attract young

III. Possible Future Events/Activities:

Develop action kits for Diabetes Caucus member to effectively communicate the "diabetes message."

Being involved in the Diabetes Caucus allows members to communicate the "diabetes message": prevention saves money and improve lives, helps, reversed a non-sensical government health policy. We could develop an action kit with talking points, contact information, and sample letters to help members use the Caucus membership to their advantage in their district.

Conduct meeting/event in conjunction with National Diabetes Education Project

See "Oversight of National Diabetes Education Project" under Section II.

Conduct event in Washington on non-invasive and other advancements diabetes technologies

There are numerous companies across America who are in development of technologies, non-invasive or otherwise to help people with diabetes. The Caucus could invite them to Washington, D.C. to demonstrate their innovations. This would expose the public to new technologies and allow Caucus members to showcase products from their districts.

Hold Informal Hearing with Managed Care Plans on Diabetes Care

See "Quality of Care Issues" in Section II. An informal hearing or other public event could focus attention on this emerging problem.

IV. On-Going Projects for 1998

There are a number of annual projects for the Congressional Diabetes Caucus which should be pursued regardless of any new initiatives.

- Monitor Implementation of new Medicare self-management training and blood-testing strips benefits
- Monitor appropriation of new research funds for type 1 diabetes, and programs for Native Americans.
- Monitor appropriation for diabetes telemedicine project
- Maximize FY 1999 NIDDK research budget, monitor results of Diabetes Research Working Group
- Ensure people with diabetes are adequately represented in reauthorization of National Institutes of Health

Arasider FY

REMARKS TO CONGRESSIONAL DIABETES CAUCUS

October 28, 1997

You all know the statistics:

- Not only are there 8 million Americans diagnosed with diabetes, but also another 8 million who are believed to have the disease and just not been diagnosed.
- People with diabetes are two to four times more likely to suffer from cardiovascular disease, and two to four times more at risk for a stroke.
- Nearly two-thirds of people with diabetes suffer with high blood pressure, as well.

Cost of Diabetes. The American Diabetes Association estimates that we spend \$92 billion per year on diabetes care. Of that total, \$45 billion is directly attributable to the disease, while indirect medical costs such as work loss, disability and premature death account for the remainder.

Historic Investments for Diabetes. Thanks to strong bipartisan support, our balanced budget agreement included new investment in treatment, prevention and research for American with diabetes. So important are these new investments that the American Diabetes Association described them as being "as important for people with diabetes as the discovery of insulin in 1921."

Those new investments are:

- **A New Medicare Benefit to Help People With Diabetes Better Manage Their Care.** The balanced budget expands Medicare's coverage of benefits for people with diabetes by \$2.1 billion over five years. In so doing, it expands the number of people able to take advantage of self-management tools will increase the number of Americans who properly manage their diabetes, thereby helping to prevent the debilitating and costly complications too often associated with the disease.

Under the new balanced budget, Medicare will **cover self-management training offered by physicians and other certified providers rather than only in hospital-based programs** as it traditionally has. This will help ensure that more beneficiaries with diabetes can access the necessary education to manage this disease. In addition, Medicare will **make blood glucose monitors (including testing strips) available to all beneficiaries with diabetes**, whereas Medicare currently covers only insulin-dependent patients. Ensuring Medicare beneficiaries have access to these supplies will help improve their treatment and has great potential to reduce costs. This new legislation was introduced and strongly advocated by Rep. Furse, Rep. Nethercut, and Senator Breaux.

