

## Appendix B

Novo Nordisk: National Diabetes Initiative  
Overview of Primary Polling Research  
July 2, 2003

**THE GINGRICH GROUP**

## INTRODUCTION

Diabetes affects roughly 17 million people in the U.S. today, and there are approximately 6 million people who are living undiagnosed with diabetes, nearly a third of those with the disease are unaware of their condition. In addition, there are 16 million pre-diabetics in the U.S.

Most of the country's 17 million diabetics have Type 2, which is caused by insulin resistance and can be triggered by environmental factors such as obesity. Those with Type 1 diabetes, which is caused by the body's destruction of its own insulin-producing cells, affects 10% of all those with diabetes and is generally diagnosed in childhood.

In the United States, diabetes is the seventh leading cause of death overall, and the sixth leading cause of death by disease. In measuring the effects of diabetes on the quality of life, diabetes is the leading cause of adult blindness, kidney failure, and non-traumatic lower-limb amputations. Persons with diabetes are also 2 to 4 times more likely to suffer from heart disease and stroke than those without the disease.

Twenty percent of those aged 65 years or older have diabetes and alarming new statistics show

that Type 2 diabetes among young people below the age of 20 is on the rise.

Diabetes has a particularly adverse affect on certain races and ethnicities. For instance, Hispanic/Latino Americans, Black Americans, and Native Americans are, on average, 2 times more likely to have diabetes than White Americans of similar age.

According to Center for Disease Control (CDC) estimates, diabetes has increased nearly 50 percent in the past 10 years and is expected to grow 165 percent by 2050 if incidence rates follow current trends.

### **The Research Program: Understanding Public Perceptions about Diabetes**

The Gingrich Group, with tactical support from the Winston Group polling firm, conducted a research program from March through June 2003 to accomplish the following five objectives: 1) develop a comprehensive knowledge base on public attitudes and knowledge of diabetes; 2) identify the language and most effective messengers to communicate the challenge and seriousness of diabetes effectively with the American public; 3) identify potential solutions and raise awareness;

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4) develop a working model to understand optimal ways to raise awareness; 5) develop a working model to understand the motivation and behavior pattern of those who transition to successfully managing diabetes.

### Key Questions:

- What is the American public's knowledge about diabetes? Are they aware of the risk factors, causes, and comorbidities?
  - What is the public's attitude toward diabetes? How do perceptions of diabetes compare to other perceptions of other diseases?
  - What vehicles or people influence the public's perception of diabetes?
  - Given the multitude of statistics on diabetes, what will be the most effective message to grab people's attention?
  - Similarly, what will be the message that motivates people to achieve healthier lifestyles and prevent diabetes or improve self-management?
- What information needs to be communicated to the public and to the medical and legislative establishments to motivate them to action?
  - Are there incentives the government could offer Americans to improve their diet, fitness level, and overall health?

## **THE RESEARCH PROGRAM: UNDERSTANDING THE DIABETES ENVIRONMENT**

### **Methodology**

- Ten focus groups were conducted at the beginning of April through early May in five cities: Alexandria, VA; Kansas City, MO; Milwaukee, WI; Boston, MA; and San Antonio, TX. The 4 groups in Alexandria and Kansas City consisted of members of diabetes target groups: men and women 55 years of age and older as well as 3 separate groups of Hispanic, African-American and Caucasian females between the ages of 25 and 50. In Milwaukee, one focus group was conducted with men and women whose answers to screening questions indicated that they were at a high risk for diabetes, and the other was comprised of Certified Diabetes Educators (CDEs). In Boston, the research focused on physicians including general practitioners, optometrists, and podiatrists, and parents of children with Type 1 diabetes. The last two focus groups were held in San Antonio, TX and consisted of parents of children with Type 2 diabetes and a second group of CDEs. These focus groups gave us the ability to identify the attitudes, concerns, and knowledge of each target group towards diabetes in

general and in relation to other prominent diseases. The focus groups also allowed us to evaluate the current health care environment and learn how diabetes is both viewed and treated within the medical community. The focus group setting gave diabetes educators as well as parents an opportunity to offer their own ideas about what can be done to improve the lives of people with diabetes nationwide, including both children and adults. The information gained from the focus groups was also used to develop the content of a national survey.

- In addition, two national surveys of 1000 adults were conducted March 25-27 and May 19-20, respectively. The surveys included a slight oversampling of minorities to ensure a universe that included at least 100 African-American and 100 Hispanic respondents in order to enhance the viability of the data. The questions and content of the first survey were based on research gathered from the focus groups in Alexandria and Kansas City. The initial

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survey focused primarily on attitudes of the general public toward health care in general, the factors that constitute a serious disease, the view of diabetes as it relates to other serious diseases, the public's overall perception and knowledge of diabetes, and level of support for plans of action. The second national survey conducted in May was developed based on conversations with parents, physicians, and certified diabetes educators. This survey more closely examined environmental factors associated with diabetes, motivations for improving health and getting tested for diabetes, and measured Americans' understanding of the causes of diabetes. Solutions for dealing with the diabetes epidemic were also tested.

- Finally, a series of one-on-one interviews were conducted with 15 people who had either Type 1 or Type 2 diabetes. Various CDEs recommended these men and women for the interviews because they were considered model patients who had learned to successfully manage their diabetes (June 4-11). The interviews

aimed at understanding how one learns to incorporate diabetes into his/her life. The patients were asked to describe both their initial reaction to being diagnosed with diabetes and their interactions with members of the medical community, as well as identify any obstacles or set-backs they experienced in dealing with diabetes.

Together, this package of in-depth research forms a comprehensive picture of diabetes from those at the center of the epidemic, including doctors, diabetes educators, parents, and patients, as well as those high risk groups that represent the primary diabetic population.

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The first priority of the research was to find out the state of knowledge among key groups and the population as a whole with respect to diabetes.

### **Target Group 1: Seniors 55+**

A striking aspect of the senior focus group was the demonstrated lack of curiosity about diabetes and feelings of risk among the seniors in the group, as well as the high level of responsibility the seniors place on their doctors--in terms of both educating them about diabetes and demonstrating why they should be concerned about a particular disease. Seniors are not fully aware of the implications and severity of diabetes. Although they acknowledge the dangers of diabetes once presented with statistical information, this information alone is not enough to ensure diabetes testing or a change in lifestyle. Unless it is known to run in the family, seniors do not believe themselves to be at great risk for diabetes.

*“My father developed neuropathy, but wouldn’t take a glucose test. But since it doesn’t run in my family, it is probably not diabetes.”*

As a result, less than a third of the seniors thought they were at risk for diabetes. In addition, the seniors admitted that they had never had someone discuss in detail the specifics of diabetes with

them, nor were they ever notified, through a physician or otherwise, that they might be at risk for the disease.

### **Target Group 2: Hispanic women, ages 25-50**

The Hispanic women demonstrated a fairly good working knowledge of diabetes. 80% of Hispanic women personally know someone with the disease, and nearly 70% of Hispanic women believe that, as a minority group, they are at risk for diabetes. Yet, despite the heightened awareness and increased perception of risk for Hispanics, only three women in the focus group had ever been tested for diabetes. Diabetes ranked only fourth in a list of 5 serious diseases, with cancer, AIDS, and heart disease were of greater concern to respondents.