- **Status:** HCFA is reaching out to groups, researchers, experts to figure out what education works best, for who, and how often glucose needed etc. They intend to have the regs out on time. **The reimbursement for testing strips goes into effect 1/1/98 and the rest of the law 7/1/98.**
- **A \$150 million investment in diabetes research to prevent and cure juvenile or Type I diabetes.** Between 700,000 and one million Americans suffer from Type 1 diabetes. Half of those individuals are children. Each year about 30,000 Americans are diagnosed with Type I diabetes. These funds, which represent the largest single new investment in Type 1 diabetes, will be allocated by Health and Human Service Secretary Donna Shalala. Increasing our research efforts for Type I diabetes also will help improve our knowledge about all types of diabetes.
- **Status:** NIH has been working concrete proposals on this and plans to have this to the Secretary plan to announce these by the end of the year. Held an Advisory Meeting on this on October 7th assessing the needed areas of research. Addressed areas such as patient-oriented innovative research, investigator initiated research, major clinical trials. Making recommendations to the Secretary.
- **A \$150 million investment for prevention and treatment of diabetes among Native Americans, who are almost three times as likely to die from the disease as other Americans.** In some tribes, more than one-third of the population suffers with diabetes. Native Americans are also far less likely to receive adequate treatment to manage the disease. This funding will help improve prevention efforts and help identify the disease in its early stages. Money will also go to expanding access to affordable treatment, so that more Native Americans get the care they need to help reduce the costly and devastating complications.
- **Status:** IHS met in early October with tribes and tribes will be getting back to them with proposals. (CJ -- according to OMB and based on conversations with IHS, this one has been a little slower to get off the ground. OMB staff tells me they have been pushing on this with no luck and it may be helpful to have you or Josh call Kevin about this).
- **A New Diabetes Quality Improvement Project.** This summer the President also announced a major year-long collaborative effort to develop more consistent quality measures for diabetes patients, health plans, and health providers across America. The coalition between HCFA, FAACT, ADA, NCQA and now joined by CDC, AAFP, ACP etc, are coming together to develop a common set of performance and outcome measures are being developed. Together, in this unprecedented agreement these organizations will work to ensure that millions of consumers, purchasers, and health care providers have a common set of standards for diabetes care and utilize this new information to improve care.

- **Status:** This group has met several times and is on track to develop draft recommendations by January and final in June. More critical organizations, such as CDC, AAFP, ACP and others have joined this important coalition.

Congressional Caucus Priorities. See attached

- We just received your priorities and are reviewing them. In particular, I would like to encourage your interest in the National Diabetes Education Program. I agree with you that they share your goals. I have spoken to the leaders of this program and they informed me that they would welcome your interest and collaboration.
- With regard to improving physician knowledge of diabetes care, I believe the Diabetes Quality Improvement does share some of your same goals of improving physician knowledge of this disease. Would encourage you to work with them as well. With regard, to quality of care issues, CDC is doing some of this work, We are interested in these ideas as well.
- Also we would support hearings on managed care.

To: Interested Parties
Fr: Christopher Porter

Legislative Director, Rep. Furse

Re: October 29th Meeting of Congressional Diabetes Caucus

Da: 10/28/97

The Congressional Diabetes Caucus will meet at 2PM on Wednesday, October 29th, at 2PM in 2359 Rayburn HOB. The Congressional Diabetes Caucus is has 101 bipartisan members, and is chaired by Rep. Elizabeth Furse (D-OR) and Rep. George Nethercutt (R-WA).

The meeting will be members-only, is scheduled to last approximately 30 minutes, and is designed to be a discussion on how to publicize the Administration's "Commitment to Fight Diabetes" (particularly the Medicare, research, and telemedicine initiatives), as well as determine an agenda for the Diabetes Caucus for the duration of the 105th Congress.

I. Proposed Agenda for Diabetes Caucus Meeting:

1. Introduction by Reps. Furse and Nethercutt (>5 mins)
Outline of achievements in diabetes:
--Medicare coverage of self-management training/strips
--Research funding for Type 1
--Research funding for Native Americans
--Diabetes Telemedicine Project
--NIH Diabetes Research Working Group
2. Remarks by Erskine Bowles, Chief of Staff to the President and former JDF President (5 mins.)
3. Remarks by Chris Jennings, Deputy Assistant to the President for Health Policy (5 mins.)
--Update on Medicare benefits implementation by HCFA before 7/1/98;
4. Discussion of publicizing recent achievements (5 mins.)
5. Discussion of future diabetes agenda (10 mins.)
--Opportunity for Caucus members to discuss concerns

II. Possible New Issues for the Caucus:

Medicare Coverage of Insulin Pump

Grant Bagley, Kyle J. Furse
A. Webb

Currently, HCFA does not cover insulin pump therapy. The insulin pump is a computerized device that regulates blood sugar levels, in lieu of traditional multiple daily injections. The pump is very effective for certain types of people with diabetes, and HCFA coverage of the insulin pump is supported by ADA, JDF, AACE, AADE, and manufacturers. -Curt

Medicare Coverage of Pancreas Transplantation Grant

For selective populations of people with diabetes, pancreas transplantation is the only known "cure" for diabetes. Successful pancreas transplantation patients have a 77% chance of achieving insulin independence within one year. HCFA does not cover pancreas transplantation, and has insisted on studies to prove "quality of life" improvements despite the fact that such an improvement is self-evident.

Curt

Noninvasive Blood Glucose Meter/Technology Issues

There are a number of companies across the country pursuing the development of a noninvasive blood glucose meter. There is concern among some manufacturers that the FDA does not adequately understand diabetes. (Congresswoman Furse and Mr. Barton recently inserted language in the FDA reform bill alerting the agency to the importance of a noninvasive blood glucose meter.)

Quality of Care Issues (Managed Care and/or Medicaid)

As Congress turns to examine managed care, it's important that the unique health needs of people with diabetes don't get left out of the discussion. In addition, it has come to our attention that services for people with diabetes is extremely inconsistent across different managed care plans and each needs to be fully evaluated. A corollary to this issue is the increasing role of managed care in the Medicaid program, and its impact on care for people with diabetes.

Oversight of National Diabetes Education Project

The National Diabetes Education Project is a joint venture between the NIDDK and the CDC to educate the public about the serious health issues of diabetes. To date, the NDEP has held meetings and discussions without any input from the Caucus. It appears that the NDEP and the Caucus have very similar goals, and the potential for collaboration should be examined.

Promoting Diabetes Research at NASA

Currently, NASA is engaged in diabetes research in protein crystal growth, culture of human islet cells, and fiber optic probe technology for diabetic retinopathy. There are a number of companies pursuing this research and the Caucus may be interested in strengthening political support for these efforts.

Islet Cell Transfer: Macroencapsulation, Microencapsulation, and Xenotransplantation

Islet cell transfer is one of the most promising areas of diabetes research, but remains subject to political attacks. Scientists across the country are examining different facets of islet cell research, including macroencapsulation, microencapsulation, and xenotransplantation involving pigs.

Improving Physician Knowledge of Diabetes Care Issues

The GAO report issued earlier this year on quality of care for Medicare beneficiaries with diabetes. The GAO report clearly demonstrated that physicians often lack the necessary education and expertise to adequately treat people with diabetes. Improving patient care by working with providers is one of the top priorities of the Diabetes Quality Improvement Project, and the Caucus could oversee their work.

Recruitment of NIH Diabetes Researchers

The recent NIH conference on diabetes confirmed that there is a shortage of quality scientists going into diabetes research. While attracting quality research is partially a function of the funding levels, it is also clear that the diabetes research community is somewhat static. The Caucus might want to explore ways (perhaps with scientific organizations) to attract young

III. Possible Future Events/Activities:

Develop action kits for Diabetes Caucus member to effectively communicate the "diabetes message."

Being involved in the Diabetes Caucus allows members to communicate the "diabetes message": prevention saves money and improve lives, helps, reversed a non-sensical government health policy. We could develop an action kit with talking points, contact information, and sample letters to help members use the Caucus membership to their advantage in their district.

Conduct meeting/event in conjunction with National Diabetes Education Project

See "Oversight of National Diabetes Education Project" under Section II.

Conduct event in Washington on non-invasive and other advancements diabetes technologies

There are numerous companies across America who are in development of technologies, non-invasive or otherwise to help people with diabetes. The Caucus could invite them to Washington, D.C. to demonstrate their innovations. This would expose the public to new technologies and allow Caucus members to showcase products from their districts.

Hold Informal Hearing with Managed Care Plans on Diabetes Care

See "Quality of Care Issues" in Section II. An informal hearing or other public event could focus attention on this emerging problem.

IV. On-Going Projects for 1998

There are a number of annual projects for the Congressional Diabetes Caucus which should be pursued regardless of any new initiatives.

- Monitor Implementation of new Medicare self-management training and blood-testing strips benefits
- Monitor appropriation of new research funds for type 1 diabetes, and programs for Native Americans.
- Monitor appropriation for diabetes telemedicine project
- Maximize FY 1999 NIDDK research budget, monitor results of Diabetes Research Working Group
- Ensure people with diabetes are adequately represented in reauthorization of National Institutes of Health

DIABETES CONTROL IS PREVENTION: AN OVERVIEW

1-3

INTRODUCTION

Diabetes Prevention and Control is a 2-hour live satellite video conference presented by the Centers for Disease Control and Prevention's Division of Diabetes Translation. This enlightening interactive program uses CNN's Susan Rook in her Talk Back Live format to engage over 20,000 participants nationwide from over 800 downlink sites across the country in a dialogue about one of the nation's most serious health problems, diabetes. This videoconference will be broadcast to diabetes control program sponsored locations around the country where public health professionals, community leaders, policy makers, health insurance payors and health care professional will participate. This conference will engage people who can make a difference in an authentic and fresh dialogue on the problems of diabetes to bring about new partnerships and innovative solutions.