### **Target Group 3: African-American women, ages 25-50**

African-American women were also more knowledgeable about diabetes than non-minorities. In terms of viewing diabetes as a serious disease, their awareness of the complications and co-morbidities was tempered by their belief that diabetes is a disease one can live with. Diabetes was given an average grade of only 3 on the 1-5 scale delineating seriousness.

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Most African-American women do not believe that diabetes will drastically change their quality of life even though most African-American women (like Hispanic women) have more frequent contact with friends and family members who have diabetes. Moreover, 8 out of 10 women admitted that they would find it “very hard” to sustain a strict diet regimen, a statistic that may signal a potential roadblock in terms of affecting positive change among this group. Also, despite the fact that the majority were aware of African-Americans’ heightened risk for diabetes, an “it won’t happen to me” attitude still prevailed. One woman said that although diabetes runs in her family, she does not feel personally threatened.

### **Target Group 4: Caucasian women, ages 25-50**

For the most part, the Caucasian women demonstrated very little knowledge about diabetes. Many of them were confused as to the cause of diabetes, questioning whether diabetes was a result of how poorly one treats one’s body or if it had only to do with heredity. Only three women from the focus group believed they were at risk for diabetes, and the women were unsure as to the seriousness of the threat posed by the disease or whether death was a consequence of diabetes. None of the women, though, had ever discussed

diabetes with their doctor, except one woman with gestational diabetes.

### **First Diabetes National Survey: March 25-27, 2003**

This national survey explored the factors that constitute a serious disease in people’s minds and gauged Americans’ perception of diabetes in relation to other major diseases.

The following statements highlight the defining characteristics of a serious disease as described by the public.

	Percentage
Financial Burden	39
Effect of disease on your family	25
Diminishing quality of life	25
Lack of cure	23
Curtailing life expectancy	15

Among certain groups, “The Financial Burden it will place on you or your family,” was an even more important component of a serious disease.

	Percentage
Americans on Medicaid	58
Married women w/ kids	51
Americans ages 45-54	47

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Initially, diabetes ranked as the 7<sup>th</sup> least serious disease among eight. Americans rated the following diseases on a scale of 1-10, where 10 meant the disease was extremely serious.

	Rating (1-10)
Cancer, in general	8.7
AIDS	8.5
Breast Cancer (females only)	8.3
Heart Disease	8.1
Kidney/Liver Disease	7.7
Alzheimer's	7.6
Diabetes	7.3
High Blood Pressure	6.5

Overall, Americans felt at greater risk for cancer and heart disease than diabetes. 59 percent of the population felt at risk for cancer and 57 percent felt at risk for heart disease, whereas only 48 percent felt at risk for diabetes. However, minorities were much more likely to feel at risk for diabetes than the rest of the population. In fact, African-Americans and Hispanics felt at greater risk for diabetes than even cancer and heart disease.

	Cancer	Heart Disease	Diabetes
Caucasians	64	60	46
African-Americans	47	44	55
Hispanics	46	43	59

50 percent of the overall population did not feel at risk for diabetes, and certain groups believed they were at even less risk for diabetes. These include:

	Percentage at risk
Those who rated diabetes 1-4	66
Had not tested for diabetes	60
Married men with children	60
Republicans 18-34	60
People with Medicare	57
Did not know blood sugar level	57
Ages 65+	57

9 percent of those in our survey reported having diabetes, yet 83 percent reported personally knowing someone with the disease. Despite the fact that 83 percent personally know someone with diabetes—and over half of these people claim that this has heightened both their concern and awareness about the disease—72 percent of Americans overall have never discussed diabetes with their doctor.

Those with PPO insurance plans were less likely to have had a discussion with their doctors than those with other types of insurance (77% = No), whereas African-Americans (40%) and those with African-American doctors (47%) were most likely to have discussed diabetes. The survey also revealed

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another important discrepancy. Whereas 72 percent of Americans claim they have never discussed diabetes with their doctor, 60 percent believe they have been tested for diabetes. This supports a key finding in the focus groups: Many Americans believe they have been tested for diabetes through some routine screen or blood work and have calculated that since their physician never mentioned the negative results of the presumed test they must not be a candidate for diabetes.

### Target Group 5: High Risk individuals

*Note: The High Risk group was chosen on the basis of four factors: age, race/ethnicity, family history of diabetes, and weight. A mix of Hispanics, African-Americans and Caucasians were recruited, yet all had to be more than 15 pounds overweight and had to believe that they were not at risk for diabetes. The Hispanics and African-Americans could have been as young as 20 years of age, however, Caucasians to be deemed "high risk" were required to be at least 35 years old and have a family member with diabetes. As it turned out, the group consisted of 4 men and 6 women.*

Almost everyone in the group could name a friend, spouse, or family member who had suffered with diabetes, and as a result, the participants rated diabetes relatively high as a serious disease. Despite the group's level of experience with diabetes, however, not a single individual had discussed diabetes with his/her own doctor.

In addition, the group demonstrated a clear lack of knowledge about diabetes. No one could correctly identify the difference between Type 1 and Type 2, including the two men whose wives had diabetes. One man thought there was a Type 1, Type 2 and Type 3 diabetes. In addition, when asked to describe the "typical person" with diabetes and list his/her attributes, the group espoused some common myths about the causes of diabetes, including attributing alcoholism and the intake of too much sugar with the onset of diabetes. They all believed that anyone could get diabetes. One woman claimed that diabetes "has no face, and yet, has everyone's face." Yet, none were worried about diabetes from a personal standpoint. The attitude was: "anyone can get diabetes, except I won't get it." The high risk individuals believed they were correct in their view of being at little or no risk of diabetes on account of having no family history of the disease.

### Second Diabetes National Survey: May 19-20, 2003

In the May national survey, an interesting change occurred in the question dealing with Americans' perceived risk of diabetes. While, the March results showed that 48 percent of Americans feel at risk

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for diabetes, in May that number dropped to only 38 percent of Americans.

	May	March
At Risk	38	48
Not at Risk	61	50

Following the overall trend, minorities' perceptions of risk also decreased in May.

	May	March
Caucasians	37	46
African-Americans	43	55
Hispanics	44	59

However, the overall ratio between minority and non-minority views of risk for diabetes remained unchanged.

The May results reflect the difference in attitudes toward diabetes when taken out of the context of a serious disease overview. In March, the discussion of serious diseases including cancer and heart disease influenced people's perception of diabetes and heightened their concern for major diseases in general. In May, diabetes was taken out of the context of other diseases. When Americans are asked to indicate merely their risk for diabetes, only 38 percent feel at risk in this instance.

The second national survey also tested important perceptions of diabetes as gleaned through the focus groups with Target Groups 1-5. Among the various perceptions of diabetes, Americans were most likely to agree with the statement: "Diabetes doesn't concern me because I have seen other people manage and live fine."

	Percentage
Diabetes doesn't concern because I have seen other people manage and live fine.	36
Diabetes and its consequences are serious and scary.	22
Because it's manageable, I don't view it as seriously as I do others.	9
Would dramatically affect the way I live my life.	6

Moreover, 58 percent of Americans identified with one statement that came out of the focus groups in which a woman contemplated her reaction to being diagnosed with diabetes. She said:

*"I don't think I would view diabetes that seriously initially. I would think, "Thank God it's not cancer."*

A majority of Americans said they would have a similar reaction, in that they would be relieved that the diagnosis of diabetes was not a diagnosis of cancer.