OBJECTIVES

The objectives for the conference are:

- ❖ to increase awareness of the impact of diabetes
- ❖ to highlight existing efforts to reduce the burden of diabetes
- ❖ to mobilize communities to action to improve diabetes outcomes

MODERATORS/GUESTS

The program is moderated by Susan Rook. The host is Frank Vinicor, MD, Director of the Division of Diabetes Translation, CDC. He will be joined by several expert guests throughout the program.

DESCRIPTION OF PROGRAM

The program will feature a live studio audience in-the-round with Susan Rook as the celebrity moderator. To drive the discussion the program will include video newsmagazine segments showcasing unique and innovative approaches to managing diabetes from across the US.

This includes home videos from state diabetes control programs showing their activities, and PSAs from national co-sponsors including the American Diabetes Association, American Association of Diabetes Educators, Juvenile Diabetes Foundation, and more. Viewers will have ample opportunity to interact with guests through toll-free phone, fax, and TTY numbers.

The following is a brief description of some of the areas that will be covered during this program by segment and some of the guest experts that will provide information about specific topics.

SEGMENT 1: A LIFE OF BALANCE

Reflects individual goals and capabilities now attainable. This segment will focus on the impact of diabetes on America, why we need to control diabetes, and what care is needed to prevent diabetes complications. Guest experts for this segment include: Mayer Davidson, MD, President, American Diabetes Association, and Lorraine Valdez, RN, CDE, Indian Health Service Diabetes Program.

SEGMENT 2: A COMMUNITY OF SUPPORT

Will identify many of the key players helping to improve diabetes outcomes, and illustrate through video clips, newsmagazines and audience participation, some of the current efforts that are making a difference in outcomes. Guest experts for this segment include: Jan Norman, RD, CDE, AADE President; and Program Director, Washington State Diabetes Control Program, and Gerald Durlley, Ph.D, MDiv., Past - President Concerned Black Clergy, Director, Health Promotion Resource Center- Morehouse School of Medicine.

SEGMENT 3: A PROGRAM OF PREVENTION

Will discuss the deeper meaning of Diabetes Control is Prevention, and how we can work together to solve the problems caused by diabetes. Guest experts for this segment include Charles Clark, MD, Chair of the National Diabetes Education Program (NDEP) and Jaime Davidson, MD, President of the Texas Diabetes Advisory Council.

(33)



DIABETES

CONTROL IS PREVENTION

Via Satellite Broadcast
October 30, 1997
1-3 PM EST

Join CDC, state and territorial diabetes control program representatives and other partners in a satellite broadcast dedicated to finding ways to prevent unnecessary losses caused by diabetes in our communities.

Conference Goals

- Increase awareness of the impact of diabetes
- Highlight existing efforts to reduce the burden of diabetes
- Mobilize communities to action to improve diabetes outcomes

Intended Participant Outcomes

- Agree that improving quality of diabetes care will reduce diabetes-related complications
- Describe existing national, state and local activities that reduce the burden of diabetes outcomes
- Identify new opportunities for collaborative efforts to improve diabetes outcomes
- Agree to initiate actions to improve access to quality diabetes care

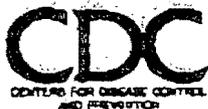
Intended Audiences

State, territorial and local public health officials, community leaders, policy makers, state/local business leaders, managed care professionals, and other advocates and potential advocates for diabetes prevention and control.

Preregistration

To preregister for the Satellite Broadcast, call 1-800-41-TRAIN.

For more information, call your state or territorial diabetes control program (*see Government blue pages for phone number*).



U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
 Public Health Services
 Centers for Disease Control and Prevention
 National Center for Chronic Disease Prevention
 and Health Promotion



Betty Bednarczyk

Christine Cassel

Robert Georgine

Val Halamandaris

Nan Hunter

Risa Lavizzo-Mourey

Ben Lytle

Beverly Malone

Paul Montrone

Herbert Pardes

Christopher Queram

Thomas Reardon

Steven Sharfstein

Mary Wakefield

Alan Weil

Stephen Wiggins

Donald Berwick

James Chao

Diane Graham

Sandra Hernandez

Sylvia Drew Ivie

Sheila Leatherman

Randy MacDonald

Gerald McEntee

Phillip Nudelman

Ronald Pollack

Robert Ray

Kathleen Sebelius

Peter Thomas

Gail Warden

Sheldon Weinhaus

Richard Sorian

Secretary Alexis Herman

Secretary Donna Shalala

Janet Corrigan

Should ask about

- ① → ~~need to~~ justice medical privacy concerns
what is difference from Sec. report
- ② Non-discrimination stuff
Ron Pallock - 2y resolve this
- ③ ~~getting in front~~
Addressing business criticisms
(document they sent)
- ④ how to proceed w/ announcement.
(although ~~partial~~
~~decision~~)