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Moreover, the second national survey revealed an equally problematic finding, this time with regard to Americans' overall knowledge about the causes of diabetes. The survey tested Americans' knowledge of various risk factors for diabetes including four major risk factors such as weight, race/ethnicity, family history, and child's birth weight, as well as two misnomers such as stress and affinity for eating sweets. The survey found that family history and being overweight well-known factors attributing to diabetes, yet only 35 percent of Americans were aware that giving birth to a baby weight 9lbs. or more heightened risk for diabetes.

	Yes	No
Family History	93	6
Minority	45	44
Eat a lot of sweets	54	42
Overweight	93	6
Stress	63	30
9lb.+ baby	35	51

Most Americans believe that stress and eating a lot of sweets, both of which are not major risk factors for diabetes, cause diabetes. They were more likely to choose the two incorrect responses than they were two very important risk factors: minority status and birth weight of children.

**In fact, the survey revealed that only 14% of the population is well educated on the causes of diabetes.** Only 14 percent of Americans answered 5-6 of the risk factor questions correctly, compared to 21 percent who got almost all of the questions wrong.

## HOW PEOPLE LEARN WHAT THEY KNOW

The second priority of the research was to examine the ways in which people learn about diabetes and other health care issues, and which groups or people represent the best and most influential messengers on the subject of diabetes.

### **Target Group 1: Seniors 55+**

Reliance on doctors was most strongly demonstrated in the senior focus group. The seniors claimed that, above all else, they would be prompted to get tested for diabetes based on a doctor recommendation. On the issue of responsibility, seniors placed the bulk of responsibility for doctors as well, suggesting that it is a doctor's job to educate individuals on diabetes. Some believed that doctors held the primary responsibility of diabetes education even at the national level. National education efforts were also expected to come from the American Diabetes Association (ADA). Only two seniors thought diabetes education should be a government initiative, and only two seniors thought that it should be a person's own responsibility to educate himself or herself about the disease.

Why do seniors place so much responsibility on doctors versus the government and other organizations? The seniors cite a lack of trust in the latter. They claim that some organizations have

too many special interests, that money plays too large a role, and bottom-line: they simply do not trust them.

### **Target Group 2: Hispanic women, ages 25-50**

As with the seniors, the Hispanic women designated doctors as the most influential messengers for information on health issues, followed by friends or colleagues with personal experience and family members. Three women pointed to medical websites and two others to medical journals as places they look to in order to receive accurate and credible health information. Two women also mentioned community hospital awareness campaigns as being credible and influential. The Hispanic women also identified four groups that they said they would not listen to or trust to provide the most accurate and credible information on health issues. These included members of Congress, the President of the United States, Corporations/TV commercials, and celebrity spokespeople.

In a related question, 7 out of 10 claimed they access the Internet on a regular basis, and 7 out of 10 also stated they access health information on the web.

The Hispanic women pointed to doctors as the figure most responsible for educating them personally about

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diabetes. On the national level, most believed the ADA has the primary responsibility, although some mentioned the American Association of Diabetes Educators (AADE) as well. Yet, none of the Hispanic women claimed to know anything about the AADE.

### **Target Group 3: African-American women, ages 25-50**

7 out of 10 African-American women chose doctors as the best source of credible health information and the person most likely to influence them to change their behavior. The women also relied heavily on friends or colleagues with personal experience, and many reported trusting their family members as well (especially if a family member had diabetes). University studies and medical websites were listed as being credible sources for health information. The African-American women were least likely to listen to the President of the U.S. when it comes to health information, and also indicated that celebrity spokespeople, members of Congress, the news media, and corporations delivering health information would have little or no influence on them. All the women in this group were highly skeptical of the government and did not seem to welcome the government's involvement. However, one woman supported the

idea of government involvement for the following reason:

*“Not because I would rely on them, but because it's their responsibility. They have the money to fund these initiatives.”*

### **Target Group 4: Caucasian women, ages 25-50**

Doctors and friends or colleagues with personal experience were equally likely to influence the Caucasian women to change their behavior toward their own health. A few also mentioned that they would take advice and accept health information from family members. The women did not feel that celebrity spokespeople or members of Congress were appropriate messengers, however they were more likely than any other group to accept the President of the U.S. as a messenger.

### **First Diabetes National Survey: March 25-27, 2003**

On the national level, respondents also reported getting most of their general health care information from doctors (41%). Although, 57 percent of Americans indicated receiving health care information through sources other than physicians including family and friends, the Internet, television, newspapers, etc.

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	Percentage
Doctors/Nurses	41
Family/Friends/Co-workers	14
Internet	9
Other	9
Television	8
Insurance companies	6
Magazines	6
Newspapers	5

Furthermore, 74 percent of Americans think it is important that the government plan an initiative to try to get everyone tested for diabetes. Among those who are most favorable to the idea of a government initiative on diabetes, are African-Americans (90% in favor) and Hispanics (89% in favor).

### **Target Group 5: High Risk individuals**

Doctors were once more the preferred messenger of health information and most likely to influence the participants to improve their overall health and lifestyle. Friends with personal experience came in second, followed by family members and community hospital awareness campaigns. University studies and medical websites were also cited by the participants as popular resources for health information.

## 2<sup>nd</sup> Diabetes National Survey: May 19-20, 2003

Physicians remain the most trusted, preferred messenger of health care information. Yet, there is an opportunity to reach people through different means.

The 2<sup>nd</sup> Diabetes National survey found that:

- 40% of Americans said inconvenience and cost of visiting the doctor is the biggest reason for not getting tested for diabetes.
- 48% of Americans said they would prefer to receive health information and education either in group, community, or one-on-one settings.
- 30% of Americans turn to the Internet or other resources “often” because their doctor did not give enough or incomplete information on a disease, condition, concern of theirs.

Moreover, 57 percent of Americans responded that if their doctor did not mention his concern about a condition or disease they would be concerned.

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Minority groups such as Hispanics and African-Americans and low-income Americans were, however, considerably more likely to trust their doctors.

Doctor Does Not Mention Concern	Yes (not concerned)	No
Overall	38	57
African-Americans	47	48
Hispanics	49	47
15K-30K	45	49

In fact, Hispanics trusted physicians to the extent that if their doctor did not mention his concern, a plurality would not be concerned.

## DIABETES AND THE HEALTHCARE SYSTEM

Crucial to our understanding of diabetes and our efforts to fulfill the study's two main objectives—to identify potential solutions and develop a working model to understand the motivation and behavior pattern of those who transition to successfully managing diabetes—is a clear grasp of how the entire health care system, with regard to diabetes, operates.

The third part of the research involved talking to those groups and individuals with the most involvement in the treatment of diabetes as well as the greatest impact on people with diabetes. In order to recommend improvements to the current system, one must understand the strengths and weaknesses that exist.

### **Certified Diabetes Educators (CDEs)**

Diabetes education, the CDEs stressed, is about teaching HABITS. In order for someone to manage diabetes well and become a successful example, he/she must get to the point where treatment, diet, and exercise are routinely incorporated into everyday life. And these efforts must be SUSTAINED. The problem is that many types of insurance view diabetes education as a once-in-a-lifetime consultation. Others, such as Medicare, stipulate that diabetes education must be undertaken in a group setting. CDEs believe the

key to improving results for the patient is to offer flexible and personalized care.

The CDEs also identified Americans' attitude toward chronic diseases in general as being a roadblock in transforming views and about diabetes and changing behavior. Americans, they believe, are used to taking care of acute problems and relying solely on a cure. Americans want "Easy." Their frustration and lack of patience with chronic diseases mirrors that of the medical practice in general. CDEs believe that the entire medical system, beginning with the training of physicians, is geared toward treating acute illnesses and problems. The medical insurance industry reflects this as well.

The CDEs identified what they believe to be the main difference between diabetes educators and physicians: *"Doctors [unlike the CDEs] don't think they have control over their patients; rather, patients have control over themselves."* The CDEs believe physicians' lack of perceived control or influence leads to resignation. Hence, doctors experience greater frustration in helping manage patients' diabetes. CDEs, on the other hand, work under the assumption that they can convert patients. It is not only the job of CDEs to change

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the behavior of patients, but it is also their primary focus. Unlike doctors, they are also more willing to entrust patients with the monitoring of their own health. This involves teaching people fully about their condition, and **empowering** the patient. As one CDE says, *“I found that if the patient understands why they’re doing something they’re more likely to do it.”* Furthermore, all CDEs agreed that there should be Standards of Care for physicians, as well as incentives for patients to lead healthy and active lives.

In terms of recognizing the characteristics that make someone more or less likely to manage diabetes well, the CDEs believe attitude is the key. Whether someone sees themselves as a victim or believes they have control over their health and their destiny determines how ineffective or effective they are at managing diabetes. The San Antonio CDEs suggested that no matter how good the diabetes educator or management training is, patients have to be in the right frame of mind in order to succeed. They stress that it takes time and compassion to help someone achieve the right attitude, and on-going education and support is the solution.

Moreover, greater education about diabetes prior to patients’ diagnosis would help, as those who

seem better situated to handle their diabetes and manage it successfully are those patients who already *“perceive it as being a problem.”*

One success indicator:

*“They perceive this disease as being one that’s bad and they need to take care of it.”*

However, CDEs do identify a difference between working with people with Type 1 versus Type 2. Because Type 1’s are usually diagnosed in adolescence, they tend to display signs of rebellion in dealing with diabetes and the lifestyle changes it requires. Their attitude is, *“I don’t want to do that.”* The Type 2 individuals, on the other hand, are generally older and are more apt to display signs of denial or disbelief. The CDEs characterize their reaction to diabetes as this: *“What do you know about how I feel?”*

Since, those with Type 2 don’t necessarily feel bad they often don’t perceive diabetes to be a big deal. In addition, Type 2 diabetes develops slowly and over time and many with adult-onset do not feel ill, and are more likely believe that by merely taking a pill or two they do not have to be as attentive to their diabetes. Thus, CDEs suggest that despite the initial rebellion Type 1 individuals take it more

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seriously because there are immediate and identifiable changes that take place: many are hospitalized when first diagnosed with Type 1 and insulin shots are administered right away. Also, the parents of Type 1 individuals tend to “go crazy,” and as a result of their concern for their child, they drive home the message that Type 1 is very serious.

If the CDEs were to construct an ideal system, this system would focus on improving the following four things:

- Access (Physicians often do not refer for fear of losing patients)
- Follow-up
- Support
- Community Education Programs (Diabetes education in schools, churches, workplaces, etc.)

### Physicians

There is no formal procedure in place with regard to a medical checklist or procedure for engaging patients. The physicians’ approaches varied, and many claimed that the appearance of the patient was very important. The closest thing to a standard check-list of subjects by which physicians generally inquire about is as follows: family history, smoking

history, social support network, and chief complaint.

The overall demeanor of the physicians throughout the course of the focus group was one of detached ambivalence. However, at one point in the focus group, the doctors did pause and address an answer with great attention. This question addressed the physicians’ *own* concern and opinion as to which disease they most feared. The physicians feared cancer the most, followed by HIV and then heart disease. Whereas diabetes had been mentioned as a disease their patients feared, diabetes was not of great personal concern to any physician. Moreover, there is no recognition that they have a bias when looking at a patient, a particularly important point given the major differences between what they said they are concerned about for their patients and what they are concerned about themselves. However, physicians explained that they generally diagnose patients with diabetes based on screenings rather than demonstrated symptoms.

Physicians, in contrast to the CDEs, believe that people with Type 1 diabetes are the most non-compliant patients, as a result of a “more hardened attitude” toward their diabetes.

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All agreed with the following comment:

*“I find that my Type II diabetics the ones that are on oral control with pills are more concerned about their diabetes than Type I, the ones that are on insulin. I don't know I have always said that and I will say it right now. They are more concerned about their disease they take care of themselves. I don't know if anybody else finds that.”*

Only one physician could identify the ADA Guidelines for diabetes testing, and he did so incorrectly, and only one physician (an internist) knew what a CDE was. The others relied on their nurse practitioner to deliver diabetes education to their patients. In the podiatrists' and optometrists' offices, they acknowledged merely referring diabetic patients back to the general practitioner for diabetes treatment and information and/or handing patients an educational flier on the disease.

Most of the physicians were reluctant to identify any flaws in their medical education, although one family physician who graduated from medical school 20 years ago acknowledged that over the course of his practice he has had to re-learn how to treat diabetes. He said that treatment for diabetes is *“really different now than then.”*

Physicians also acknowledge that most of their patients are not fully aware of the exact tests being administered during routine check-ups and assume

that they have been tested for diabetes. 9 out of 11 doctors agreed with the following statement:

*When we asked participants whether they've ever been tested for diabetes, most assumed that their doctor had performed the test at some point during routine check-ups.*

### Parents of Children with Type 1 Diabetes

This focus group demonstrated the heroic nature of Type 1 parents, in terms of the extraordinary efforts these parents undertake to care for their children as well as the obstacles they and their children have had to overcome in dealing with diabetes. The parents acknowledged struggling more with the fact that their child had diabetes, than did the children themselves. The most difficult aspects of diabetes for the children was adhering to the diet and trying to overcome the feeling of being isolated or different from other kids.

Parents also expressed that as their children get older, both they and their children find it more difficult to manage diabetes. They claimed that as kids get older, they are busier, have less time to devote to their health, and are faced with social pressures which make it more difficult to remain regimented and not resent having diabetes. Yet, for the most part, the parents were not concerned about their child's

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ability to manage diabetes in school. Many indicated that the school is generally understanding about their child's diabetes, and expressed that they have a good relationship with the school nurses as well.

These parents were very aware of their child's medical condition and very knowledgeable about diabetes in general. Their families' lives changed dramatically as a result of their child's diabetes, and sacrifice was common. The parents of Type 1 children felt that a disproportionate amount of attention was paid to Type 2 diabetes and believed that the American public was generally ignorant about Type 1 and unaware of how serious the disease is. They were not optimistic about a cure.

The parents of Type 1 children were also hostile toward parents of Type 2 children, because in many cases, they faulted the parents for putting their children at risk. They stressed that efforts to raise awareness about Type 1 and Type 2 diabetes are two separate campaigns, and resented ads that were negative or incited fear.