Juvenile Diabetes Foundation International
The Diabetes Research Foundation

FOR IMMEDIATE RELEASE

Contact: Eric Schutt
Juvenile Diabetes Foundation
202/371-9746
Vanessa McGowan
Juvenile Diabetes Foundation
212/479-7530

**Juvenile Diabetes Foundation Applauds President Clinton's Leadership in
Bi-Partisan Effort To Include \$150 Million for Type I Diabetes Research in Balanced Budget**

Mary Tyler Moore represents 16 million Americans threatened by diabetes
at Presidential Announcement

New York, NY (August 8, 1997) – Mary Tyler Moore and volunteers of the Juvenile Diabetes Foundation International (JDFI) gathered in Washington today to applaud President Clinton's leadership in a Bi-partisan effort to include \$330 million for new diabetes programs in the Balanced Budget Act of 1997 – in particular, the \$150 million that is provided for Type I diabetes research programs.

In addition to other important initiatives, The Act provides for \$30 million per year for five years for innovative research and treatment programs focusing on the prevention and cure of Type I diabetes.

"Insulin is not a cure," said Mary Tyler Moore, JDFI's International Chairman. "With this initiative, we can capitalize on years of research progress and start to move advances out of the laboratories to the bedsides of our loved ones."

"With the tremendous human and economic tolls taken by this devastating disease and its complications, it is more than appropriate that a full frontal attack on diabetes be launched by the federal government," said Robert Wood Johnson IV, Chairman of JDFI. "This long awaited increase contains a significant infusion of new funds for research into Type I diabetes, and provides renewed hope for millions of Americans."

"Diabetes has reached epidemic proportions worldwide and the numbers are steadily increasing," stated James E. Mulvihill, D.M.D., President and CEO of JDFI. "We know that this extraordinary initiative will help attract the attention of our leading scientists, and encourage them to apply their knowledge to the complex and myriad problems of diabetes in new and imaginative ways."

The mission of the Juvenile Diabetes Foundation International is to find a cure for diabetes and its complications through the support of research. JDFI was founded in 1970 by parents of children with diabetes who were convinced that through research, diabetes could be cured. With chapters from coast to coast and affiliates around the world, JDFI gives more money to diabetes research than any other non-profit, non-governmental health agency in the world. In 1996, JDFI awarded \$30.3 million to diabetes research worldwide, bringing the cumulative dollar commitment to \$220 million.

###



Juvenile Diabetes Foundation International
The Diabetes Research Foundation

FOR IMMEDIATE RELEASE

Contact: Eric Schutt
Juvenile Diabetes Foundation
202/371-9746
Vanessa McGowan
Juvenile Diabetes Foundation
212/479-7530

**Juvenile Diabetes Foundation Applauds President Clinton's Leadership in
Bi-Partisan Effort To Include \$150 Million for Type I Diabetes Research in Balanced Budget**

Mary Tyler Moore represents 16 million Americans threatened by diabetes
at Presidential Announcement

New York, NY (August 8, 1997) – **Mary Tyler Moore and volunteers of the Juvenile Diabetes Foundation International (JDFI) gathered in Washington today to applaud President Clinton's leadership in a Bi-partisan effort to include \$330 million for new diabetes programs in the Balanced Budget Act of 1997 – in particular, the \$150 million that is provided for Type I diabetes research programs.**

In addition to other important initiatives, The Act provides for \$30 million per year for five years for innovative research and treatment programs focusing on the prevention and cure of Type I diabetes.

“Insulin is not a cure,” said Mary Tyler Moore, JDFI’s International Chairman. “With this initiative, we can capitalize on years of research progress and start to move advances out of the laboratories to the bedsides of our loved ones.”

“With the tremendous human and economic tolls taken by this devastating disease and its complications, it is more than appropriate that a full frontal attack on diabetes be launched by the federal government,” said Robert Wood Johnson IV, Chairman of JDFI. “This long awaited increase contains a significant infusion of new funds for research into Type I diabetes, and provides renewed hope for millions of Americans.”

“Diabetes has reached epidemic proportions worldwide and the numbers are steadily increasing,” stated James E. Mulvihill, D.M.D., President and CEO of JDFI. “We know that this extraordinary initiative will help attract the attention of our leading scientists, and encourage them to apply their knowledge to the complex and myriad problems of diabetes in new and imaginative ways.