### **Parents of Children with Type 2 Diabetes**

Among these parents, there was a demonstrated confusion between Type 1 diabetes and Type 2 diabetes. Very few could identify the differences

between the two types, and yet they all believed that Type 1 was a more serious form of diabetes and more difficult to handle. In addition, insulin was viewed as signaling "bad diabetes."

Parents of Type 2 children view tight management of diabetes as preferential and important, but not essential. All encouraged their children to undertake lifestyle changes, however, very few families changed their own lifestyles because of their child's diabetes. They were largely concerned about stigmatizing their child and worried that their child felt different from other children. Parents claimed that one of the main obstacles to helping their children manage the disease properly was peer pressure. However, one woman identified a cultural component of the diabetes diet that may be a formidable obstacle or inconvenience to many like her. The woman said, "Instead of cooking Hispanic food, I now cook 'White food!'" She claimed that accommodating the dietary needs of her child had fundamentally altered the way she and her family ate. This was one instance where the focus on changing the child's behavior inadvertently changed the family's behavior as well. The parents were also skeptical about a cure, and most of them did not feel that it was important to them to understand the types of research that are being done towards a cure for diabetes.

## **DIABETES AND THE HEALTHCARE SYSTEM**

One woman, whose response typified the skepticism in the room, said that she thinks the U.S. has a cure for AIDS at the moment but does not believe that she or anyone participating in the focus group has enough money to get it. This distrustful attitude of the medical industry extended to those in the business of diabetes as well.

Although the parents indicated that they knew about CDEs, only two had sent their children to see a certified diabetes educator. Yet, most parents said that their child had received nutrition classes and other forms of information. Almost all of the Type 2 children remained with their family practitioners.

## MESSAGE & MOTIVATION

### First Diabetes National Survey: March 25-27, 2003

In the portion of the first national survey that dealt with messaging, respondents were read what was deemed to be the top 5 statistics about diabetes and its consequences and were asked to indicate whether that statistic made them view diabetes as very serious, somewhat serious, not very serious, or not serious at all.

- Roughly 17 million people have diabetes in the U.S. today and over a third of those with the disease do not know it.
- Persons with diabetes are 2 to 4 times more likely to suffer from heart disease and stroke than those without the disease.
- People with diabetes live 15 years less, on average, than people without diabetes.
- More people die every year from diabetes than from breast cancer and AIDS combined.
- Diabetes kills one American every three minutes, and every three minutes, four more are diagnosed.

For each statistic, at least 90 percent of Americans said that it made them view diabetes as “Serious.” 97 percent—the highest percentage for any of the statistics—of Americans claimed they viewed

diabetes as a serious disease on account of the following statistic:

- Roughly 17 million people have diabetes in the U.S. today and over a third of those with the disease do not know it.

The national survey tested not only the impact of each of the top 5 diabetes statistics, but the effect of diabetes information on Americans’ perceptions of the seriousness of diabetes overall. Prior to education in the form of diabetes information and statistics, survey participants rated diabetes a 7.6 on a scale of 1-10, where 10 was “extremely serious,” thereby rendering it the 7<sup>th</sup> most serious disease behind cancer, heart disease, and others. After hearing the statistics though, Americans rated diabetes slightly under 8.7, almost on par with cancer. In addition, education positively affected even those most resistant to the idea that diabetes was a serious disease. Those people that gave diabetes an initial mean rating of 3.07 gave diabetes a final rating of 7.04 *after* the statistics—an increase of more than 200%.

In other ways, the survey found that education does make a difference. For instance, among those who incorrectly assumed that “If I have no family history of diabetes, it is highly unlikely that I will ever get the disease,” 80 percent had never

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discussed diabetes with their doctor. Conversely, those who had discussed diabetes with their doctor disagreed with the statement (73-25). On a slightly different positive note, the survey did indicate that the message linking over weight with diabetes may be reaching Americans. Among those who were concerned that their weight may be a health risk, 65% believed they were at risk for diabetes. (Compared to the national average of only 48%). Also, overweight Americans feel at almost the same risk for diabetes as heart disease (68-65 heart disease risk - diabetes risk).

### Target Group 1: Seniors 55+

In terms of motivating factors for diabetes testing, the seniors claimed that above all else, they would be prompted to get tested for diabetes based on a doctor recommendation. Outside of a doctor's recommendation, 50 percent they said that they would get tested for diabetes if screening were available to them at work or in their local pharmacies. 4 out of 10 would get tested for diabetes based on a family member's recommendation only 1 person cited that knowing their insurance would pay for it would be an incentive to get tested. In general, the group said that testing for diabetes would depend on whether or not they believed it was *necessary*, and whether or not they were experiencing symptoms. As a

result, only one senior claimed that he/she was highly likely to go get tested for diabetes. The likelihood of most of the others ranged from 2-5 on a scale of 10 (where 10 represents "very likely").

The most powerful messages with the senior group were those that described major complications, especially those that drastically reduce seniors' self-sufficiency and shortened life-spans. Seniors, more than other groups, were more motivated by negative messages regarding the consequences of diabetes.

They preferred the following messages:

- As a result of diabetes, you may be dependent on machinery such as a kidney dialysis machine.
- Presently, there is no cure for diabetes.
- People with diabetes live 15 years less, on average, than people without diabetes.
- It is the leading cause of blindness in adults, and accounts for the majority of non-traumatic lower-limb amputations.

On the question of whether the seniors would change their lifestyle if it meant they could prevent diabetes, most agreed they would. However, the seniors admitted that they would need test results

## MESSAGE & MOTIVATION

indicating diabetes or a doctor's recommendation to alter their lifestyle as prerequisites for any change in their behavior, diet, or concern regarding diabetes. The focus group also demonstrated that despite the alarming statistics about diabetes, perceptions of the disease and the need to alter one's health patterns, they were fairly resistant to change. One senior commented:

*"They provide medications so you don't have to change."*

### **Target Group 2: Hispanic women, ages 25-50**

Hispanic women were much more amenable to the idea of taking advantage of free diabetes screening. Nine out of 10 claimed that they would get tested simply if diabetes screening were available to them at work or in their local pharmacy. Unlike the seniors, free screening was reason enough to participate. One previously skeptical woman chimed in enthusiastically:

*"Work would be great!"*

The "fact" that had the most impact on Hispanic women scored fifth with the senior group. The Hispanic women were primarily shocked to find that:

- More people die every year from diabetes than from breast cancer and AIDS combined.

The Hispanic women also seemed taken aback by the statistic claiming that diabetes shortens life

expectancy by fifteen years, and many of the women's thoughts went straightaway to their children. The diabetes statistics had quite a powerful impact on changing the Hispanic women's perceptions of diabetes, as all stated that they view diabetes as more serious than before. Whereas most still feared cancer more than diabetes, the group acknowledged that the level of funding and research for diabetes should equal that of cancer. Over half of the group said that after hearing the diabetes facts, they would "seriously consider" getting tested, and two women said they would definitely have a conversation with their doctors about diabetes. Despite their acknowledgement of the heightened seriousness of diabetes in their mind, the statistics did not work in heightening their feelings of personal risk. Thus, it is especially important that any message on diabetes accomplish two goals:

- 1) Reinforce the idea that diabetes is a serious disease
- 2) Drive home the message that millions of Americans are at risk, and YOU might be one of them.

### **Target Group 3: African-American women, ages 25-50**

For the African-American women, the statistics emphasizing the risk of death from diabetes had a profound effect, which they clearly demonstrated when ranking the list of 17 facts. Like their Hispanic sisters, these women were most struck by the following fact:

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- More people die every year from diabetes than from breast cancer and AIDS combined.

The women in the group were not only surprised by the statistic, but they claimed it shed a whole new light onto the seriousness of diabetes.

*“I never associated [diabetes] with death, always with a lifestyle change.”*

African-American women also reacted to the following message:

- Roughly 17 million people have diabetes in the U.S. today.

One woman commented: *“It scares me to know the word [on diabetes] is just not out there and needs to be.”* The group, as a whole, acknowledged their lack of awareness as to the sheer number of people affected by diabetes in the United States, and expressed their consternation that one could have diabetes for many years without knowing it.

Overall, the African-Americans left with a greater sense of fear about diabetes than before, as one woman was convinced of the following:

*“I believe 5-6 of us have [diabetes] in here and don’t know it.”*

The African-American group was not only more receptive to diabetes messaging but was, also,

more willing to change their lifestyle in order to prevent diabetes. This is due, in large part, to existing awareness of diabetes and better knowledge of minorities’ risk of diabetes. Although African-Americans seem more willing to change than do non-minority groups (i.e. there is less denial and reticence), the difficulty, as will be discussed later, lies in the fact that changing the lifestyle of minorities presents more of a challenge than changing the lifestyle of non-minorities.

### **Target Group 4: Caucasian women, ages 25-50**

Like the African-American and Hispanic groups, the Caucasian women were clear that the same death statistics had the greatest impact on them overall. These women were clearly agitated by the statistics, and they wanted more information as well as confirmation that these were in fact true.

- More people die every year from diabetes than from breast cancer and AIDS combined.

The Caucasian women were also particularly moved by the following two facts:

- Diabetes kills one American every three minutes, and every three minutes, four more are diagnosed.
- Presently there is no cure for diabetes.

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For one woman, the lack of a cure for diabetes seemed especially daunting, as she viewed diabetes as a *“life sentence of self-discipline I lack greatly.”*

Despite their shock at the statistics linking death and diabetes, none of the women were willing to put diabetes on par or almost on par with cancer in terms of seriousness. And yet, half of the women claimed that they now want to be tested for diabetes—a dramatic improvement when you consider that so few believed they were at risk for diabetes or that they should be concerned about the disease at the start of the focus group.

### **Target Group 5: High Risk individuals**

The group of participants deemed “High Risk” individuals for diabetes were, by far, the most resistant to diabetes messages and were most likely to deny their risk for the disease. As the only other mixed-gender focus group considered a “target group,” their preference for messages matched those of the senior mixed-gender group. Like the seniors, the high risk participants were impacted most by the statistic highlighting the complications of diabetes, namely kidney dialysis, amputations, and blindness. They, too, were surprised by the statistics regarding diabetes as a major killer but were focused primarily on the affects of diabetes that would render them

incapacitated in some way. The message they chose as the most influential was:

- As a result of diabetes, I may be dependent on machinery such as a kidney dialysis machine.

Also similar to the senior group, the statistics had very little impact in terms of heightening this group’s sense of risk or encouraging them to alter their lifestyle so as to help prevent diabetes. For instance, only 2 people indicated that they felt more at risk for diabetes as a result of reading the statistics, and almost half claimed that they would not regard diabetes any more seriously simply on the basis of hearing the facts. The high risk individuals, who said the statistics did not prompt them to view diabetes more seriously than before, contended that “diabetes is not in my family” and “[diabetes is not something] I’m thinking about.” Moreover, the high risk individuals completely resisted the notion that they were, in fact, at a heightened risk for diabetes, despite the moderator’s explanation of the screening questions and purpose of the focus group. Skeptical remarks soon followed:

*“What does that really mean? A lot of people can fall into categories...”*

They also expressed a deep reluctance to change their behavior in order to diminish their risk for

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diabetes. One woman said if she were told she had a 20% chance of developing diabetes, she would not take any steps to avoid developing the disease. However, if being at high risk meant she had an 80%-90% chance of having diabetes then maybe she would act on it. Others did not care what their percentage of risk turned out to be: they would merely continue to rely on their doctor and the results of blood glucose tests and worry about diabetes if and when they had a problem. In terms of whether or not financial incentives would make those in the group more or less likely to change their behavior and lifestyle, no one said they would change their life significantly. Not a single person was convinced that they should take preventive measures other than getting tested for diabetes periodically. The prevailing sentiment was:

*"I will worry about it when I have to."*

The participants did want to see a national initiative aimed at educating Americans about diabetes in general, as well as ways to avoid the disease and/or prevent complications. However, the prospect of financial incentives to reward healthy behavior did not seem to motivate these people to change their lives dramatically even though they said it would be a good thing.

Although the high risk individuals seemed, at this point, hopelessly stuck in denial, and resistant to

attempts to motivate them to embrace the idea of change, education still proved that it could be effective. Following the explanation of why the participants were at risk for diabetes, they each received a packet of educational materials from the American Diabetes Association (ADA). Although, some of the group's members, particularly the men, still scoffed at the idea that they might be at risk for diabetes, many of the women changed their mind. In terms of whether or not the information was enough to motivate them to change their lifestyle, many claimed that they would need to have the following circumstances occur as well:

- *If diabetes was like heart disease, in that it was the number one killer of women.*
- *If someone close to me dies of something, then I might change.*
- *It would have to be said by my doctor.*
- *You have to have faith in your doctor.*
- *If my brother came down with something, I would consider it because we're very close (i.e. genetically).*
- *Once it hits you, then you change.*

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### CDEs

Diabetes educators identify certain traits or emotions that patients who are more resistant to change and accept diabetes might display. These include:

- Depression
- Lack of interest
- Angrier
- Denial

One CDE explains this about diabetes and the challenge educators have in dealing with patients newly diagnosed:

*“It’s a very difficult disease. And it takes a long time for people to accept it. Now I’m going to have to change my behavior; I’m going to have change my lifestyle. I may have to be on medicines for the rest of my life. I’m also going to be looking forward to all these complications. It’s a very difficult disease. So people initially are very angry and they deny it.”*

Another problem CDEs encounter when trying to deal with patients with diabetes is their view that diabetes is their “*destiny*.” They often subscribe to the notion, “*Everyone in my family has it, so what’s the big deal?*” Yet, when it comes to patients being receptive to diabetes education and the advice of the educators, they explain that each individual has a uniquely different response; and, as such, their education methods do not differ greatly based on

which type of diabetes a patient has. They argue that patients who initially resent education simply need more time and more encouragement, which diabetes educators more than physicians are in a position to give. In this way, education is viewed as a crucial supplement to the physicians’ standard treatment of patients with diabetes. However, the educators also believe that poor education, very low income, and lack of health insurance are obstacles to successfully managing diabetes. They explain that people with little education or low income have to fight harder to care for themselves properly, and acknowledge that without the ability to easily obtain diabetes resources, the regimen is much harder to follow. Successful patients, on the other hand, are more willing to work with educators to try new approaches and new methods for treating their diabetes. They take greater responsibility and a hands-on approach with regard to their own health. Successful patients want to learn more about diabetes and exhibit a sense of pride that helps maintain their motivation through the frustrating period of trial and error that often characterizes the first couple of years of patients’ experience with diabetes.