The mission of the Juvenile Diabetes Foundation International is to find a cure for diabetes and its complications through the support of research. JDFI was founded in 1970 by parents of children with diabetes who were convinced that through research, diabetes could be cured. With chapters from coast to coast and affiliates around the world, JDFI gives more money to diabetes research than any other non-profit, non-governmental health agency in the world. In 1996, JDFI awarded \$30.3 million to diabetes research worldwide, bringing the cumulative dollar commitment to \$220 million.

###



Juvenile Diabetes Foundation International
The Diabetes Research Foundation

FOR IMMEDIATE RELEASE

Contact: Eric Schutt
Juvenile Diabetes Foundation
202/371-9746
Vanessa McGowan
Juvenile Diabetes Foundation
212/479-7530

**Juvenile Diabetes Foundation Applauds President Clinton's Leadership in
Bi-Partisan Effort To Include \$150 Million for Type I Diabetes Research in Balanced Budget**

Mary Tyler Moore represents 16 million Americans threatened by diabetes
at Presidential Announcement

New York, NY (August 8, 1997) – Mary Tyler Moore and volunteers of the Juvenile Diabetes Foundation International (JDFI) gathered in Washington today to applaud President Clinton's leadership in a Bi-partisan effort to include \$330 million for new diabetes programs in the Balanced Budget Act of 1997 – in particular, the \$150 million that is provided for Type I diabetes research programs.

In addition to other important initiatives, The Act provides for \$30 million per year for five years for innovative research and treatment programs focusing on the prevention and cure of Type I diabetes.

"Insulin is not a cure," said Mary Tyler Moore, JDFI's International Chairman. "With this initiative, we can capitalize on years of research progress and start to move advances out of the laboratories to the bedsides of our loved ones."

"With the tremendous human and economic tolls taken by this devastating disease and its complications, it is more than appropriate that a full frontal attack on diabetes be launched by the federal government," said Robert Wood Johnson IV, Chairman of JDFI. "This long awaited increase contains a significant infusion of new funds for research into Type I diabetes, and provides renewed hope for millions of Americans."

"Diabetes has reached epidemic proportions worldwide and the numbers are steadily increasing," stated James E. Mulvihill, D.M.D., President and CEO of JDFI. "We know that this extraordinary initiative will help attract the attention of our leading scientists, and encourage them to apply their knowledge to the complex and myriad problems of diabetes in new and imaginative ways."

The mission of the Juvenile Diabetes Foundation International is to find a cure for diabetes and its complications through the support of research. JDFI was founded in 1970 by parents of children with diabetes who were convinced that through research, diabetes could be cured. With chapters from coast to coast and affiliates around the world, JDFI gives more money to diabetes research than any other non-profit, non-governmental health agency in the world. In 1996, JDFI awarded \$30.3 million to diabetes research worldwide, bringing the cumulative dollar commitment to \$220 million.

###



Juvenile Diabetes Foundation International
The Diabetes Research Foundation

FOR IMMEDIATE RELEASE

Contact: Eric Schutt
Juvenile Diabetes Foundation
202/371-9746
Vanessa McGowan
Juvenile Diabetes Foundation
212/479-7530

**Juvenile Diabetes Foundation Applauds President Clinton's Leadership in
Bi-Partisan Effort To Include \$150 Million for Type I Diabetes Research in Balanced Budget**

Mary Tyler Moore represents 16 million Americans threatened by diabetes
at Presidential Announcement

New York, NY (August 8, 1997) – **Mary Tyler Moore and volunteers of the Juvenile Diabetes Foundation International (JDFI) gathered in Washington today to applaud President Clinton's leadership in a Bi-partisan effort to include \$330 million for new diabetes programs in the Balanced Budget Act of 1997 – in particular, the \$150 million that is provided for Type I diabetes research programs.**

In addition to other important initiatives, The Act provides for \$30 million per year for five years for innovative research and treatment programs focusing on the prevention and cure of Type I diabetes.

"Insulin is not a cure," said Mary Tyler Moore, JDFI's International Chairman. "With this initiative, we can capitalize on years of research progress and start to move advances out of the laboratories to the bedsides of our loved ones."

"With the tremendous human and economic tolls taken by this devastating disease and its complications, it is more than appropriate that a full frontal attack on diabetes be launched by the federal government," said Robert Wood Johnson IV, Chairman of JDFI. "This long awaited increase contains a significant infusion of new funds for research into Type I diabetes, and provides renewed hope for millions of Americans."

"Diabetes has reached epidemic proportions worldwide and the numbers are steadily increasing," stated James E. Mulvihill, D.M.D., President and CEO of JDFI. "We know that this extraordinary initiative will help attract the attention of our leading scientists, and encourage them to apply their knowledge to the complex and myriad problems of diabetes in new and imaginative ways."

The mission of the Juvenile Diabetes Foundation International is to find a cure for diabetes and its complications through the support of research. JDFI was founded in 1970 by parents of children with diabetes who were convinced that through research, diabetes could be cured. With chapters from coast to coast and affiliates around the world, JDFI gives more money to diabetes research than any other non-profit, non-governmental health agency in the world. In 1996, JDFI awarded \$30.3 million to diabetes research worldwide, bringing the cumulative dollar commitment to \$220 million.

###



Juvenile Diabetes Foundation International
The Diabetes Research Foundation

FOR IMMEDIATE RELEASE

Contact: Eric Schutt
Juvenile Diabetes Foundation
202/371-9746
Vanessa McGowan
Juvenile Diabetes Foundation
212/479-7530

**Juvenile Diabetes Foundation Applauds President Clinton's Leadership in
Bi-Partisan Effort To Include \$150 Million for Type I Diabetes Research in Balanced Budget**

Mary Tyler Moore represents 16 million Americans threatened by diabetes
at Presidential Announcement

New York, NY (August 8, 1997) – Mary Tyler Moore and volunteers of the Juvenile Diabetes Foundation International (JDFI) gathered in Washington today to applaud President Clinton's leadership in a Bi-partisan effort to include \$330 million for new diabetes programs in the Balanced Budget Act of 1997 – in particular, the \$150 million that is provided for Type I diabetes research programs.

In addition to other important initiatives, The Act provides for \$30 million per year for five years for innovative research and treatment programs focusing on the prevention and cure of Type I diabetes.

"Insulin is not a cure," said Mary Tyler Moore, JDFI's International Chairman. "With this initiative, we can capitalize on years of research progress and start to move advances out of the laboratories to the bedsides of our loved ones."

"With the tremendous human and economic tolls taken by this devastating disease and its complications, it is more than appropriate that a full frontal attack on diabetes be launched by the federal government," said Robert Wood Johnson IV, Chairman of JDFI. "This long awaited increase contains a significant infusion of new funds for research into Type I diabetes, and provides renewed hope for millions of Americans."

"Diabetes has reached epidemic proportions worldwide and the numbers are steadily increasing," stated James E. Mulvihill, D.M.D., President and CEO of JDFI. "We know that this extraordinary initiative will help attract the attention of our leading scientists, and encourage them to apply their knowledge to the complex and myriad problems of diabetes in new and imaginative ways."

The mission of the Juvenile Diabetes Foundation International is to find a cure for diabetes and its complications through the support of research. JDFI was founded in 1970 by parents of children with diabetes who were convinced that through research, diabetes could be cured. With chapters from coast to coast and affiliates around the world, JDFI gives more money to diabetes research than any other non-profit, non-governmental health agency in the world. In 1996, JDFI awarded \$30.3 million to diabetes research worldwide, bringing the cumulative dollar commitment to \$220 million.

###



Juvenile Diabetes Foundation International
The Diabetes Research Foundation

FOR IMMEDIATE RELEASE

Contact: Eric Schutt
Juvenile Diabetes Foundation
202/371-9746
Vanessa McGowan
Juvenile Diabetes Foundation
212/479-7530

**Juvenile Diabetes Foundation Applauds President Clinton's Leadership in
Bi-Partisan Effort To Include \$150 Million for Type I Diabetes Research in Balanced Budget**

Mary Tyler Moore represents 16 million Americans threatened by diabetes
at Presidential Announcement

New York, NY (August 8, 1997) – Mary Tyler Moore and volunteers of the Juvenile Diabetes Foundation International (JDFI) gathered in Washington today to applaud President Clinton's leadership in a Bi-partisan effort to include \$330 million for new diabetes programs in the Balanced Budget Act of 1997 – in particular, the \$150 million that is provided for Type I diabetes research programs.

In addition to other important initiatives, The Act provides for \$30 million per year for five years for innovative research and treatment programs focusing on the prevention and cure of Type I diabetes.

"Insulin is not a cure," said Mary Tyler Moore, JDFI's International Chairman. "With this initiative, we can capitalize on years of research progress and start to move advances out of the laboratories to the bedsides of our loved ones."