The diabetes educators were divided in their views of whether it is getting easier or more difficult for people to change their lifestyle and manage

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diabetes. CDEs who claim that it is getting easier cite liberalized meal plans, greater awareness of diabetes, and the popularity and everyday reinforcement of fitness and exercise. Those who argue that today's environment makes it more difficult for people to manage their diabetes cite high levels of stress, long work hours, abundance of fast food options, the increase in sedentary jobs and lifestyles, expense of medications and healthy foods, and the diminishing sense of safety and security that precludes people from walking or biking in neighborhoods or areas in which they otherwise would.

The CDEs also offered various slogans for a nationwide campaign to prevent Type 2 diabetes. The slogans they mentioned are as follows:

- "You deserve it [to feel great and be healthy]!"
- "Take pride in yourself and your health!"
- "Exercise!"

In addition, they stressed that any message should acknowledge that change is difficult and that implementing change takes time. In terms of changing people's behavior, the CDEs say that the process referred to as "baby steps" works. By setting small and continual goals for people, it helps keep them motivated and positive. The educators also believed that incentives such as lowering insurance rates, gym

memberships, and coupons for popular goods or entertainment could be effective in motivating people. In addition, people stay motivated by rewarding themselves with simple pleasures, and the educators always encourage their patients to do so.

### Physicians

Overall, physicians are quite skeptical that people with diabetes do enough to effectively manage their condition. Although they claimed that people with Type 1 diabetes were more non-compliant and resistant to medical advice than people with Type 2 diabetes, in general, they believed:

*"I think it would be the rare patient that could effectively manage his or her own diabetes."*

According to doctors, the patients with diabetes they find most resistant to suggestions and medical advice include Christian Scientists, patients who cannot identify their primary care doctor and/or haven't seen him/her in well over a year, those who maintain that they "feel perfectly well," and those people the doctors refer to as "hopeless cases." Hopeless cases refer to patients who are so unhealthy in terms of their weight, diet, smoking habits, etc. that they would need to modify nearly everything about their lifestyle in order to be compliant with regard to their diabetes. Physicians were skeptical and even seemed somewhat

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reluctant to attempt to change such people, as they would be asking so much of these patients: They believed the effort needed to change may be too great.

When it comes to the effectiveness of “death” statistics, the physicians were very nearly split on the issue. 6 doctors agreed that threatening people with their own mortality works in some cases, yet 5 doctors disagreed. Most preferred to emphasize the positive messages of diabetes, and only interject the negative aspects of the disease if it was one aspect of a message strategy that also included humor and positive reinforcement.

### **Parents of Children with Type 1 Diabetes**

According to this group of parents, the children with Type 1 diabetes find the strict diet the most difficult aspect of diabetes. The parents expressed that not only is it hard to control what your child eats, especially as he or she gets older and is more active and away from the home, but it is also hard to limit what kids eat when they are in their growing years. Moreover, parents said that peer pressure was often very difficult for children, especially when he or she feels isolated from other children because of their inability to eat the same things. For instance, one parent said that her child complains, *“Only I can’t eat things.”*

Other aspects of diabetes that the children of these parents find difficult include:

- Acceptance of the fact that he/she has diabetes
- Exercise (tendency to be lazy)
- Wearing glasses (prescription changes so often)
- Receiving the insulin shot
- Remembering to always carry all diabetes supplies
- Overall amount of work and attention to health diabetes requires

Parents acknowledged that as their children become older, it becomes increasingly more difficult to manage the disease.

In terms of how their children were able to get motivated to take control of their diabetes, one woman described the following scenario:

*“Her pediatrician was just blunt, straight out. She said, ‘There’s no cure and there may never be a cure.’ She just told her, ‘You’re going to live with this for the rest of your life and there’s never been a cure and there may never, ever be a cure.’”*

Although the parents wanted their children to receive a strong message about the seriousness of diabetes and understand the importance of careful management, the parents were very much

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opposed to negative messages, especially those that might frighten or depress their children. The parents suggested that a one-on-one approach, whereby an older person with diabetes sits down with their children and discusses his/her own experience with diabetes and its complications could offer them gentle guidance that would be more effective than verbal scare-tactic messages.

### **Parents of Children with Type 2 Diabetes**

Similar to the Type 1 parents, the parents of children with Type 2 diabetes claim that the largest obstacle they face in sustaining their children's motivation levels is combating peer pressure and their children's resentment in being "different." The parents claimed that their children struggle most with being on a restricted diet, in large part due to peer pressure in the form of teasing or taunting from other kids as well as the feeling of being different or isolated from other kids who can eat anything. Other parents explained that keeping their kids on a strict diet was also very difficult given the number of fast food restaurants and the fact that they cannot watch their child during the school day. They acknowledged that the temptation to eat the wrong foods was very strong and sometimes difficult for their child to adjust to, especially given the fact that children don't always

understand why. As a result of the difficulty these kids have with diet and peer pressure, most of the parents also believe that it is easier for them to manage their children's diabetes while at home versus at school. One mother explains:

*"It's a lot easier for him to manage at home. So actually there is two different environments. [Diabetes] is more difficult for him at school because of all the temptations and the peer pressure from the other jocks. And then at home he's safe. Nobody is there to make fun of him or say 'Come on have some more French fries.'"*

A majority of parents said that they were not at all prepared to deal with their child's diabetes. A few were surprised that diabetes could affect a young child, explaining that they always thought of diabetes as a disease that affected older people. Another mother claimed that she didn't believe diabetes would affect her personally:

*"I had heard about it and I've worked with some people that have had it, but I didn't think at all that it would happen to our family."*

The parents also gave suggestions for messages they believe should appear in a national diabetes initiative.

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They were asked the following question, “If there was one thought that you would want everybody to have in terms of diabetes, given your experience, what is the one thing that you want everybody to have?”

They responded as follows:

- *I would start with nutrition.*
- *I would be really honest, sometimes that's what it takes. I am thinking about the AIDS [commercial] where the kids are talking and then all of a sudden one of them says, "I have AIDS." You're thinking, "This isn't a milk commercial?" This looks like a milk commercial. It is these young kids saying that they have AIDS. Stuff like that. I think that diabetes should be out there in grocery stores, in the malls.*
- *They show about smoking and drinking and drugs and sex, never, never about diabetes.*
- *I think if there was one message you wanted to put out with regard to diabetes, use a central theme, that it can happen to anybody no matter what their race, sex, ethnicity, and in any age group.*
- *[Diabetes] is not prejudiced. It is just like AIDS.*

## Second Diabetes National Survey: May 19-20, 2003

Physicians remain the most trusted, preferred messenger of health care information. Yet, there is an opportunity to reach people through different means.

The Second Diabetes National survey found that:

- 40% of Americans said inconvenience and cost of visiting the doctor is the biggest reason for not getting tested for diabetes.
- 48% of Americans said they would prefer to receive health information and education either in group, community or one-on-one settings.
- 30% of Americans turn to the Internet or other resources “often” because their doctor did not give enough or incomplete information on a disease, condition, concern of theirs.

Americans positively responded to a variety of initiatives to promote awareness and specifically be tested themselves. The following table shows

**MESSAGE & MOTIVATION**

what percentage of Americans said they would be likely to be tested as a result of a specific initiative.