"With the tremendous human and economic tolls taken by this devastating disease and its complications, it is more than appropriate that a full frontal attack on diabetes be launched by the federal government," said Robert Wood Johnson IV, Chairman of JDFI. "This long awaited increase contains a significant infusion of new funds for research into Type I diabetes, and provides renewed hope for millions of Americans."

"Diabetes has reached epidemic proportions worldwide and the numbers are steadily increasing," stated James E. Mulvihill, D.M.D., President and CEO of JDFI. "We know that this extraordinary initiative will help attract the attention of our leading scientists, and encourage them to apply their knowledge to the complex and myriad problems of diabetes in new and imaginative ways."

The mission of the Juvenile Diabetes Foundation International is to find a cure for diabetes and its complications through the support of research. JDFI was founded in 1970 by parents of children with diabetes who were convinced that through research, diabetes could be cured. With chapters from coast to coast and affiliates around the world, JDFI gives more money to diabetes research than any other non-profit, non-governmental health agency in the world. In 1996, JDFI awarded \$30.3 million to diabetes research worldwide, bringing the cumulative dollar commitment to \$220 million.

###

March 28, 1997

TO: Sarah Bianchi
FROM: Joan Stieber, HCFA/OLIGA
RE: Further background material on diabetes

Attached, as requested, is some further background material on diabetes, including:

- (1) Fact sheets from the CDC (including some information available on the Internet). Note that the statement on the top sheet ("27% of all Medicare costs annually are to treat persons with diabetes") has been misunderstood by some people to mean that 27% of Medicare costs are for diabetes-related care -- a very different thing than the costs of all services provided to persons with diabetes. For further discussion of this point, see the Dec. 10, 1996 memo from Bruce Vladeck to the Secretary (in the package FAXed to Jean Lambrew on March 10, 1997).
- (2) Testimony by the American Diabetes Association (ADA) before the Ways & Means Committee, July 25, 1995.
- (3) "Direct and Indirect Costs of Diabetes in the United States in 1992" -- a study by the ADA, with summary cover sheet.
- (4) "Health Care Expenditures for People With Diabetes Mellitus, 1992" -- an article by Rubin, et al., published in the Journal of Clinical Endocrinology & Metabolism, April 1994.

Two further points FYI:

- (1) In the briefing package FAXed to you on March 10, in the document called "Comparison Between H.R. 58 (Furse Bill) and Administration Proposals for Expanded Diabetes Benefits", the second bullet point says: "While H.R. 58 refers to "testing strips", we assume it intends to expand coverage for blood glucose monitors as well as strips." We have since learned that that is incorrect. H.R. 58 proposes expanded coverage of only the testing strips that are used in conjunction with glucose monitors, not coverage of the monitors themselves. In contrast, the Administration's bill would expand coverage for both monitors and testing strips (with a 10% payment reduction for the strips).
- (2) Nancy De Lew (OLIGA Deputy Director) attended the Secretary's meeting with the ADA on March 11, 1997. She says that the meeting focused primarily on NIH, with the ADA urging support for expanded NIH research on diabetes. The ADA was supportive of HCFA activities, although they believe that coverage of testing strips would be sufficient without coverage for glucose monitors (see point above).

If you have any further questions about these materials, please give me a call at (202) 690-6884.

**MESSAGE FOR CENTERS FOR DISEASE CONTROL AND PREVENTION
DIABETES CONFERENCE PARTICIPANTS**

March 24, 1997

We must recognize the benefits of early preventive interventions if we are to ensure a better quality of life for more Americans and begin to control the costs of many chronic diseases. Diabetes can lead the way in these efforts. This all too common, serious, and costly disease, which particularly impacts those least able to deal with the condition -- communities of color and the elderly -- can serve as a model for demonstrating a new approach to reducing health problems: early preventive care; patient involvement and responsibility; state and local program participation; and public, private, voluntary, and academic coordination.

These are the elements which must come together if we are to make an important difference in the everyday lives of people with diabetes. With what we know today, people with diabetes do not have to experience blindness, amputations, kidney failure, heart attacks, and reduced quality of life.

It is vitally important for you to continue to do excellent work; to continue to assist people to learn how to manage their own diabetes; and to establish programs early in the natural history of diabetes so we can decrease dependency on complicated, expensive treatment. You are the public health leaders, and through your leadership, we can move forward to reduce the devastating burden of diabetes by emphasizing the importance of prevention.



Newt Gingrich
Speaker of the House of Representatives



Erskine Bowles
Chief of Staff to the President