	Percentage
If you received a free pamphlet or mailing that explained diabetes and offered a quick test to determine if you were at risk	80
If your workplace or local pharmacy were to offer free diabetes testing	77
If the President or members of Congress launched a national initiative asking all Americans to get tested for diabetes	74
Your member of Congress invited you to a town hall meeting where you could be tested for diabetes	48
If your member of Congress sent you a mailing indicating his/her concern about diabetes and urging you to speak with your doctor about being tested for diabetes	48

The higher risk groups of African-Americans and Hispanics responded more favorably to these initiatives than the country as a whole, reflecting that a larger portion of these groups do believe they are at risk for diabetes than does the overall population.

	African-Americans	Hispanics
If you received a free pamphlet or mailing that explained diabetes and offered a quick test to determine if you were at risk	89	84
If your workplace or local pharmacy were to offer free diabetes testing	88	83
If the President or members of Congress launched a national initiative asking all Americans to get tested for diabetes	82	81
Your member of Congress invited you to a town hall meeting where you could be tested for diabetes	61	59
If your member of Congress sent you a mailing indicating his/her concern about diabetes and urging you to speak with your doctor about being tested for diabetes	67	66

## MESSAGE & MOTIVATION

### Successful Diabetes Patients:

Americans already living with diabetes were able to offer valuable insight. Through their testimony, these patients have provided messages that will resonant with the rest of the American public.

### What/who caused you to take control?

- Empowerment through education: the feeling that one could conquer diabetes and assurance that one's whole life was not going to change because of diabetes.
- Working toward a goal: overcoming blurred vision, having a baby, recovering from a heart attack, preventing the worsening of existing complications
- The drive to live a long and healthy life free of complications for oneself and family.
- Diabetic role model: *"[My father] was in his 80s when he died. If I can keep this thing in check, I can live a healthy life too."*
- Diabetes educators: "because their caring makes me want to care more; because somebody cares.

### Greatest difficulties in living with diabetes

- Scheduling: *"It's working your schedule into other people's schedules."*
- Feeling ill as a result of low blood sugar and fluctuating blood sugar levels

- Maintaining routine: *"Sometimes I think 'Oh, I have to do this,' and I don't like doing it, but I do it."*
- Constant testing
- Diet restriction
- Eating so many times during the day

### How do you sustain motivation?

- Religion: "I do a lot of praying and look to the Lord to help."
- Fear of complications: "I worry about it a lot. That makes me stay on track."
- Pride and accomplishment: "Tell me I can't do something and I will do it!"
- Most of all: **EDUCATION!**

- **4 components:**

1. Someone who understands

*"Having someone who understands what your problems are I think mostly."*

2. Reassurance

Educator told her: "Call me at home. Call me any time you want to."

*"Well that helped me more than anything because when I'd really get in trouble I'd call her at home, which I didn't abuse. But it was good to know that I could because I needed it so much."*

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### 3. Guidance

*“I feel like I would be dead if I didn’t know how to take care of myself. They’re the ones that taught me.”*

### 4. Encouragement

*“Their attitude. They would always tell me I’m doing good, but I didn’t see any good about it at the time.”*

## CONCLUSIONS

*The “Take Control” Diabetes Action Plan:* reflects the challenges and opportunities identified by the Gingrich Group’s research program and targets key groups that constitute the present and future battle on how to successfully manage diabetes.

Immediately following the main research findings are a list of potential steps and solutions. Most of the steps we recommend will not only increase awareness and concern for diabetes among the general public but provide a best-practices scenario for dealing with diabetes that will lead to improved education and lives for those currently living with diabetes.

### **Key Finding #1**

#### **Lack of Communication & Teamwork between Physicians and Nurses/Educators**

- Physicians & CDEs diverged on their perceptions of compliance for Type 1 and Type 2 individuals.
- Physicians did not know what a CDE was.
- Physicians are often disinclined to refer patients to CDEs.

#### **Solutions**

- Increase CDEs’ Access to Patients
- Raise overall awareness of Diabetes and importance of education among Doctors

- Improve Doctors’ knowledge of behavioral component of Diabetes

### **Key Finding #2**

#### **No Standard Procedure for Physician Check-ups**

- Lack of doctrine with regard to patient visits & referrals
- Presence of bias (and lack of recognition of bias)
- With no standard procedure in place, patients make assumptions such as “I must be okay.”

#### **Solutions**

- CDE suggestion: Develop and enforce Standards of Care for physicians
- Develop standard diabetes procedures & doctrine and teach this in all medical schools
- To compensate for lack of standards, modify ADA guidelines to include testing for overweight individuals with certain BMI
- Legislate automatic glucose testing

## CONCLUSIONS

### Key Finding #3

#### Health Care vs. Healthy Behavior

- The US healthcare system fundamentally designed for acute not chronic illness
- Key is not only to change behavior but *sustain* behavior
  - Understand forming habits takes TIME
  - Understand forming habits requires PERSONALIZATION
  - Understand forming habits requires EMPOWERMENT
- Change will require reform of medical & insurance practices

#### Solutions

- Greater emphasis on behavioral approaches to medicine during education
- Propose legislation that will require insurance companies to expand coverage of diabetes education to include more frequent and non-traditional education

### Key Finding #4

#### Social Impact of Diabetes & Lasting Impressions

- Cultural impact—diet and the concept of “White” food
- Perceived stigmatization of child
- Insulin signifies “Bad” diabetes

#### Solutions

- Community-based education and support
- Other non-traditional methods of education and care such as diabetes mentor programs and patient-patient education

## CONCLUSIONS

### Key Finding #5

#### **Denial is very strong.**

- Family or close personal relations with diabetics does not imply there is heightened awareness about the disease
- Lack of knowledge about diabetes in general
  - Demonstrated surprise as to the seriousness of diabetes' consequences & high rate of incidence
  - Misperceptions as to the causes of diabetes reinforces denial

#### **Solutions**

- Broad-based education campaign undertaken on the national level
  - Campaign should address all aspects of managing disease.
  - Provide hope and positive reinforcement, yet also motivate by raising awareness of consequences of inaction.

### Key Finding #6

#### **Minorities had some understanding that they were at higher risk as a group, but did not personalize it.**

- Felt at greater risk for diabetes than cancer, but regarded cancer as more serious
- More likely to rely on doctor
- Cultural component an obstacle in successful management of diabetes

## CONCLUSIONS

### Message Context

- When given the proper tools, people do want to manage diabetes.
- Americans respond well to positive messages about diabetes, yet also need a sense of personal consequence and risk.
- Although cancer is regarded as the most serious disease, diabetes can be seen as in the same league as cancer.

## APPENDIX

### Basic Facts

- Only 14% of population is well educated on the causes of diabetes.
- Seventy-five percent of Americans chose the optimistic, hopeful statement as the prime motivator for getting tested for diabetes vs. the scare tactic approach.
- Most powerful message/statistic regarding diabetes: *More people die every year from diabetes than breast cancer and AIDS.*
- Physicians remain the most trusted, preferred messenger of health care information. Yet, there is an opportunity to reach people through different means!
  - 40% of Americans said inconvenience and cost of visiting the doctor is the biggest reason for not getting tested for diabetes.
  - 48% of Americans said they would prefer to receive health information and education either in group, community or one-on-one settings.
  - 30% of Americans turn to the Internet or other resources **often** because their doctor did not give

enough or incomplete information on a disease, condition, concern of theirs.